



# **Best Practices in American Indian & Alaska Native Public Health**

A Report from the Tribal Epidemiology Centers 2013



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## EXECUTIVE SUMMARY

The Tribal Epidemiology Centers, funded in part by the Indian Health Service and National Institutes for Health, are twelve unique centers serving American Indian and Alaska Native people throughout the United States.

**Our mission is to improve the health status of American Indians and Alaska Natives by identification and understanding of health risks and inequities, strengthening public health capacity, and assisting in disease prevention and control.**

We envision our group to be a strong, interwoven group of centers working together to develop a National Tribal Epidemiology Center narrative; enhanced data access and stewardship; respected multi-directional public health collaborations; and a diverse sustainable funding base. We work together for the betterment of the health of American Indian and Alaska Native people living in a variety of settings in the United States.

This report represents a collaborative effort of the Tribal Epidemiology Centers and is the first such report. We are keenly aware of the data quality questions it raises, but hope by presenting this information; we are able to highlight the successes of various Tribal Epidemiology Centers across the nation. We face many challenges on a daily basis in the areas of data availability and quality, but woven together we present a strong story.

The TECs have broad work-plans based on constituent identified needs, both tribal and urban in focus. However, we are charged with a common work-plan across the nation. Tribal Epidemiology Center functions have been outlined in Patient Protection and Affordable Care Act, Indian Health Care Improvement Act as follows:

“In consultation with and on the request of Indian tribes, tribal organizations, and urban Indian organizations, each service area epidemiology center established under this section shall, with respect to the applicable service area—

- (1) Collect data relating to, and monitor progress made toward meeting, each of the health status objectives of the service, the Indian tribes, tribal organizations, and urban Indian organizations in the service area;
- (2) evaluate existing delivery systems, data systems, and other systems that impact the improvement of Indian health;
- (3) assist Indian tribes, tribal organizations, and urban Indian organizations in identifying highest-priority health status objectives and the services needed to achieve those objectives, based on epidemiological data;
- (4) make recommendations for the targeting of services needed by the populations served;
- (5) make recommendations to improve health care delivery systems for Indians and urban Indians;
- (6) provide requested technical assistance to Indian tribes, tribal organizations, and urban Indian organizations in the development of local health service priorities and incidence and prevalence rates of disease and other illness in the community; and
- (7) provide disease surveillance and assist Indian tribes, tribal organizations, and urban Indian communities to promote public health."

***Public Law 104-191, 110 Stat. 1936***

***The Tribal Epidemiology Centers have been granted some authorities by law.***

***An epidemiology center operated by a grantee pursuant to a grant awarded under subsection (d) shall be treated as a public health authority (as defined in section 164.501 of title 45, Code of Federal Regulations (or a successor regulation)) for purposes of the Health Insurance Portability and Accountability Act of 1996 (Public Law 104-191; 110 Stat. 1936).***

***The Secretary shall grant to each epidemiology center described in paragraph (1) access to use of the data, data sets, monitoring systems, delivery systems, and other protected health information in the possession of the Secretary.***

***The activities of an epidemiology center described in paragraph (1) shall be for the purposes of research and for preventing and controlling disease, injury, or disability (as those activities are described in section 164.512 of title 45, Code of Federal Regulations (or a successor regulation)), for purposes of the Health Insurance Portability and Accountability Act of 1996 (Public Law 104-191; 110 Stat. 1936).***



This report specifically addresses some of the successes of individual TECs and it also highlights significant challenges that the TECs have had in securing access to data and ensuring that data provided to our constituents is accurate, reflecting the state of health inequity present for American Indians and Alaska Natives.









## INTRODUCTION

The following report has been written to illuminate the situation, response and impact of Tribal Epidemiology Centers (TECs) to improve American Indian/Alaska Native (AI/AN) public health surveillance data availability and data quality. Facing multiple historical, social, economic and health challenges, the AI/AN population remains a small and often hard to reach population, creating difficulty in accurately including AI/AN data in local, state and national health status reports. Due to the unique sovereign government-to-government relationship between AI/AN Tribes and the U.S. federal government and a legacy of legal and jurisdictional rulings, AI/AN people are a minority population which differs from other U.S. racial and ethnic minorities.

In response to increasing severity and costly health disparities between the AI/AN population and other races/ethnicities, TECs were established beginning in 1996 to address AI/AN population health data deficiencies and gaps as a foundation for improving health policy and expenditure decisions on the local, state and national levels. Today, there are 12 TECs serving the nation's twelve Indian Health Service (IHS) Areas and urban Indian health programs.

TECs have become valuable to Tribal communities, governmental agencies and academic institutions in the effort to reduce costly health disparities.

- TECs provide a vital link to AI/AN health data. This data influences health care policy, funding, and decision-making, and it strengthens the public health capacity of communities.
- TECs provide quality data analysis, culturally appropriate health information and technical assistance resulting in Tribal communities

gaining greater knowledge, empowerment, and influence over their own health care and wellness.

- TECs have trusted relationships with AI/AN communities, Tribal governments and AI/AN health organizations.
- TECs contribute to community-initiated strategies and interventions that reduce health disparities.

The information in this report emphasizes the need for data availability and quality to substantiate health care decisions, and the innovative and individualized programmatic response of TECs to engage Tribal communities to meet that need. TECs have been able to demonstrate improved data access, quality and utilization. Although many obstacles continue to impede optimal representation of AI/AN in health status data, TEC staff and partners collaborating to reduce health disparities remain committed to continuing innovative, strategic and financially responsible efforts to improve health statistics.

## Indian Country and Indian Health

Federally-recognized tribes of American Indians and Alaska Natives have a unique historic and legal government-to-government relationship with the U.S. government. This relationship has been given substance through numerous Supreme Court decisions, treaties, legislation, and Executive Orders, and entitles AI/ANs and their descendants to special rights, including health benefits. Under this trust responsibility, the U.S. has a legal obligation to protect Tribes' assets and provide needed services to Indian people.

The provision of health services grew out of this relationship. The federal trust responsibility for the provision of medical care and maintenance of public health functions was transferred to the Indian Health Service (IHS) in 1955. Today the national Indian Health Care Delivery System (IHCDS) consists of approximately 594 healthcare facilities located in 35 states, including 49 hospitals and 545 ambulatory facilities (231 health centers, five school-based health centers, 133 health stations, and 180 Alaska Native village clinics), where direct healthcare services are provided by some 3,000 priority primary care providers. The three main components of the IHCDS are: 1) programs that are operated by IHS directly; 2) programs that are tribally-operated; and 3) urban Indian health programs. Together, these components are referred to as IHS/Tribal/Urban, frequently abbreviated as I/T/U.

As part of its responsibility to ensure provision of public health functions to the 565 federally-recognized Tribes, the IHS, in partnership with tribes, has been working to build and sustain healthy communities. However, national health statistics clearly show that AI/ANs suffer some of the worst health disparities in the nation. The IHS Strategic Plan includes a vision of AI/AN communities with improved health status and well-being which includes adoption of healthy lifestyles.

Functional community-based public health infrastructure is needed to monitor and address public health issues such as injury prevention, suicide surveillance, environmental surveillance, and other local priorities. There must be sustained and active wellness programs with improved access to appropriate clinical, community and behavioral health information and referral services, and an organized emergency preparedness management program. To achieve this vision, the AI/AN public health infrastructure requires increased capacity for monitoring and addressing public health concerns.

There are challenges as a result of problems related to the regulation of federal statutes and treaty obligations regarding healthcare for AI/ANs. Specifically, the federal government entrusts IHS to fulfill federal statutes and treaty obligations to provide healthcare for AI/AN. In 11 of the 12 IHS service areas, IHS restricts services to members of federally-recognized tribes, disqualifying thousands of un-enrolled or non-federally recognized AI/ANs. In California, descendants of Indians residing in California in 1852 are also eligible for health services provided by IHS in addition to federally-recognized tribal members. Additionally, urban areas may offer better educational and employment opportunities; movement to urban areas has resulted in significant healthcare challenges for many AI/AN. Since most IHS clinics and hospitals are located on or near tribal lands, AI/ANs who reside in urban areas may not have access to these health centers.



## Tribal Epidemiology Centers

In 1996, amid growing concern about the lack of adequate public health surveillance and data for disease control for AI/AN populations, Tribal Epidemiology Centers (TECs) were established under the reauthorization of the Indian Health Care Improvement Act (IHCIA).

A cornerstone to improved public health capacity is ensuring the existence of valid and reliable data. Data analysis and information communication is needed by AI/AN communities and/or organizations in order for tribal leadership to have facts and tools needed to better prioritize their community health improvement decisions.

TECs operate on core funding provided through cooperative agreements with the IHS, and play a critical role in building public health capacity among AI/AN communities. Working with tribal entities and urban AI/AN communities, TECs provide a variety of public health services including: data dissemination, surveillance, applied epidemiologic studies, training, responses to public health emergencies, technical assistance, and disease control and prevention activities. TECs also support national public health goals by working to improve data for GPRA (Government Performance and Results Act) reports and by monitoring the Healthy People 2020 objectives at the tribal level.

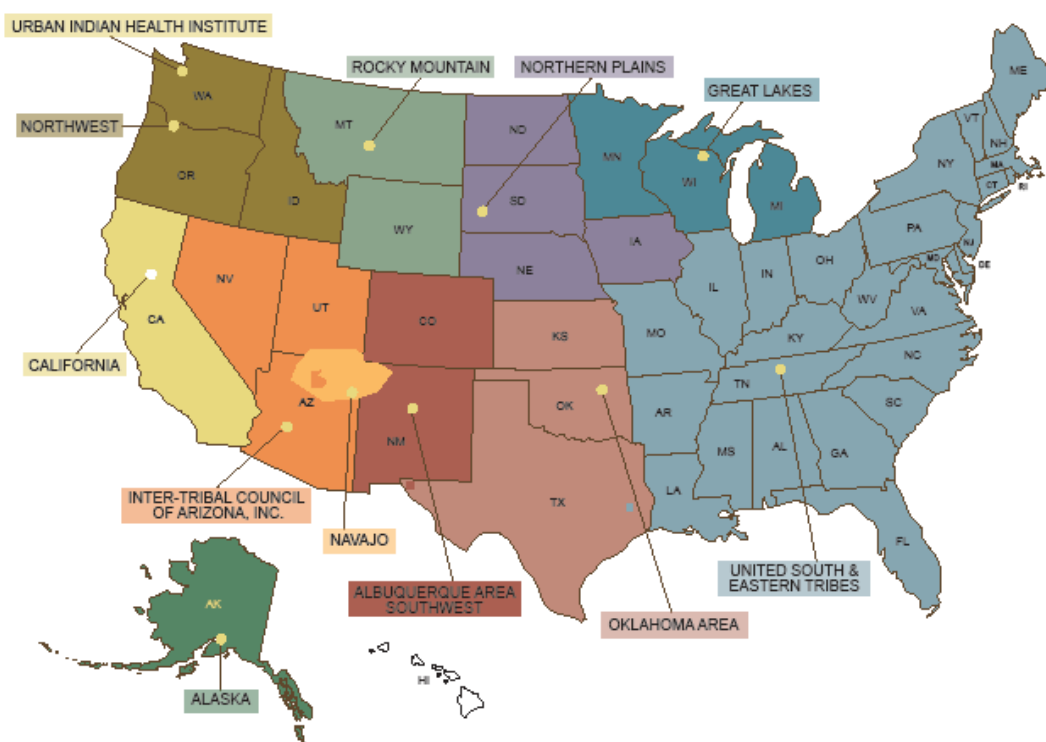
IHCIA was permanently reauthorized in 2010. This reauthorization defined TECs as “public health authorities” for purposes of the HIPAA Privacy Rule for data sharing. The permanent reauthorization of IHCIA directs the Secretary of the Department of Health and Human Services (DHHS) to grant each TEC access to use of the data, data sets, monitoring systems, delivery systems, and other protected health information (PHI) in the possession of the Secretary. It also requires that the Centers for Disease Control and Prevention (CDC) provide technical assistance, and that CDC work closely with each TEC in strengthening AI/AN disease surveillance.

Each of the 12 TECs in the U.S. is designated to serve AI/AN populations within the 12 IHS administrative areas, and one serves urban AI/ANs across the nation, see figure 1. TECs are striving to maintain a strong core of data collection, dissemination, surveillance, and epidemiologic studies. Through these efforts, each TEC is uniquely positioned to evaluate tribal and community-specific

health status, enhancing the ability of IHS to better understand and further develop the link between public health problems and behavior, socioeconomic conditions, and geography.

Detailed information about each of the TECs, their parent organizations and the communities served, along with highlights of their work, can be found in the section entitled ***Overview of Tribal Epidemiology Centers***.

Figure 1. TEC Service Areas



TECs are located at parent organizations, which act under a cooperative agreement with the IHS to operate a Tribal Epidemiology Center, and is authorized by Section 214 (a)(1), Public Law 94-437, Indian Health Care Improvement Act as amended by P.L. 573. In the conduct of this public health activity, they may collect or receive protected health information for the purpose of preventing and controlling disease, injury, or disability, including but not limited to, the reporting of disease, injury, vital events such as birth or death, and the conduct of public health surveillance, public health investigations, and public health interventions for Tribal communities they serve. Further, the IHS considers this to be a public health activity for which disclosure of protected health information (PHI) by covered entities is authorized by 45 CFR 164.512(b) of the Privacy Rule.





## **About This Report – Statement of the Problem**

This report is a result of collaboration between the Tribal Epidemiology Centers (TECs). TECs have a proven history of collaborating on joint projects and provision of technical assistance to one another.

In 2009, a national TEC workgroup was formed to work on a joint report that was initially envisioned as a national health profile of Indian Country. TEC staff from all 12 centers began holding monthly conference calls and planning for a report that standardized health status reports across all TECs leading to a more comprehensive picture of Indian health. Upon examination of available data, it was determined that standardization of data and reporting is not yet fully feasible.

The objective of this report is to focus on the various challenges in collecting, accessing, analyzing and reporting health data for AI/AN populations, and the work that the TECs do, individually and collectively, to provide AI/AN communities with the best public health surveillance and interpretation of health data possible.

The tribal, federal, state, and local health jurisdiction information that TECs collect, disseminate, and study, provide a unique lens to view the status of AI/AN populations throughout the U.S. However, improved transparency and reciprocity between tribal, state, and national data sets would allow for more complete and accurate studies at each level and, ultimately, greater understanding of the population's health. This information is critical for monitoring and improving programs which are working to eliminate disparities and enhance wellness.

Despite the challenges, the national network of TECs has been able to develop a variety of best practices in supporting AI/AN population disease surveillance, analysis and reporting. This report highlights some of these best practices.





## OVERVIEW OF TRIBAL EPIDEMIOLOGY CENTERS

We envision our group to be a strong, interwoven group of centers working together to develop a National Tribal Epidemiology Center narrative; enhanced data access and stewardship; respected multi-directional public health collaborations; and a diverse sustainable funding base. We work together for the betterment of the health of American Indian and Alaska Native people living in a variety of settings in the United States.

The National TEC Program Mission is: “to improve the health status of American Indians and Alaska Natives by identification and understanding of health risks and inequities, strengthening public health capacity, and assisting in disease prevention and control.”

The TECs have much in common. We share the mission of improving AI/AN health by identifying health risks, strengthening public health capacity, and developing solutions for disease prevention and control.

However, each TEC is unique. We vary widely in structure, staffing, and programs. The uniqueness of each TEC is in response to the priority needs of the tribes and urban populations we serve as well as to the presence or absence of funding sources for additional projects and programs. Since it is recognized by the national TEC Program that the core Indian Health Service’s funding for TECs is inadequate to address the needs, many TECs seek additional funding for projects and programs that align with the overall mission and vision of the TECs as well as the National TEC Program.

This section gives an overview of each of the 12 TECs; including information on the population they serve, parent organization, history and scope, staffing, highlights of their current work, project accomplishments, and key partnerships.



## Alaska Native Epidemiology Center (ANEC)







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## ALASKA NATIVE EPIDEMIOLOGY CENTER

[www.anthctoday.org/epicenter](http://www.anthctoday.org/epicenter)

### **American Indian/Alaska Native Population in Alaska and the Alaska Tribal Health System (ATHS)**

Alaska is home to 229 federally-recognized tribes that are indigenous to a state that is one-fifth the size of the contiguous United States. The 141,921 Alaska Native/American Indian (AN/AI) people that reside in Alaska make up roughly 20% of the state's total population. Many AN/AI people reside in remote areas of the state; 60% of Alaska's 336 communities are accessible only by airplane or boat. Most of these communities have fewer than 500 people that reside in them.

The Alaska Tribal Health System (ATHS) serves AN/AI people statewide. For many, the first level of care is at village clinics. Through a hub and spoke-like health care delivery network Alaska Native people and others have access to health care and other health related services. These village clinics are staffed by providers known as Community Health Aides or Community Health Practitioners (CHA/Ps). CHA/Ps are trained community health workers who provide basic primary and emergency care. CHA/Ps refer to their regional or sub-regional tribal health facility providers, as appropriate. Regional facility providers (physicians, nurse practitioners, or physician's assistances) then refer patients, as needed, to the Alaska Native Medical Center, located in Anchorage, Alaska. There are 36 tribal health centers, 6 regional tribal hospitals, 1 referral hospital and medical center (ANMC) and 180 village clinics as well as contracted health care in Alaska.

## **Parent Organization**

The Alaska Native Tribal Health Consortium (ANTHC) is a statewide non-profit health services organization owned and operated by AN/AI people with the mission, “providing the highest quality health services in partnership with our people and the Alaska Tribal Health System.” ANTHC is a consortium of consortia. All Alaska Native people, through their tribal governments and through their regional nonprofit organizations, own the Consortium. Under the authority of Indian Self-Determination and Education Assistance Act Public Law 93-638, ANTHC entered into a Self-Governance Agreement (the Alaska Tribal Health Compact) with the IHS in December 1997 for management of statewide health services formerly provided by the IHS for all AN/AI people. ANTHC also supports THOs that comprise the ATHS. ANTHC is the largest self-governance entity in the United States. ANTHC employs approximately 2,000 people and has an operating budget of more than \$430 million per year. A 15-member Board of Directors governs the Consortium and is comprised of representatives of tribes and tribal health organizations across Alaska.

The vision of ANTHC, “Alaska Natives are the healthiest people in the world” and the ANTHC mission statement guide management and employees. ANTHC’s structure consists of four main divisions: 1) the Alaska Native Medical Center (ANMC); 2) the Division of Environmental Health and Engineering (DEHE); 3) the Division of Community Health Services (DCHS); and 4) the Consortium Business Support Services. ANMC is a medical center that provides secondary and referral-based specialty care to AN/AI people from around the state. DEHE provides safe water as well as wastewater facilities and health care facility construction to communities. DCHS provides state-wide public health and research services, as well as providing wellness promotion and disease prevention initiatives. The Alaska Native Epidemiology Center (ANEC) resides within the Division of Community Health Services.

## **The Alaska Native Epidemiology Center (ANEC)**

Since the beginning of the national Tribal Epidemiology Center (TEC) Program in 1996, ANEC has been serving AN/AI people throughout the state of Alaska. Now in its 18th year of service, ANEC’s specific mission is to: “contribute to the wellness of AN/AI people by monitoring and reporting on health data, providing technical assistance and developing initiatives that promote health”.

The regional tribal health organizations (THOs) and the AN/AI communities they serve are the focus of ANEC's mission. ANEC four main functional units are: 1) Data Dissemination and Translation; 2) Technical Assistance and Training; 3) Surveillance and Applied Epidemiologic Studies; and 4) Development and support of Health Promotion and Disease Prevention programs. ANEC has significant experience and expertise in data collection, analysis, interpretation, and reporting, as well as in quantitative and qualitative research. Core funding is provided through a cooperative agreement with the IHS. Additional funding for the other ANEC projects comes from various other sources including cooperative agreements, grants, private foundations, and others.

### **ANEC Staff**

ANEC currently supports a total of 22 part-time and full-time staff. The staff are organized into four major workgroups: 1) Health Status/Data Reporting; 2) Alaska Native Tumor Registry; 3) Colorectal Cancer Control and Prevention Initiatives; 4) Maternal and Child Health Initiatives and Intimate Partner/Sexual Violence Prevention.

ANEC has a TEC Director, a Program Administrator, six epidemiologists, a Programmer/Analyst, a media specialist/webmaster, one endoscopist, two research nurse coordinators, three patient navigators and other key support staff members working on projects. In addition, ANEC contracts with a PhD level biostatistician and an external epidemiologist, as needed. ANEC related work is solely supported through grant-related funding.

### **ANEC Projects**

As mentioned above, ANEC has four functional units: 1) Data Dissemination and Translation; 2) Technical Assistance and Training; 3) Surveillance and Applied Epidemiologic Studies; and 4) Development and support of Disease Control and Prevention Programs. ANEC's projects fit within one of these units. The remainder of this description will highlight some of the projects.

**1) Data Dissemination and Translation Unit:** This unit is responsive to data requests from a variety of sources including staff of Alaska THOs or other medical and public health professionals and programs that serve the AN/AI community. ANEC creates and distributes various health related reports including **Regional Health Profiles** and the **Alaska Native Health Status Report**. These reports provide detailed regional-level and statewide data to THOs. THOs are also able to

identify specific topics of interest and find the information in reports or fact sheets on the ANEC website (<http://www.anthctoday.org/epicenter>). In addition to dissemination via the web, ANEC staff produce data books, manuscripts and present findings to the tribal leadership and staff at local, and state meeting, as well as at national conferences.

**2) Technical Assistance and Training Unit:** This unit provides technical assistance and training to providers and public health program staff at the ANMC, THOs, the Alaska Area IRB, and other entities that are planning and implementing quality improvement projects or epidemiological studies focused on promoting better health among AN/AI people. ANEC provides assistance to THO grant writers and program managers on developing program evaluation plans for their projects. ANEC staff assists THOs with study design, survey design, focus groups, in-depth interviews, data analysis, data reporting, and implementing program evaluation.

ANEC sponsors periodic trainings on these and similar topics. In addition, ANEC has sponsored internships and mentorships to facilitate pathways for AN/AI students into public health. Every regional THO in Alaska has benefited from services provided by ANEC.

**3) Surveillance and Applied Epidemiology Studies Unit:** This unit houses the National Cancer Institute's SEER Alaska Native Tumor Registry (ANTR), maintains and analyzes data sets which are critical to tracking the status of AN/AI health, and conducts applied studies of importance to improving Alaska Native health. ANTR became a part of ANEC in January, 2006. ANTR monitors the leading cause of mortality among AN/AI people – cancer. The Alaska Native Tumor Registry (ANTR) was initiated in 1974 in collaboration with the National Cancer Institute (NCI) and the CDC's Arctic Investigations Program and continues to this day.

ANEC staff support and have working relationships with other departments that maintain registries, for example the ANTHC Diabetes Registry, ANMC Neurology, ANMC's CRC First Degree Relatives Registry, Alaska Trauma Registry, etc. In addition to the registries, ANEC regularly analyzes and reports on the Behavioral Risk Factor Surveillance System (BRFSS) data. A current BRFSS project is working at improving risk factor estimates for Alaska Native people.

ANEC has completed a qualitative research study on knowledge, attitudes, and behaviors among parents and among adolescent girls with regards to the HPV vaccine. ANEC recently completed a comparative study of fecal occult blood tests for colorectal cancer screening in the Alaska Native population and is working on another comparative study in order to find other ways of improving colorectal cancer screening particularly among those people living in remote communities. This unit also produces reports and presents findings to THO leadership, staff, and others, as appropriate.

**4) Disease Control and Prevention Unit:** This unit develops projects that focus on primary and secondary prevention of infectious and chronic diseases as well as injuries among AN/AI people. In addition to working towards improving colorectal cancer (CRC) screening through outreach, education, systems change, and research, ANEC is working on violence and injury prevention. ANEC recently completed a revision to the bulletin ***Healthy Native Families: Preventing Violence at All Ages***, which highlights the data and data gaps for intimate partner and sexual violence among Alaska Native people. ANEC is currently working on updating the ***Alaska Native Injury Atlas*** in collaboration with the Injury Prevention Program. Also through participation in numerous Advisory Boards and Committees, such as the Healthy Alaskans 2020 project, and the State of Alaska's Maternal Infant Mortality Review Board, ANEC's staff contribute to disease control and prevention statewide efforts.

## **Partnerships**

Additionally, ANEC has strong working relationships with various tribal, state, and national entities including the Alaska Native Health Board, the State of Alaska Department of Health and Social Services, the University of Alaska, the Centers for Disease Control and Prevention (CDC) Arctic Investigations Program, as well as with other non-profit health-related organizations. As noted above, ANEC participates in numerous tribal, state, and national groups in order to stay informed, provide advice, facilitate AN/AI data interests, and help to shed light on AN/AI areas of health concern.

Here are some recent examples of ANEC's partnerships: ANEC is currently collaborating with seven THOs, the CDC and the Indian Health Service to improve colorectal cancer screening. ANEC partners with the State of Alaska to deliver a biennial conference on Maternal and Child Health and Immunizations. ANEC ANTR staff collaborate with many external organizations, such as the State

of Alaska Cancer Registry, the University of New Mexico Tumor Registry, the Cherokee Nation Cancer Registry, the CDC, the National Cancer Institute, the Mayo Clinic, the International Union for Circumpolar Health, the Native Cancer Research Council, and the International Cancer Council. ANEC is partnered with a variety of organizations including the Governor's Task Force to address the prevention and control of Intimate Partner and Domestic Violence. ANEC staff partnered with the State of Alaska Violent Death Reporting Surveillance System staff to complete a bulletin on suicide in Alaska.



**Roald Helgesen**  
Chief Executive Officer

August 16, 2013

Dear Tribal Epidemiology Center's Community Health Profile Working Group,

As the Chief Executive Officer of the Alaska Native Tribal Health Consortium (ANTHC), I recognize the value of our EpiCenter and the collective work of the national TEC Program. ANTHC, a consortium of consortia, serves tribes and tribal health organizations throughout our state and the Alaska Tribal Health System (ATHS). The Alaska Native Epidemiology Center serves a vital and vibrant role in the services that we provide to our partners across the state.

The ANEC has began operating in Alaska since 1996 and has been part of ANTHC since 2004. Prior to 1996, many of the services provided by ANEC were not available. Today ANEC serves 4 important functions in our ATHS. These functions are: 1) Data Dissemination and Translation; 2) Technical Assistance and Training; 3) Disease Control and Prevention Programming; and 4) Disease Surveillance and Applied Epidemiologic studies.

The Alaska Native Epidemiology Center, as one of the twelve TECs nationwide, brings significant capacity and the resources to our organization and its tribal partners. The presence of ANEC at ANTHC allows for development and implementation of programs and projects that would not otherwise happen. These programs and projects address critical areas of need such as health status monitoring, improving Colorectal Cancer Screening, and improving screening for Domestic Violence, and many others that will improve patient care and population health. These programs and projects fill gaps in our service portfolio not filled by other means.

ANEC is vital for ensuring our tribal health organizations, through data and analysis, have access to meaningful data and health information in order that we may continue to improve our health systems and, ultimately, it is a fundamental cornerstone to achieve our vision that Alaska Natives are the healthiest people in the world.

In summary, ANEC is an essential contribution to our Alaska Tribal Health System helping address unmet needs and improving the health and wellness of our people.

Sincerely,

A handwritten signature in blue ink that reads "Roald Helgesen". The signature is fluid and cursive, with the first name "Roald" being more prominent than the last name "Helgesen".

Roald Helgesen





## Albuquerque Area Southwest Tribal Epidemiology Center (AASTEC)





## **Albuquerque Area Southwest Tribal Epidemiology Center (AASTEC)**

Albuquerque Area Indian Health Board  
(AAIHB)

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### **American Indian/Alaska Native Population in the Albuquerque Area**

AASTEC currently serves the American Indian population in New Mexico, Southern Colorado, and El Paso, Texas, including the off reservation American Indian population in the Albuquerque metropolitan area. According to the 2010 U.S. Census, there are approximately 104,000 American Indian/Alaska Natives in the Albuquerque Service Area, including the 20 Pueblos, two Apache Nations, three Navajo Bands (not included in the IHS Navajo Area), and the Southern Ute Tribe and Ute Mountain Ute Tribe in Southern Colorado. In 2010, AASTEC provided services to 86,078 people.

### **Parent Organization**

AASTEC is operated under the authority of its parent organization, the Albuquerque Area Indian Health Board, Inc. (AAIHB). The AAIHB is composed of representatives from seven consortium tribes in New Mexico and Southern Colorado. AAIHB was incorporated in 1980 with a mission to: 1) advocate for tribal communities in areas of health, 2) collaborate with tribal communities to address health and health education concerns, and 3) engage communities in the use of research to address community health needs. The communities of the seven AAIHB consortium tribes have a population total of 21,600 American Indians.

The officers of AAIHB – Chair, Vice-Chair and Secretary/Treasurer – are elected every two years from the board members representing the seven consortium tribes. The board provides guidance and leadership, from their own community perspective, to all of the activities of AAIHB. The AAIHB offices are located in Albuquerque, which is centrally located and affords access to numerous resources such as the Indian Health Service (IHS) Albuquerque Area Office, the

University of New Mexico, and the State of New Mexico Department of Health. The AAHIB provides health promotion and prevention education services, as well as specialized health services to its consortium Tribes and to other AI communities and groups in New Mexico and Southern Colorado. In addition to AASTEC, current services offered include audiology, HIV/AIDS prevention education, colorectal health education, public health research and capacity building, advocacy, student development, IRB, and technical assistance in the areas of community mobilization, group facilitation, public health skills development, community needs assessment, cultural sensitivity, program planning, leadership development, and non-profit board membership.

### **Albuquerque Area Southwest Tribal Epidemiology Center (AASTEC)**

AASTEC was founded in 2006. The mission of AASTEC is to promote American Indian health and well-being by assisting tribes and off-reservation American Indian groups in building public health capacity and reducing health disparities in the Albuquerque Area through the collection, management, analysis, interpretation, and reporting of epidemiologic data. AASTEC works for all 27 tribes in the Albuquerque Area and is supported by an Executive Council representing the nine Indian Health Service (IHS) Units within the Albuquerque Area, as well as one representative from each of the primary intertribal organizations in the Albuquerque Area – AAHIB and the All Indian Pueblo Council (AIPC). AASTEC's health priorities are determined by the Executive Council and include the following domains for 2012-2017: behavioral health (i.e. substance abuse, depression and suicide), cancer, diabetes, oral health, heart disease, and injury prevention.

### **AASTEC Staff**

AASTEC staff members include the director, two staff epidemiologists, a tribal survey coordinator, and an administrative assistant.

### **AASTEC Projects**

AASTEC is involved in a host of projects and activities in collaboration with the 27 Tribes it serves. Key project activities include surveillance/monitoring of health status and health care delivery, community health assessment, community health profile development, program evaluation, epidemiological research, and capacity development. A sample of AASTEC's current projects is highlighted in the following paragraphs:

### ***Tribal BRFSS Surveys***

One of the key methods that AASTEC utilizes to better understand health care delivery and health status in the tribal communities it serves occurs through the administration of tribal Behavioral Risk Factor Surveillance System (BRFSS) surveys. To date, AASTEC has partnered with Albuquerque Area Tribes to complete 8 Tribal BRFSS surveys and is currently involved in the planning and administration of a BRFSS survey in an additional 4 Tribal communities. The BRFSS survey contains valuable information related to: health care access, health care utilization, health care affordability and insurance status, health care status and health behavior across a host of health priority areas. The aim of our Tribal BRFSS project is to assist tribes in identifying health related assets and needs, monitoring trends in community health status and health care access over time, and identifying key leverage points for intervention. AASTEC is also currently in the process of comparing two BRFSS data collection methodologies – in-person interviewing vs. random digit telephone dialing – in partnership with four Tribes in the Albuquerque Area.

### ***New Mexico YRRS***

AASTEC also assists state and academic partners in administering the New Mexico Youth Risk and Resiliency Survey (YRRS) on a biennial basis. AASTEC's efforts primarily center upon oversampling American Indian youth to ensure the provision of meaningful state-level health risk behavior and resiliency data for American Indian youth in New Mexico. For the 2011 YRRS cycle, we administered the YRRS to a supplemental sample of 36 middle and high schools with high Native American student enrollment. Each of these schools is located either within or adjacent to tribal communities in our region. As a result of AASTEC efforts, the 2009 NM YRRS survey was successfully administered to an additional 2,039 AI adolescents enrolled in middle and high schools in New Mexico, and the 2011 NM YRRS included a supplemental sample of 3,471 AI youth. We also achieved a high response rate on both of these surveys (average 76.5%), which exceeds previous state averages.

### ***Tribal Health Program Database Development***

In an effort to achieve health data equity and promote data sovereignty among the 27 Tribes we serve, AASTEC staff assists tribal health programs with the design, administration and maintenance of customized ACCESS databases that enable community health staff to monitor the health status of the tribal

members they serve and evaluate program activities and services. These efforts currently extend to tribal diabetes programs, elder programs, community fitness/wellness centers and Community Health Representative (CHR) programs in several Tribes throughout the Albuquerque Area.

### ***Tribal Colorectal Health Program***

AASTEC has also partnered with the Centers for Disease Control and Prevention and the Indian Health Service Division of Epidemiology and Disease Prevention to develop and implement a Tribal Colorectal Health Demonstration Project. This project has five main objectives, which aim to address the disproportionately poor colorectal cancer screening rates identified via AASTEC's Tribal BRFSS project, including:

1. Build knowledge and skills among Community Health Representatives (CHRs) to bolster their involvement in tribal colorectal health education, outreach and navigational services.
2. Develop multidisciplinary colorectal health workgroups in participating Tribes to strengthen collaboration between CHRs and clinic providers to expand tribal community colorectal cancer control efforts.
3. Develop culturally appropriate colorectal health education materials for American Indian communities including flipcharts, radio public service announcements, digital stories, interactive games, etc.
4. Share successful strategies, materials and lessons learned with tribal communities throughout the country to strengthen local colorectal cancer control efforts.
5. Test promising colorectal health interventions in participating Tribes.

In 2012-2013, this program is being expanded to include a randomized trial to test the hypothesis that interventions that mitigate structural and patient barriers (direct mailing of fecal occult blood test (FOBT), and outreach, respectively) can lead to increased colorectal cancer screening within American Indian populations.

### **AASTEC Partners**

In addition to the 27 Tribes it serves, AASTEC maintains a strong partnership network with other entities throughout the region. AASTEC and its parent organization AAIHB, have a long history of collaboration with the New Mexico Department of Health (NMDOH), which is the public health authority for the



state. AASTEC staff serves on many NMDOH committees, such as the NM YRRS steering committee, the New Mexico Indicator Based Information System (IBIS), New Mexico Pregnancy Risk Assessment Monitoring System (PRAMS); Homicide-Domestic Violence Death Review Committee, and the NM Behavioral Risk Factor Surveillance System (BRFSS) steering committee. AASTEC has also begun interacting with the Colorado Department of Health and the Texas Department of Health to establish working relationships to better serve the Albuquerque Area Tribes located in these states.

Other key AASTEC partners include the University of New Mexico Health Sciences Center, the New Mexico Public Education Department, the Southwest Tribal Tobacco Coalition, the All Indian Pueblo Council, the Albuquerque Area Indian Health Service, First Nations Community Healthsource, and the New Mexico Tumor Registry.



# Albuquerque Area Indian Health Board Inc.

Tóhajiilee Band of Navajos \* Jicarilla Apache Nation \* Mescalero Apache Tribe  
Ramah Band of Navajos \* Southern Ute Indian Tribe \* Ute Mountain Ute Tribe

August 20, 2013

Dear Colleagues,

It is with great pleasure that I present the Albuquerque Area Southwest Tribal Epidemiology Center (AASTEC) on behalf of its parent organization, the Albuquerque Area Indian Health Board, Inc. (AAIHB). AASTEC was established in 2006 with a mission to collaborate with the 27 Tribes in the Albuquerque Area to provide high quality, culturally-congruent health research, surveillance and training to improve the quality of life of American Indians. Current AASTEC services are organized around four essential domains – epidemiology/surveillance, research and evaluation, capacity development, and public health practice. AASTEC possesses a remarkable amount of research and epidemiological expertise, and partners with all 27 Tribes in our area to:

- Improve quality of health data for American Indians
- Ensure relevance of health data for American Indian populations
- Promote data access for Tribes
- Enhance representation of American Indians in health data

AASTEC also upholds the mission of AAIHB, which is to advocate on behalf of American Indians through the delivery of quality health care services, which honor spiritual and cultural values. AAIHB supports AASTEC in all of its endeavors and provides timely and representative tribal input and consultation via its representative Board of Directors. In conjunction with the AASTEC Executive Council, the AAIHB BOD meets on a routine basis and provides advisement and feedback to AASTEC to ensure that its approaches are aligned with tribal priorities and the cultural strengths and values of the respective tribal communities.

We fully support AASTEC and are continually impressed with the volume and quality of work it produces on an annual basis. The tribal communities in our area greatly benefit from this valuable resource, and we stand together in our collective efforts to address the health needs of the communities we serve and eliminate health disparities which continue to impact American Indian people throughout our nation.

Sincerely,

Nancy Martine-Alonzo  
Executive Director  
Albuquerque Area Indian Health Board, Inc.

## California Tribal Epidemiology Center (CTEC)





## **California Tribal Epidemiology Center (CTEC)**

California Rural Indian Health Board (CRIHB)

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## **American Indian/Alaska Native Population in the California Area**

California has the largest population of American Indian/Alaska Native (AIAN) in the nation. The 2010 U.S. Census reported that 362,801 individuals identified themselves as AIAN alone, and 723,225 individuals identified themselves as AIAN alone or in combination with one or more races, accounting for 13.9% of the nation's AIAN population. California has 109 federally recognized tribes and over 40 tribes seeking recognition or restoration. All of the Indian Health Service (IHS) funded facilities in California are governed by tribes and are sanctioned by Public Law 93-638. Many AIANs in California utilize Indian health programs for health care. Eligibility for IHS services in California are AIANs who are enrolled members of a federally recognized tribe or descendants of Indians documented in a survey of AIANs conducted by the U.S. government in California in 1852. There are 40 Indian health programs throughout California with a total of 70 clinics.

## **Parent Organization**

The California Rural Indian Health Board, Inc. (CRIHB) is a network of tribal health programs (THPs), controlled and sanctioned by Indian people and their tribal governments, and is committed to the needs and interests that elevate and promote the health status and social conditions of the Indian people of California. CRIHB provides advocacy, shared resources, training and technical assistance to enhance the delivery of quality comprehensive health related services. CRIHB is a 501(c)3 non-profit corporation that has been operating since 1969. CRIHB is one of 12 Area Indian Health Boards in the U.S. and operates under the Indian Self-Determination Act (PL 93-638) as a tribal organization. CRIHB works closely with other IHS Area Health Boards, and meets biannually with the Northwest Portland Area Indian Health Board. Essential to the capacity

of CRIHB is the tribal guidance and direction provided by its Board of Directors, the Tribal Government Consultation Committee, and the Traditional Indian Health Committee. The CRIHB Board of Directors meets quarterly and consists of representatives selected by tribal health boards of its member programs. These leaders make recommendations to the CRIHB Board of Directors, serve on state and national workgroups such as the National Congress of American Indians and the National Indian Health Board, and consult with state and federal elected officials on a government-to-government basis.

In addition, CRIHB serves as the parent organization for the California Tribal Epidemiology Center (CTEC). CRIHB is home to several other statewide programs including the California Dental Support Center housed in the Health Systems Development Department and the California Child Development Fund awarded to the Tribal Head Start Department. CRIHB is also the parent organization of two programs that extend into other states: the Access to American Indian Recovery and the Tobacco Education Technical Support Center; both are programs in the Family and Community Health Department. Today, CRIHB successfully operates an average of 30 grants and contracts a year funded through federal, state and private foundations for a total of approximately \$14 million.

### **California Tribal Epidemiology Center (CTEC)**

CTEC's mission is to improve American Indian health in California to the highest level by engaging American Indian communities in collecting and interpreting health information to establish health priorities, monitor health status, and develop effective public health services that respect cultural values and traditions of the communities. Indian people have been conducting health studies for thousands of years. Investigating and finding ways to heal is an inherent part of Indian culture. CTEC is built on those very same foundations. Since inception in September 2005, CTEC has worked to expand the availability of epidemiological services to AIAN communities throughout California to establish health priorities, monitor health status and investigate health problems and health hazards, and conduct evaluation and research on programs and policies. CTEC's ability to collect, analyze and disseminate information to increase awareness of health disparities is strengthened by strong partnerships with our THPs and collaborative partners. CTEC maintains strong ties and networks with our tribal communities which include elders, tribal leaders, cultural specialists, youth groups, community health representatives, counselors, and



teachers. An Advisory Council consisting of tribal community members, tribal health providers and technical advisors makes recommendations on the operations and products of CTEC. CTEC is tasked with serving all AIANs in California and has 23 member THPs representing 84 tribes and their communities. By utilizing this network of tribes and THPs, we have coordinated meetings and roundtable discussions to obtain input on data collection and analysis in research studies and presentation of findings in health reports. Ensuring that health data and information are relayed back to the tribal communities and stakeholders is a key component to fulfilling the mission of both CRIHB and CTEC. CTEC disseminates reports and presents to partner THPs and tribal organizations, both locally and nationally, on interpreting research findings and possible implications.

### **CTEC staff**

CTEC staff members include the PhD-level Director, a Medical Epidemiologist, 2 MPH-level Epidemiologists, a CDC Public Health Associate and two Research Assistants.

### **CTEC Projects**

***TEC Consortium (TECC)*** is a partnership, which is funded by the CDC, between the Northwest TEC, the Oklahoma City Area Inter-Tribal Health Board (OCAITHB) TEC and CTEC since 2006. TECC has worked on assessing Tribal Health Program capabilities, and developed an Injury Prevention Toolkit for Indian Country.

***Record linkage studies*** using IHS and state health databases to correct for racial misclassification were conducted. In 2006 the linkage measured disparities in deaths; in 2007 disparities in hospitalizations for AIANs and in 2010, misclassification in cases of pandemic (H1N1) influenza-09. We are in the process of performing linkage studies involving data for sexually transmitted diseases (STDs) and injuries and developing another on substance abuse treatment and hospitalizations.

***Indian Health Priorities Survey*** was developed to understand the health needs of California AIAN communities. CTEC collects health priority surveys through meetings with THPs, community health events, and the CTEC website. The results of the surveys, along with the available data on AIANs, guide the focus areas of

CTECs work. From 2008-2010, CTEC collected 594 Priority Assessment surveys, and the top five priorities are: Diabetes; Drug Abuse; Alcohol Abuse; Eating Healthy, Exercise and Controlling Obesity; and Mental Health. The next round of the Priorities Survey (data from 2011 onwards) is currently underway, with 462 surveys collected.

***Community Health Profiles*** were developed and disseminated for the entire state of California in 2009 and member THPs in 2010 using the best available data sources for AIANs. The profile is a resource to assist THPs, tribal leaders and clinic staff in further understanding how data is collected and reported for AIANs living in California; in completing grant applications that require data, facts and figures; or in deciding where to allocate time, money, and efforts related to health issues.

***Tribal Asthma Survey Project (TASP)*** was conducted in 2009-2010 in collaboration with the California Department of Public Health, Health Investigations Branch, California Breathing to document the prevalence of asthma in AIANs and potential allergens in housing through collecting and analyzing population-based surveys. A total of 610 surveys were collected at 10 tribal events. Over 21% (n=131) of participants had been diagnosed by a doctor or other health professional with asthma. Thus, 14% of males and 25% of females had asthma. Asthma in women was higher for those with pets with fur or feathers in the home in the past 6 months, those who had seen mold in the home greater than the size of a dollar bill, and in those who had smelled a moldy or musty odor.

***The Native Oral Health Project (NOHP)*** was awarded to the California Tribal Epidemiology Center (CTEC) in April 2012 by the National Institute of Dental and Craniofacial Research (NIDCR). The main goal of this study is to evaluate the feasibility and acceptability of storytelling as a means of spreading oral health educational messages among AI/AN women. As part of this project, storytelling sessions have been conducted in 3 regions of northern California – Hoopa Valley, Eureka/Arcata, and the Redding region. An Advisory Board comprising of community representatives from all over California (including the 3 sites) provide input and guidance on a regular basis.

***American Indian Vaccination Promotion Campaign*** was developed with the CRIHB Family and Community Health Services Department in 2010. Influenza H1N1 vaccine promotional materials were created for THP providers, tribes, and



schools using Indian themes, language, images, and metaphors to effectively improve preparedness and response in the community. These materials include a series of seven posters, seven fact sheets, a tribal head start toolkit, a THP toolkit, as well a statewide radio and video public service announcement campaign.

### **Partnerships**

Partnerships with the California Indian Health Service Area Office, California Department of Public Health, University of California at San Francisco, and the University of California, Davis are established on a project-by-project basis. CTEC has an MOU with the University of California, Davis Comprehensive Cancer Center to partner on AIAN cancer-related projects. CTEC is also currently collaborating with Boston University, University of California at San Francisco, and the University of Washington, as part of an NIH-funded feasibility study on oral health, led by CTEC.



**CALIFORNIA RURAL INDIAN HEALTH BOARD, INC.**

**4400 Auburn Blvd. • 2<sup>nd</sup> Floor • Sacramento • CA 95841 • (916) 929-9761 • Fax (916) 929-7246**

Dear Tribal Epidemiology Center Community Health Profile Workgroup,

As the Executive Director of the California Rural Indian Health Board, Inc. (CRIHB) and having served in this capacity since 1987, I am deeply aware of the capacity and the rich resources provided by the California Tribal Epidemiology Center (CTEC). In 2004 the California Indian Health Service Area Office Tribal Advisory Council urged IHS to fund a Tribal Epidemiology Center in California.

Since 2005, CTEC has been operating at CRIHB and has provided numerous epidemiologic services not previously available to California Tribal and Urban Health Programs and the AIAN population in California. CTEC is critical for ensuring our Tribal Health Programs in California have access to meaningful data and health information to better improve our tribal health care systems and reduce the burden of disease in our communities. For example, CTEC is conducting a Tribal BRFSS, which will provide much need up-to-date information regarding the health status of AIANs in California. In addition, in the summer 2010, CTEC partnered with the California Department of Public Health to study the HINI hospitalization rates for Tribal and urban Indian health program patients.

CTEC has demonstrated a growing capacity through its knowledge, experience, and expertise to successfully address these issues on behalf of the AIAN population in California. For example, CTEC encompasses highly qualified PhD-, masters-, and MD-level epidemiologists with research and cultural-competency support staff.

Each year, too many AIANs in California experience serious health problems. As the Director of CRIHB, which houses CTEC, I look forward to future work of CTEC which will continue to raise awareness of these health issues.

Sincerely,



James A. Crouch, MPH  
Executive Director

## Great Lakes Inter-Tribal Epidemiology Center (GLITEC)





## **Great Lakes Inter-Tribal Epidemiology Center (GLITEC)**

Great Lakes Inter-Tribal Council (GLITC)

PO Box 9

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### **American Indian/Alaska Native Population in the Bemidji Area**

The Bemidji Indian Health Service Area includes the states of Michigan, Minnesota and Wisconsin and the city of Chicago. Most Tribes in the Indian Health Service (IHS) Bemidji Area are Chippewa (Ojibwe), though there are also Dakota, Ho-Chunk, Menominee, Mohican, Odawa, Oneida, and Potawatomi nations. In Michigan, Minnesota, and Wisconsin, according to the 2010 Census, 0.9% (177,449 people) of the population was AI/AN alone; in combination with another race, this figure rises to 1.6% (327,223 people).

### **Parent Organization**

The Great Lakes Inter-Tribal Council, Inc. (GLITC) is a consortium of twelve federally recognized Indian Tribes in Wisconsin and Upper Michigan. GLITC was chartered as a non-profit corporation under Wisconsin law in 1965. GLITC was established to provide a means by which member Tribes could unite against the threat of termination. It is located on the Lac du Flambeau reservation. For 50 years, GLITC has used a broad range of knowledge and experience to advocate for the improvement and unity of Tribal communities and individuals. Today, the GLITC mission has evolved to support member Tribes in expanding self-determination efforts by providing services and assistance.

### **Great Lakes Inter-Tribal Epidemiology Center (GLITEC)**

The Great Lakes Inter-Tribal Epidemiology Center serves 34 Tribes, three Service Units and four Urban Indian Health Programs. GLITEC is in its sixteenth year of operation, originating in 1996. Program advisement is provided through each state's Tribal Health Director's Association. GLITEC staff strives to support Tribal

communities in their efforts to improve health by building capacity to collect and use data while advocating on the local, state and national levels to improve data quality.

The following principles of operation support GLITEC services:

1. Respect for Tribal authority and direction in service requests
2. Data confidentiality, protection and security
3. Tribal ownership of data
4. Establishing transparent, trusting relationships
5. Inclusion and representation

**GLITEC Staff:** The staff includes the director, four masters-level epidemiologists, an MIS analyst, a data entry specialist, an administrative assistant and fellows and/or interns.

### **GLITEC Project Highlights**

GLITEC has conducted or participated in numerous projects with the American Indian/Alaska Native communities in Michigan, Minnesota, Wisconsin and Chicago. GLITEC strives to be responsive to the needs and interests of the communities; therefore, some projects are conducted area-wide, while others are done with a consortium or group of communities, or with a single community. GLITEC produces and disseminates an annual three-state American Indian/Alaska Native health profile report, aggregating data by each state individually and in combination. Tribe-specific profile reports are updated periodically and upon request.

### ***Statewide Health Improvement Program (SHIP)***

GLITEC provided various types of support to nine Tribal communities in Minnesota (all the Tribal grantees) in conjunction with the Statewide Health Improvement Program (SHIP). SHIP is a state-funded grant for which counties and Tribes (or collaborations thereof) in Minnesota were eligible to apply. SHIP addresses major underlying causes of death and illness in Minnesota- obesity and commercial tobacco abuse- in four settings (community, healthcare, schools, and workplaces), through activities that target policies, systems, and environments. Changes in policies, systems, and environments have the potential to improve the health of many people at once more efficiently than projects aimed at individuals on a one-on-one basis. Together, the seven Ojibwe Tribes in Minnesota (Bois Forte, Fond du Lac, Grand Portage, Leech Lake,



Mille Lacs, Red Lake, and White Earth), and independently the Upper Sioux Community, applied for and were awarded a SHIP grant in 2009. The following year the Lower Sioux Community was awarded a SHIP grant. GLITEC provided evaluation services for the Ojibwe collaboration (in Phase I (assessment) and Phase II (process and outcome evaluation)), the Upper Sioux Community (Phase II (process and outcome evaluation)), and the Lower Sioux Community (Phase II (process and outcome evaluation)). GLITEC also assisted the Upper Sioux Community with a community health assessment, where possible basing it off of a survey done years earlier. GLITEC analyzed the results and presented them to the community at a commercial tobacco-free powwow. GLITEC also worked with the group of Ojibwe Tribes to conduct a survey for which each community would have a representative sample size, so they could have confidence in their community's results. The survey used a stratified sample so the sample would match the age and sex distribution of American Indian/Alaska Natives statewide in Minnesota. Thus far, the aggregate survey report has been disseminated to the communities, and work is continuing on the Tribe-specific reports.

### ***CDC Community Transformation Grant***

Four Wisconsin Tribes, the CDC, other partners, GLITEC are collaborating to develop a health needs assessment and a policy scan in each of the four Tribal communities. A Leadership Team, comprised of high level Tribal officials, Tribal health directors, prevention specialists, program staff and others, provide direction in project planning, implementation and evaluation. CTG staff also work with local prevention coalitions and other community partners to conduct a Capacity Building Plan. In implementing the proposed Capacity Building Plan, CTG staff will review rates of chronic disease risk factors; conduct a policy scan and an environmental scan which will identify any policy, environmental, programmatic and infrastructural factors which might contribute to chronic disease burdens; and identify any subgroups experiencing additional health disparities. Based on the analysis of existing data and outcomes of the health needs assessments and policy/environmental scans, CTG staff with the Leadership Team will develop and submit to CDC a Community Transformation Implementation Plan (CTIP). This plan will address, using culturally-appropriate approaches, the five CDC CTG Strategic Directions: Tobacco Free Living; Active Living and Healthy Eating; High Impact Quality Clinical and Other Preventive Services; Social and Emotional Wellness; and Healthy and Safe Physical Environment.

### ***Resource Patient Management System Suicide Analysis Project***

The IHS Division of Behavioral Health requested that GLITEC analyze over ten years of suicide reporting form data and write an aggregate national report as well as reports for each IHS Area. The analysis will review the relationship between independent variables/contributing factors (such as age, gender, alcohol or drug use, prior attempts, etc.) and their influence on dependent variables (seven identified types of suicidal behavior) (e.g. ideation with plan and intent, completed suicide). Simple descriptive statistics and bivariate analyses will be conducted. Because these data have been collected for over ten years, but never analyzed before, GLITEC hopes the aggregate report will draw attention to the suicide epidemic in Indian Country, and that IHS Area reports will help inform each Area of specific trends and local issues to increase community awareness and prevent suicide.

### ***Strategic Prevention Framework State Incentive Grant (SPF SIG)***

Substance Abuse Mental Health Services Administration's (SAMHSA) Strategic Prevention Framework State Incentive Grant (SPF SIG) project was intended to build alcohol and other drug abuse (AODA) prevention capacity and infrastructure with ten of the 11 Tribes in Wisconsin; prevent the onset and reduce the progress of substance abuse including childhood and underage drinking using evidenced-based prevention programs; and reduce substance abuse and substance abuse-related problems in Tribal communities. As part of this program, GLITEC worked with BEAR Consulting to complete Pre and Post Intervention Epidemiological AODA Profile Reports, with priority areas including binge drinking and underage drinking; developed a cross-site evaluation plan as well as Tribal/program specific evaluation plans; and provided training and technical assistance for participating Tribal communities to build epidemiological capacity to collect and analyze data (e.g. all Tribes created their own stratified sample following training from GLITEC).

### ***Wisconsin Native Youth Tobacco Survey (WNYTS)***

GLITEC assisted the Wisconsin Native American Tobacco Network (WNATN) with a survey of Native youth in Wisconsin regarding traditional and commercial tobacco. A statewide tobacco survey of AI/AN youth that included each reservation had never been done in any state before. GLITEC created and piloted the instrument, created the sampling/collection protocol, analyzed the data, and wrote reports, as well as assisted with data collection and logistics.



**Partnerships**

Various public and private partners include Tribes, urban Indian communities, other departments within the Great Lakes Inter-Tribal Council, Inc., state health departments, other Tribal Epidemiology Centers, nonprofits, federal agencies, universities across the region, and institutions such as Mayo Clinic.



## GREAT LAKES INTER-TRIBAL COUNCIL, INC.

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July 1, 2013

Dear Local, State, and Federal Officials,

The Great Lakes Inter-Tribal Epidemiology Center (GLITEC) has been providing services to the Native American tribes in the Bemidji Area since 1996. It is one of the original epi centers to be funded and is in its 17th year of operation. While GLITEC is located on the Lac du Flambeau Indian Reservation in northern Wisconsin, it serves all tribes, Service Units and Urban Indian Health Centers in Michigan, Minnesota and Wisconsin.

Continuing funding for GLITEC and the other tribal epidemiology centers will allow these centers to further their mission to assist tribal communities to collect and use data and impact state, regional and federal agencies through improving data quality for the American Indian/Alaska Native population. The benefits to the tribal communities are numerous:

- Strengthening their capacity to collect and use data
- Providing tribe-specific profile reports
- Providing an area-wide aggregate profile report bi-annually
- Conducting requested epidemiologic studies
- Providing evaluation consultation
- Assisting in public health accreditation readiness
- Participating in health promotion and disease prevention activities

Diabetes, heart disease and cancer are more prevalent in Native American populations than in any other, and the data collected and disseminated via GLITEC can help in finding new inroads to prevention and better overall health.

The Great Lakes Inter-Tribal Council, Inc. (GLITC) benefits through the recognition it receives by administering the three-state program. All GLITC programs can benefit from program collaboration and data technical assistance. The staff epidemiologists work in tandem with several of our prevention programs.

GLITEC provides invaluable services to the tribes and state and federal agencies. Its research is having a positive impact on Native American health. We respectfully request that you continue to fund GLITEC and the other tribal epidemiology centers so that they can continue their work which benefits so many.

Sincerely,

  
Michael W. Allen, Sr.  
Executive Director





**Inter Tribal Council of Arizona, Inc. Tribal  
Epidemiology Center (ITCA TEC)**

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**American Indian/Alaska Native (AI/AN) Population in the Phoenix and Tucson Areas**

The ITCA TEC serves American Indian Tribes in the Phoenix Area and Tucson Area of the Indian Health Service (IHS). This includes Tribes in Arizona, Nevada and Utah, with exception to the Navajo Nation. According to the 2010 U.S. Census, in the three states that make up the Phoenix and Tucson Areas, a total of 436,053 individuals identify as AI/AN alone or in combination. After excluding the approximately 170,000 AI/AN residing on the Navajo Nation, the U.S. Census estimates that over 265,000 AI/AN reside in Arizona, Nevada, and Utah. The 2010 U.S. Census reported that 138,312 individuals in Arizona, 55,945 in Nevada, and 50,064 in Utah identified themselves as AI/AN alone or in combination with one or more other races.

Combined there are 46 federally-recognized Tribes, Colonies, Bands, and Community Councils served by the ITCA TEC. There are 44 Tribes in the Phoenix Area with nine service units, and two Tribes in the Tucson Area. According to the 2011 IHS user population estimates, the Indian user population was 164,065 for the Phoenix Area, and 26,564 for the Tucson Area.

**Parent Organization**

The Inter Tribal Council of Arizona (ITCA) was established as an association of Tribal governments in 1952 to provide a united voice to address common issues of concern. The highest elected officials (Chairpersons, Presidents, or Governors) of 20 federally-recognized Tribes in Arizona represent the membership of ITCA. These leaders have a comprehensive view of the conditions and needs of the Tribal communities they represent. The ITCA was incorporated as a 501(c)(3) nonprofit charitable organization in July 1975. The focus of the organization was,

and continues to be, directed at strengthening the soundness, durability, and integrity of Tribal governments. In applying the purposes of the organization, which are to “use any lawful means to provide its member Tribes as sovereign nations and American Indian Tribes with a united voice, and the means for united action on matters that affect them collectively or individually,” and with the guidance of Tribal leadership, ITCA, Inc. was established as an accessible resource to Tribal governments on their pathway to self-determination and self-governance.

Over the past 35 years, there has been major growth in the scope of services provided by the tribes as well as an increase in the overall responsibilities of governance. This growth began with the passage of the Indian Self-Determination and Education Act of 1974, referred to as P.L. 93-638, which provided tribal governments the lawful basis to assume responsibility for federal programs. Throughout its years of operation, the ITCA, Inc. has adjusted its capacity to best meet the needs of the evolving responsibilities of tribal governments through policy research, advocacy, training, technical assistance, and resource development. Tribal governments have now forged a strong intergovernmental working relationship with the federal and state governments based on their legal sovereign status resulting in access to new resources and programs for Tribes.

ITCA, Inc. is sanctioned by its member Tribes to administer federal and state programs. The work of ITCA, Inc. is performed under the direction of Mr. John R. Lewis, Executive Director, employs a staff of 70, and administers about 45 programs. At least 95% of funds received by ITCA, Inc. supports tribal programs via the pass-through of funding to member Tribal governments, or through the provision of training and technical assistance to Tribes. The ITCA, Inc. has a long history of addressing health-related issues, including providing capacity building activities, as demonstrated through numerous programs and funding sources awarded to ITCA, Inc. which include the Centers for Disease Control and Prevention, the Indian Health Service, National Institutes of Health, and the U.S. Department of Agriculture, among others. Some of the major health issues addressed include cancer, oral health, women and children’s health issues, health data and evaluation, human services, tobacco cessation, teen pregnancy and HIV/AIDS/STD prevention.



## **ITCA Tribal Epidemiology Center (TEC)**

The ITCA TEC's **mission** is to build tribally-driven public health and epidemiologic capacity among tribes in the Phoenix and Tucson Indian Health Service Areas by assisting tribes with health surveillance, research, prevention, and program evaluation for planning and policy decision making in order to improve community health and wellness. The goal of the ITCA TEC is to build independent tribal capacities to collect and use community health information in directing programs, managing resources, and building relations with local, state, and federal public health systems.

The ITCA TEC provides technical assistance in the following areas:

- Improving disease surveillance capabilities through data analyses, interpretation, and dissemination of information;
- Providing communication and education for disease outbreak investigation and response;
- Developing epidemiologic studies; and
- Assisting with disease prevention and health promotion activities.

**ITCA TEC Staff:** Tribal Epidemiology Center Director, two Epidemiologists, a Part-time public health administrative specialist, and a Program manager.

## **ITCA TEC Projects**

Past and ongoing successful projects are described below.

### **Tribal Community Health Profile Project**

The main objective of this project is to assist American Indian Tribes in Arizona, Nevada and Utah, in identifying and addressing the important health issues and disparities that affect their community members and residents. Health information on American Indians and Alaska Natives (AI/ANs) is often not available, scattered among different data sources, or often characterized by poor data quality. Additionally, reliable health information is often not available at the Tribe or community level. A major part of this project involves identifying accurate and reliable data sources, using the information available to estimate the burden of disease at the Tribal level and compiling this information into a summary report. The ITCA TEC Community Health Profile Project aims to increase tribal capacity for epidemiology, data collection, and monitoring.

Through a tribally-driven and collaborative process of planning, data collection, analysis, report preparation, and information dissemination, tribal communities are engaged in defining and measuring community health status over time, and in implementing activities to improve health. Baseline and trend data from these reports are used by Tribes to prioritize or develop health promotion and disease prevention activities, serve as a reference for grant writing, and for seeking additional resources for under-addressed areas of health. In addition to preparing and updating the community health profiles on a regular basis, the ITCA TEC offers training assistance to tribal health staff in the use of the profile to support assessment, planning, and evaluation functions. Also, the ITCA TEC provides continuing technical assistance in epidemiology and share solutions found by other sites that use community health profiles.

### **Tribal Motor Vehicle Crash Injury Prevention Project (TMVCIPP)**

The TMVCIPP is a data-driven, community-based program that aims to prevent motor vehicle crash (MVC) related injuries among American Indians through coordination, collaboration, and information sharing between ITCA, tribal programs, state, and federal agencies. Through this project, participating tribes plan and lead the prevention efforts by implementing evidence-based strategies and increasing community awareness of the risk factors of MVC injuries. With assistance from the ITCA TEC, tribal coordinators promote codes and policies that support the prevention and reduction of MVC injuries, and tribal leadership becomes informed of systems approaches that address MVC injuries.

Project goals include the following: 1) Strengthen tribal government infrastructure, policies and activities that address disparities and improve current status of MVC related injuries in tribal communities; 2) Design, implement, or improve existing tribal MVC injury surveillance systems in collaboration with tribal partners; 3) Build and sustain tribal capacity to reduce MVC-related injuries and fatalities through the promotion and implementation of evidence-based MVC injury prevention strategies in collaboration with tribal partners; and 4) Promote and/or enhance career pathways for AI/AN health care professionals, paraprofessionals, researchers and students through knowledge- and skill-building trainings, technical assistance workshops and internships.



## **Southwest American Indian Collaborative Network (SAICN) - Cancer Research and Intervention Matrix**

The Southwest American Indian Collaborative Network was a special project of the ITCA, Inc. which aimed to eliminate cancer health disparities among American Indians in the Southwest through a collaborative approach with the Arizona Cancer Center and the Phoenix Indian Medical Center. The purpose of the SAICN project was to reduce cancer disparities by closing the gap between community needs and the promise of cancer prevention and cure through participatory education, training, and research programs. The ITCA TEC participated in this special project by leading the SAICN Data and Evaluation Core, which was one of the six core services implemented to address cancer health disparities at different system levels.

In an effort to provide evidence-based recommendations and promote the use of relevant data in tribal communities, the SAICN Data and Evaluation Core considered such issues as measures of cancer disparity, cancer sites, interventions that address disparities, and the impact and costs of these interventions. To generate a limited list of recommended actions that control cancer, the Data and Evaluation Core developed two comparison matrices that present scientifically sound practices for use by community health decision makers in prioritizing activities likely to reduce their respective community's burden of cancer. In their current configurations, Matrix A considers those cancers for which prevention and early detection interventions exist (cervical, breast, colorectal, tobacco-linked) and Matrix B addresses cancers for which interventions are unknown or not well developed. The matrices were converted into worksheet formats to facilitate their use at the community level. To further facilitate the application of this approach in a tribal community setting, guidelines for a five-part implementation plan were developed.

## **Substance Abuse Data Profiles**

The ITCA TEC partnered with the Arizona Substance Abuse Epidemiology Work Group within the Arizona Governor's Office for Children, Youth and Families, Division for Substance Abuse Policy to address limitations in substance abuse-related data for American Indians. This project was conducted in two phases. During the first phase, the ITCA TEC identified data-sources and barriers related to the substance abuse indicators, and gathered preliminary information about Tribal Substance Abuse Programs, data collection, management, analyses, reporting, and sharing methods conducted by the Tribal Substance Abuse

Programs. In addition, the ITCA TEC determined the feasibility of accessing and obtaining the data. During the second phase, the ITCA TEC worked closely with participating Tribes in Arizona to determine a methodology for collecting tribal-specific substance abuse data, and developed tribal-specific substance abuse profiles. Technical assistance was provided to the participating Tribes in the development of a plan for ongoing and regular data collection, analyses, and reporting.

### **Diabetes Projects – Tribal Diabetes Wellness Survey**

As a special project, the ITCA TEC partnered with a Tribal Diabetes Wellness Program to examine diabetes in the tribal community. The purpose of this analysis was to identify health and wellness issues related to diabetes prevention and treatment, and overall health by evaluating five years of health screening data. The Tribal Diabetes Wellness Center utilized the results of the data analysis in program planning, and in the development of interventions to improve the health of the Tribal members. Key findings and recommendations from this report were utilized to improve survey methods for assessing the Tribe's health status and provided baseline health data on diabetes-related indicators. The information from this report assisted the Tribal Diabetes Wellness Center and other programs to identify and reduce risk factors, and enhance the overall nutrition, fitness, and health status of the Tribal members. As diabetes is a major health concern among Tribes in the Phoenix and Tucson IHS Areas, the ITCA TEC addresses this health condition by conducting assessments, community health surveys, data analysis, and providing related technical support services. Based upon request, the ITCA TEC addresses diabetes on a larger scale through the assessment of tribal health programs including diabetes prevention and education projects and centers.

### **Tribal Public Health Accreditation Project**

To promote and increase the readiness of Tribal health departments to apply for national public health accreditation, the ITCA TEC collaborated with Red Star Innovations to conduct a baseline assessment of accreditation readiness and technical assistance needs among Tribes in the Phoenix and Tucson IHS Areas. The ITCA TEC convened a series of Accreditation Readiness Workshops that covered the accreditation process and benefits, self-assessment, and the three prerequisites of accreditation. In addition to the workshops, Tribal, state, local, and IHS stakeholders attended a Tribal Roundtable on Public Health

Accreditation to provide input and discuss tribal perspectives. Upon completion of this project, a tribal-specific accreditation readiness tool for conducting a community health assessment will be provided to the participating Tribal Health Directors and staff.

### **Partnerships**

An Epidemiology Working Group serves to provide feedback on the activities of the ITCA TEC, involve tribal public health professionals in the development of public health systems, and provide a means of communication with the tribes and project stakeholders. The ITCA TEC partners with the tribes, universities, and state and federal agencies through various programs and activities. Through grants and contracts, the ITCA TEC has on-going relationships with the faculty and staff of the University of Arizona.



July 8, 2013

Tribal Epidemiology Center Director  
Inter Tribal Council of Arizona, Inc.  
Tribal Epidemiology Center  
2214 North Central Ave.  
Phoenix, AZ 85004

RE: Letter of Support for Inter Tribal Council of Arizona, Inc. Tribal Epidemiology Center  
Grant No. AIAMP120075-01-01

Dear Tribal Epidemiology Center Director:

As the Executive Director of the Inter Tribal Council of Arizona, Inc. (ITCA) I would like to provide The Tribal Epidemiology Center (TEC) with this letter of program support. The ITCA TEC was established in 1996, and is one of the original four TECs funded through the Indian Health Service Cooperative Agreement (IHS). Over the past seventeen years, the ITCA TEC has demonstrated its benefit to the American Indian communities in the Phoenix and Tucson Service Area by providing high quality and responsive epidemiological services. The ITCA TEC is unique in the sense that this TEC provides services to 39 - 44 Tribes and bands in Arizona, Nevada, and Utah, as well as providing direct services to internal ITCA public health programs that work directly with tribal public health programs in the region.

The ITCA TEC has a strong track record of providing high quality epidemiologic services to a variety of health partners in a number of priority areas. The ITCA TEC has provided technical assistance and training to hundreds of tribal health department employees and Indian Health Service staff over the past seventeen years. Additionally, the ITCA TEC has been involved in a number of projects providing technical assistance to tribes. Some project highlights include: public health training and workshops, participation in national survey projects, data analysis and construction of community health profile (CHPs) reports, facilitation of a nationally award winning Tribal motor vehicle crash injury prevention project, and partnering with the Arizona Department of Health Services on a multi-state investigation of the risks factors of H1N1 in American Indian communities and the Rocky Mountain spotted fever outbreak on tribal lands in Arizona. During the most recent funding cycle in 2012, the ITCA TEC continues to provide services in five main areas:

- **Building public health capacity throughout the Phoenix and Tucson Services area.** Over 90 tribal health department members and Indian Health Service staff were provided training in at least one of the following areas: top public health concerns, basic epidemiology, cancer epidemiology, data management and survey design, Resource and Patient Management System (RPMS) Patient Care Components Outputs and RPMS Diabetes Module training, and Public Health Accreditation and Community Health Assessment workshops. A new *Public Health Workshop Pilot Process* is underway.

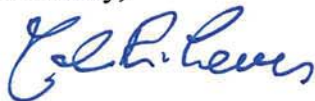
Ak-Chin Indian  
Community  
Cocopah Tribe  
Colorado River  
Indian Tribes  
Fort McDowell  
Yavapai Nation  
Fort Mojave Tribe  
Gila River Indian  
Community  
Havasupai Tribe  
Hopi Tribe  
Hualapai Tribe  
Kaibab-Paiute Tribe  
Pascua Yaqui Tribe  
Pueblo of Zuni  
Quechan Tribe  
Salt River Pima-  
Maricopa Indian  
Community  
San Carlos  
Apache Tribe  
Tohono O'odham  
Nation  
Tonto Apache Tribe  
White Mountain  
Apache Tribe  
Yavapai-Apache  
Nation  
Yavapai-Prescott  
Indian Tribe



- ***Focusing on health program quality improvement by revising and updating the program evaluation planning workshop, and providing program evaluation technical assistance for the following activities:*** ITCA Area Agency on Aging (AAA) & Arizona Indian Council on Aging (AICOA) program for elders, the NA SISTER HIV prevention and education program, the needs assessment and program evaluation of Indian Health Service dental programs, Community Tobacco Education and Prevention Program evaluation, a five year program evaluation report for Tribal Motor Vehicle Crash and Injury Prevention, and analysis and construction of the customer satisfaction reports of the tribal and urban Women, Infant, and Children's programs. TEC also conducted two evaluations of its programs and services to guide internal improvement and a long-range departmental strategic plan for 2012-2016.
- ***Collecting, cleaning, analyzing, reporting, and presenting health surveillance data*** with tribal, state, and Indian Health Service partners by using existing health data in the areas of cancer, diabetes, maternal and child health, motor vehicle crash, and injury prevention. TEC also supported several tribally-driven primary data collection data efforts including, a Behavioral Risk Factors Surveillance Survey (BRFSS), seat belt observation data collection, and two tribal health department satisfaction surveys.
- ***Responding to innovative requests for technical assistance in public health driven by our tribal partners.*** A partnership between tribes, Red Star Innovations consulting firm, and the ITCA TEC secured additional funding from the National Association of County and City Health Officials and the Robert Wood Johnson Foundation in order to provide additional training and technical assistance in the area of public health accreditation and community health assessment leading into 2014.
- ***Utilize advanced statistical methodologies in epidemiology to expand TEC's capacity and the ability to assist our Tribal and internal ITCA program partners using the latest advancements.*** Specifically, TEC is starting to expand high-quality services to include: social network analysis, multivariate statistics, geographic information system mapping and geospatial analysis, and advanced qualitative methods to work towards solving complex community health challenges with our partners.

The ITCA TEC provides a valuable service to partner tribes within the Phoenix and Tucson Service Area that cannot be met by any other agency or institution in the region. The TEC program has my strong support and ITCA looks forward to continued partnerships with Indian Health Service in the future. Please do not hesitate to contact me further with any additional questions regarding the ITCA TEC program.

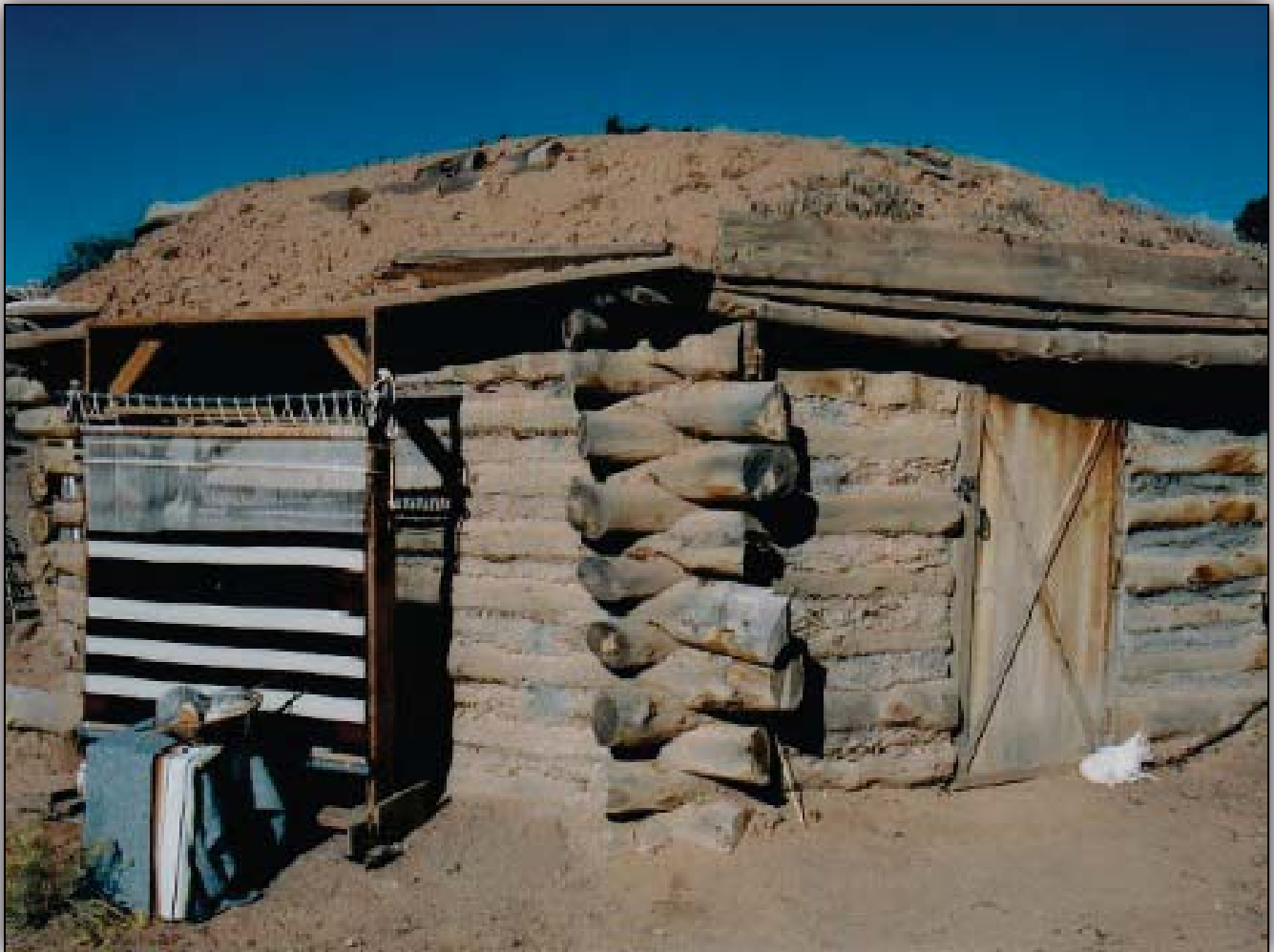
Sincerely,



John R. Lewis  
Executive Director



## Navajo Epidemiology Center (NEC)







## **Navajo Epidemiology Center (NEC)**

Navajo Division of Health (NDOH)

PO Box 1390

Window Rock, AZ 86515

Phone: 928-871-6254

Fax: 928-871-6255



## **American Indian/Alaska Native Population in the Navajo Area:**

The Navajo Nation is the largest federally recognized Indian tribe in the United States of America. The total estimated Navajo population is over 300,000. According to the recent estimated Navajo Area Indian Health Services population in 2010 was 246,000. A recent estimate of the Navajo population residing on the Navajo reservation is 235,554. An estimated 80,000 Navajo reside near or with “border towns” of the Navajo Nation.

## **Parent Organization**

The Navajo Nation is a three branch government with the Executive Branch managed by the Navajo Nation President and Vice President; The Legislative Branch conducted by the Navajo Nation Speaker and Council; and The Judicial Branch by the Chief Justice of Navajo Nation. Of the Executive Branch the Navajo Division of Health Improvement Services was established by the Navajo Nation Council in 1977 and amended in 1995 to what we now operate to as the Navajo Division of Health (NDOH). The NDOH is managed by the Executive Director Mr. Larry Curley and operates with the Executive Management with the Health Services Administrator, Chief Medical Advisor, Finance, Human Resources, Management Information System, Legislative Analysis, and the Office of Planning, Research, and Evaluation. The Navajo Epidemiology Center is one of the 14 operating programs of the NDOH parent organization.

## **Navajo Epidemiology Center (NEC)**

The Navajo Epidemiology Center (NEC) was established in 2005 as one of twelve Tribal Epidemiology Center grant recipients from the Indian Health Services of the U.S. Department of Health and Human Services. The NEC provides critical epidemiologic, public health, scientific, and data expertise to the NDOH, establish a health data center, and research center to enhance services and capacity. The NEC has forged many successful working relationships in and

around the Navajo Nation. These relationships are keys to improving public health capacity and practices on the Navajo Nation.

Expectations of the NEC are to identify the Navajo health status priorities for the Navajo Nation; develop/disseminate Navajo health reports; develop disease surveillance/prevention/control including notifiable condition reporting and conduct a Navajo Behavioral Risk Factor Surveillance System (NBRFSS); and, assist in public health emergencies – outbreak response. To accomplish these expectations, NEC must launch the NBRFSS, assist generate a Navajo Community Health Profiles, build upon the Navajo Area I.H.S. data sharing agreements, develop and obtain data sharing agreements with other health care providers on the Navajo Nation, such as, P.L. 93-638 tribal corporations and private health providers, identify and access high quality health data and disseminate epidemiological Navajo specific health reports.

Major accomplishments of the NEC were hosts of the first Navajo Nation Cancer Conference (July 2011); developed, published and disseminated two first-ever Navajo public health reports – *Cancer Among the Navajo 1995-2004* and *Report on New Mexico Navajo Mothers and Their Infants, 2000-2004*; signed memorandums of agreements with both Arizona and New Mexico to share state vital records data for tribal vital statistics reports; lead the Navajo Cancer Control Plan Internal Team; and, lead a multi-agency steering committee to design the methods and draft survey for the Navajo BRFSS. The NEC also provides technical assistance to many of the NDOH Programs to establish epidemiological frameworks to identify program effectiveness through meaningful data collections.

Aims for 2012 are to build our workforce capacity with additional epidemiologists, statistician/demographer and data manager; launch the NBRFSS and Community Health Assessment; strengthen our professional, scientific, political, and grassroots relationships among the Navajo communities, the states of Arizona, New Mexico, and Utah; and establish and implement health data sharing agreements; build health surveillance systems; publish reports on Navajo Nation Injury Report, Suicide Report, Vitals Report, update the Cancer and Maternal/Child Health reports, and the Youth Risk Behavioral Survey. An outcome of the Council of State and Territorial Epidemiologist (February 2012) is the establishment of the Navajo Nation Health Data Improvement Taskforce – lead by the NEC with objectives to strengthen

partnerships, conduct a tribal consultation and plan a Navajo Nation Health Surveillance Conference 2013. The Navajo Department of Health initiative is an opportunity for the NEC to construct a Data Center and Research Center as we continue to expand the NEC.

### **NEC Staff**

The NEC staff includes the director, an epidemiologist (funded by the Navajo Special Diabetes Project and the Navajo Health Education Program), a health planner; and an administrative assistant.

### **NEC Projects**

The NEC has multiple projects to conduct during the project period. Two major projects are through a Epidemiologist position cost-sharing agreement between the NEC and the Navajo Health Education Program and Navajo Special Diabetes Project. The major projects include data analysis and public health report generation on **HIV Screening, Youth Risk Behavioral Survey and Diabetes Program Information**.

***Navajo Behavioral Risk Factor Surveillance Survey*** is planned to launch summer 2012. A pilot Navajo Agency is selected, the methodology is in final stages, the survey instrument is in final editing stage, and we plan to present to the Navajo Nation Human Research Review Board prior to the implementation of the survey. The survey will be conducted in-person and is the first on the Navajo Nation.

***Vital Statistics*** secondary data analysis from primary sources the Arizona and New Mexico.

***Cancer Report*** data access from New Mexico to generate a second report.

***MCH Report*** data access from New Mexico to generate a second report on pregnancy risk assessment surveillance.

### **Partnerships**

Navajo Division of Health programs including the Navajo Health Education Program/HIV Prevention Program and the Navajo Special Diabetes Project.

The Arizona and New Mexico State Departments of Health

CSTE Navajo Nation Health Data Improvement Task Force including AZ, NM, UT States Department of Health, Navajo Area IHS and NDOH programs.

## Northern Plains Tribal Epidemiology Center (NPTEC)





## **Northern Plains Tribal Epidemiology Center (NPTEC)**

Great Plains Tribal Chairmen's Health Board  
(GPTCHB)

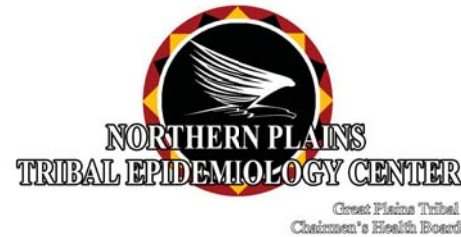
1770 Rand Road

Rapid City, SD 57702

Phone: 605-721-1922 or 800-745-3466

Fax: 605-721-1932

Email: [nptec@gptchb.org](mailto:nptec@gptchb.org)



[gptchb.org/nptec](http://gptchb.org/nptec)

### **Parent Organization**

The Great Plains Tribal Chairmen's Health Board was established in order to provide the Indian people of North Dakota, South Dakota, Nebraska, and Iowa 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. In pursuing this policy, the Board's objectives are:

1. To improve the effectiveness of the Indian Health program through responsible participation of the Indian people making decisions about their health services, in order to improve their health status.
2. To assist the Indian Health Service in establishing program priorities and in distributing existing resources.
3. To advise and assist the Director, Aberdeen Area Indian Health Service, in developing long-range program plans.
4. To represent the Indian interests and desires at all levels for health related programs.
5. To assist in development of Indian responsibility for community activities affecting health.
6. To assist member tribes in the development of health programs that will be beneficial to the Tribes.
7. To establish participation in any meetings that will provide clear and concise information to the Tribes
8. To represent the organization and member tribes in the Congress of the United States at any hearings and at National Organization meetings regarding health issues and care.



The Board is organized exclusively for non-profit purposes and will qualify as an exempt organization under Sec. 501(c)(3) of the Internal Revenue Code of 1954 (or the corresponding provision of any future United States Internal Revenue law).

### **Northern Plains Tribal Epidemiology Center (NPTEC)**

Founded in September 2003, the Northern Plains Tribal Epidemiology Center (NPTEC) is a program of the Great Plains Tribal Chairmen's Health Board (GPTCHB). Our mission is to provide leadership, technical assistance, support, and advocacy to the 18 Aberdeen Area tribal nations and communities in order to eliminate the disparities in health that currently exist for tribal people of the four-state region of Iowa, Nebraska, North Dakota and South Dakota.

Our goals are:

1. Provide Aberdeen Area tribes with reports of timely, accurate, and useful data on health priorities based on existing data sources.
2. Improve the ability of surveillance systems to measure and monitor the health status of American Indian populations through existing tracking or surveillance systems, and development of new surveillance activities
3. Support evidence-based culturally-rooted health promotion and disease prevention initiatives in clinical and community contexts
4. Build capacity to conduct health research in collaboration with academic institutions, including tribal community colleges and tribal schools, to ensure the benefits of well designed, culturally appropriate, and ethical health research reach Northern Plains AI communities
5. Improve public health and epidemiologic capacity in Northern Plains tribal communities.

Data and statistical information are critical to the public health mission of the Northern Plains Tribal Epidemiology Center. There are many different uses of data. The public health science of epidemiology relies on data to understand patterns of sickness and health in tribal communities. Data are also used to support the public health function of assuring that persons have access to appropriate health care and for assessing the effectiveness of that care. Finally, public health data may be used to inform the development and implementation of tribal, state, regional, and national health policies. Statistics are the set of tools that make it possible to analyze, study, and interpret data.



NPTEC is committed to helping Area tribes access health data in a way that is culturally appropriate and respects tribal sovereignty. The following activities advance this goal:

- Provide Aberdeen Area tribes with reports of timely, accurate, and useful data on health priorities
- Support the NPTEC mission, objectives, and activities across strategic focus areas
- Consult with tribal programs and AATCHB staff on data management issues
- Provide leadership to other public health agencies and workgroups on data issues affecting Northern Plains American Indians

NPTEC is also working to strengthen the public health infrastructure throughout the Aberdeen Area in order to address the lack of usable data for public health planning and evaluation at the local and regional levels.

The stated policy of the Indian Health Service is to encourage and increase Indian participation in every phase of the program; planning, operating, and evaluating service at all levels. The Aberdeen Area Tribal Chairmen's Health Board is established in order to provide the Indian people of the Aberdeen Area 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. In pursuing this policy, the Board's objectives are:

1. To improve the effectiveness of the Indian Health program through responsible participation of the Indian people making decisions about their health services, in order to improve their health status.
2. To assist the Indian Health Service in establishing program priorities and in distributing existing resources.
3. To advise and assist the Director, Aberdeen Area Indian Health Service, in developing long-range program plans.
4. To represent the Indian interests and desires at all levels for health related programs.
5. To assist in development of Indian responsibility for community activities affecting health.
6. To assist member tribes in the development of health programs that will be beneficial to the Tribes.

7. To establish participation in any meetings that will provide clear and concise information to the Tribes
8. To represent the organization and member tribes in the Congress of the United States at any hearings and at National Organization meetings regarding health issues and care.

The Board is organized exclusively for non-profit purposes and will qualify as an exempt organization under Sec. 501(c)(3) of the Internal Revenue Code of 1954 (or the corresponding provision of any future United States Internal Revenue law).

### **NPTEC Staff**

The NPTEC has on staff a Medical Epidemiologist/Director, a PhD-level Epidemiologist, a master-level data coordinator, and an administrative assistant.

### **NPTEC Projects**

#### Behavioral Health & Recovery Program

- Access to Recovery Program (ATR)

#### Maternal Child Health

- Northern Plains Healthy Start Program (NPHS)
- Sexually Transmitted Infections and Teen Pregnancy Prevention Initiative (STI/TPPI)
- Great Plains Ride Safe (GPRS)

#### Health Promotion & Disease Prevention

- Great Plains HIV Capacity Building Assistance (CBA/HIV)
- Cansasa Coalition
- Northern Plains Tribal Tobacco Technical Assistance Center (NPTTTAC)
- Northern Plains Tribal Cancer Data Initiative (NPTCDI)
- Northern Plains Comprehensive Cancer Control Program (NPCCCP)

#### Research & Academic Programs

- Native American Research Centers for Health (NARCH)
- Center of Excellence Childhood Obesity Program
- EPI/GIS Project: Mapping Pathways into Health

### **Key Health Topics**

## **South Dakota Tribal Pregnancy Risk Assessment Monitoring System (SDT PRAMS)**

The South Dakota Tribal Pregnancy Risk Assessment Monitoring System (SDT PRAMS) was a surveillance project of mothers with young infants that asked questions about maternal attitudes and experiences before, during and after pregnancy. The goal of the SD Tribal PRAMS' was to generate tribe- and state-specific American Indian prevalence estimates of factors related to pregnancy and early infancy. In 2008, the SDT PRAMS was one of 39 CDC-funded PRAMS projects in the US that are typically managed by state departments of health. The SDT PRAMS is the first tribally-driven PRAMS project ever conducted. The sample included women who lived on and off reservations, even if not American Indian, as long as the father of the newborn was American Indian. The project has completed a statewide surveillance report. Several presentations have resulted from the project. The SDT PRAMS data are currently being used by tribal and state department of health officials to help strengthen their capacity to improve maternal and child health in South Dakota. The report can be found at <http://www.aatchb.org/nptec/docs/SDT%20PRAMS%20Statewide%20Surveillance%20Report.pdf>

### **Partnerships**

GPTCHB primary partners are the 17 Tribes and one IHS (Trenton) Service area in the Northern Plains.

- Cheyenne River Sioux Tribe
- Crow Creek Sioux Tribe
- Flandreau Santee Sioux Tribe
- Lower Brule Sioux Tribe
- Oglala Sioux Tribe
- Omaha Tribe of Nebraska
- Ponca Tribe of Nebraska
- Rosebud Sioux Tribe
- Sac & Fox Tribe of the Mississippi Indians of Iowa
- Santee Sioux Nation
- Sisseton Wahpeton Oyate
- Spirit Lake Nation
- Standing Rock Sioux Tribe
- Three Affiliated Tribe
- Trenton Indian Service Area
- Turtle Mountain Band of Chippewa

- Winnebago Tribe of Nebraska
- Yankton Sioux Tribe

Since 2010 there has been annual Tribal engagement to evaluate, re-identify public health priorities, and to redirect GPTCHB resources to meet tribal public health needs.

In recent years, the NPTEC has developed highly collaborative and valued partnerships with the state health departments in this region. GPTCHB/ NPTEC works closely with each state health department to host annual public health meetings for the Tribal Health Directors and Tribal Leaders in the respective states. These efforts have resulted in the analysis and dissemination of the American Indian public health data to each Tribe, with available analysis of individual Tribal data upon support via Tribal resolution. Partner initiatives include:

#### State of South Dakota

- South Dakota Department of Health Cancasa Coalition
- South Dakota Smoke Free workplaces
- Community Grant Transformations (CTG)
- Annual State Meeting with South Dakota Department of Health and Tribes

#### State of North Dakota

- Annual State Meeting with North Dakota Department of Health and Tribes

#### State of Nebraska

- Annual State Meeting with Nebraska Department of Health and Human Services and Tribes

#### Centers for Disease Control and Prevention

- Northern Plains Tribal Tobacco Technical Assistance Center (NPTTAC)
- Great Plains HIV Capacity Building Assistance (HIV/CBA)
- Northern Plains Comprehensive Cancer Control Program (NPCCCP)

#### University of South Dakota (USD) via National Institute for Health (NIH)

- Center of Excellence Childhood Obesity Project

#### Indian Health Service

- Great Plains Ride Safe (GPRS)
- IHS Cancer Support Leadership Training
- Native American Research Center for Health (NARCH)

Department of Health and Human Services, Administration of Children and Families-Tribal Personal Responsibility Education Program for Teen Pregnancy Prevention (Tribal PREP)

- Sexually Transmitted Infections and Teen Pregnancy Prevention Initiative (STI/TPPI)

Office of Minority Health

- Northern Plains Tribal Cancer Data Initiative (NPTCDI)
- Northern Plains American Indian EPI/GIS Project: Mapping Pathways Into a Healthier Future
- Northern Plains Tribal Epidemiology Center

University of Nebraska Medical Center (UNMC)

- Academic Liaison

Department of Health and Human Services, Substance Abuse and Mental Health Service Agency (SAMHSA)

- Access to Recovery (ATR)

Indian Health Service, Division of Behavioral Health

- Northern Plains Behavioral Health Programs (MSPI Project)

University of Iowa, Prairie Addiction Transfer Technology Center (PATTC)

- Northern Plains Behavioral Health Programs – Native American Center of Excellence: Recovery Oriented Systems of Care (ROSC)

National Cancer Institute, Mayo Clinic, Spirit of Eagles

- Spirit of Eagles Communities Network Program

American Cancer Society

- ACS Circle of Life Curriculum

Health Resource and Service Administration (HRSA)

- Northern Plains Healthy Start (NPHS)

University of South Dakota, Sanford Research, National Indian Health

- Understanding the Context of Northern Plains American Indian Teen Pregnancy

Annual Site Visits with Universities

- University of Nebraska Medical Center
- University of Iowa
- University of South Dakota (Sanford Research)
- University of North Dakota
- North Dakota State University
- Black Hills State University



## Northwest Tribal Epidemiology Center (NWTEC)







## **Northwest Tribal Epidemiology Center (NWTEC)**

Northwest Portland Area Indian Health Board  
2121 SW Broadway, Suite 300  
Portland, OR 97201  
Phone: 503-228-4185  
Fax: 503-228-8182  
Email: [epicenter@npaihb.org](mailto:epicenter@npaihb.org)



[www.npaihb.org/epicenter](http://www.npaihb.org/epicenter)

### **American Indian/Alaska Native Population in the Portland Area**

The 2010 U.S. Census reported that in Washington, 103,869 individuals identified themselves as AI/AN alone, and 95,129 individuals identified themselves as AI/AN in combination with one or more other races, together accounting for 4.2% of the nation's AI/AN population. In Oregon, 53,203 individuals identified themselves as AI/AN alone, and 56,020 individuals identified themselves as AI/AN in combination with one or more other races; while in Idaho, 21,441 individuals identified themselves as AI/AN alone, and 14,944 individuals identified themselves as AI/AN in combination with one or more other races. Overall, in the 3 Northwest states that make up the Portland Area, a total of 344,606 individuals identify as AI/AN, alone or in combination.

There are 43 federally recognized tribes in the Portland Area – 5 in Idaho, 9 in Oregon, and 29 in Washington. The majority of the Indian Health Service (IHS) funded facilities in the Portland Area are governed by tribes and are sanctioned by Public Law 93-638. There are 34 tribally-governed facilities in Washington, 13 in Oregon and 4 in Idaho. There are also 9 service units operated directly by the IHS, including 5 reservation-based facilities, 4 urban Indian organizations (including the Seattle Indian Health Board), and one school-based clinic. According to the Indian Health Service, the most recent (FY2011) Indian user population estimate for the Portland Area was 107,281.

### **Parent Organization**

The EpiCenter serves under the auspices of the Northwest Portland Area Indian Health Board (NPAIHB), a tribal organization as defined by Public Law 93-638 and a 501(c)(3) non-profit organization, that is owned and operated by the 43 federally recognized American Indian tribes of Idaho, Oregon, and Washington.

Established in 1972, NPAIHB's mission is to assist Northwest tribes to improve the health status and quality of life of member tribes and Indian people in their delivery of culturally appropriate and holistic health care.

Delegates are the cornerstone of NPAIHB, providing direction and guidance on health related legislative activities, program direction and activities, NPAIHB program operations, and the organizational strategic plan. NPAIHB is proud of the many contributions that our member tribes have made to Indian related health issues in the Northwest and in Indian Country.

### **Northwest Tribal Epidemiology Center (NWTEC)**

In 1997, the Northwest Portland Area Indian Health Board (NPAIHB) received funding for the development of the Northwest Tribal Epidemiology Center (*The EpiCenter*), with the goal to assist member Tribes to improve their health status and quality of life.

The mission of the Northwest Tribal Epidemiology Center (The EpiCenter) is to collaborate with Northwest American Indian Tribes to provide health-related research, surveillance, and training to improve the quality of life of American Indians and Alaskan Natives (AI/ANs).

### ***Goals***

Tribal health research and surveillance priorities are identified by NPAIHB delegates on an annual basis. The EpiCenter's current goals include:

1. Assisting communities in implementing disease surveillance systems and identifying health status priorities.
2. Providing health specific data and community health profiles for Tribal communities.
3. Conducting tribal health research and program evaluation.
4. Partnering with tribal, state, and federal agencies to improve the quality and accuracy of AI/AN health data.

### **NWTEC Staff**

The EpiCenter, including all grant-funded projects administered by The EpiCenter, has over 49 employees and consultants. These include a PhD level Director, 2 medical epidemiologists (including an IHS assignee), 5 biostatisticians, 8 project directors, several PhD level Principal Investigators, 17 project

coordinators and project specialists, and over a dozen tribally-based or off-site staff and consultants. The EpiCenter also regularly offers internship opportunities to a small number of tribal members and/or college and university students.

## **NWTEC Projects**

### ***Immunization Monitoring Program***

In October 2008, the EpiCenter began the Immunization initiative to improve the rate of immunization coverage for children from birth to young adulthood in the Portland Area Indian Health Service. The Immunization Program works with all IHS and tribal clinics in Idaho, Oregon and Washington states. Services offered to all sites include; gathering of data through RPMS or electronic health records on a quarterly basis, evaluation of clinic data, and assistance in procuring vaccine supply as needed.

### ***Improving Data & Enhancing Access (IDEA-NW)***

Health status assessment for racial/ethnic groups is often hindered by the lack of complete and accurate data on race/ethnicity in surveillance systems, and AI/ANs are more likely to be misclassified than patients of other races. Death certificate race data is often recorded by coroners, funeral directors or medical examiners based on the decedent's appearance or other information. There may be hesitation to ask the next-of-kin questions about the decedent's race, and if the question is asked, the proxy may not answer as the decedent would have. Errors may be compounded when systems interact; for example, cancer and other disease registries often rely on death records for demographic data. The net result of racial misclassification for AI/ANs is under-counting of health events and underestimated disease and mortality rates.

In response to this problem, the Northwest Tribal Epidemiology Center formed the Northwest Tribal Registry Project in 1999 to conduct record linkages with various public health datasets. This project evolved into the current iteration, IDEA-NW (Improving Data & Enhancing Access), with funding from the Agency for Healthcare Research and Quality, funded from 2010-2013. IDEA-NW's goals are to improve the validity and reliability of AI/AN race data in state data systems and increase the availability of accurate and complete health status data for Northwest tribal communities, to inform public health decision-making and efforts to eliminate health disparities.

Improving race data in state data systems is achieved through record linkages with a list of known AI/ANs in the Northwest, the Northwest Tribal Registry (NTR). The NTR is generated from the registration data of Indian Health Service and tribal clinics in the Northwest, and it includes only demographic information (no health status or diagnostic information). Through a partnership with the Seattle Indian Health Board/Urban Indian Health Institute, the data set has been augmented to better represent urban AI/ANs living in the Seattle region. Other urban populations including Portland and Spokane are known to be under-represented in this work.

### ***Native Children Always Ride Safe (Native CARS)***

The goal of Native CARS is to prevent early childhood vehicle collision morbidity and mortality in AI/AN children through the use of a community based participatory research model that incorporates tribal differences in cultural beliefs, family and community structure, geographic location, law enforcement and economic factors.

Motor vehicle injuries are the leading cause of mortality for AI/AN children. Death rates from motor vehicle crashes among AI/AN under eight years of age are three times the national average. The proper use of child safety seats has been proven to reduce injury and death by 71% for infants and 54% for toddlers in passenger cars. Booster seats reduce the risk of serious injury by 59%.

American Indian children are at greater risk of preventable, injury-related deaths than other children and youth in the United States; this risk is due, in part, to the large proportion of children who are improperly secured in the car. In a recently conducted survey in six (6) NW Tribes, the majority of AI children rode unrestrained (41%) or improperly restrained (30%). The Native CARS project, funded by the National Center on Minority Health and Health Disparities (NCMHD) seeks to assist communities in assessing and forming strategies to address the disparity in vehicle collision morbidity and mortality.

### ***Northwest Native American Research Center for Health (NW NARCH)***

The overall goal of the NARCH Program is to increase the number of well-trained AI/AN researchers who are capable of conducting biomedical, clinical, behavioral or population-based research in diverse settings, especially focusing on projects relating to tribal health.

Carefully designed and implemented health research can provide solutions to help eliminate the vast disparities in health between AI/AN and non-AI/ANs. The Indian Health Service (IHS) and the National Institutes of Medicine has a joint partnership supporting the NARCH programs. The NARCH program at the NPAIHB currently hosts the Summer Research Training Institute for AI/AN Health Professionals on an annual basis. The Summer Institute regularly provided short-term, intensive education to over 100 students each summer.

The NARCH program also has two currently active research projects focusing on substance abuse and on adapting a recognized HIV prevention intervention and evaluating it for effectiveness in Indian Country.

### ***We R Native***

We R Native is a multimedia health resource for Native teens and young adults. The service includes a website ([www.weRnative.org](http://www.weRnative.org)), a weekly text messaging service, a Facebook page, a YouTube channel, a Tumblr account, a Twitter feed, and print marketing materials. Our goal is to provide holistic adolescent health information, promote positive youth development, share youth-friendly health media and current events, encourage healthy behaviors, reinforce positive messages, increase cultural identity and pride, and create a safe place where Native youth feel comfortable, empowered, and connected to other Native youth. The service is funded by the President's National HIV/AIDS Strategy and the Indian Health Service.

### **Partnerships**

The EpiCenter collaborates with its member tribes, other organization with a focus on Indian health, colleges and universities, and state health departments. We also have collaborative relationships with the other Tribal Epidemiology Centers. Our funding partners include Indian Health Service, the Centers for Disease Control and Prevention (CDC), the National Institutes of Health (NIH), the Substance Abuse and Mental Health Services Foundation (SAMHSA), the Health Resources and Services Administration (HRSA), and numerous foundations.



## **NORTHWEST PORTLAND AREA INDIAN HEALTH BOARD**

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Swinomish Tribe  
Tulalip Tribe  
Umatilla Tribe  
Upper Skagit Tribe  
Warm Springs Tribe  
Yakama Nation

The Northwest Tribal Epidemiology Center has been in existence at the Northwest Portland Area Indian Health Board for over 15 years. In 1997, the Northwest Portland Area Indian Health Board (NPAIHB) received funding for the development of the Northwest Tribal Epidemiology Center (The EpiCenter), with the goal to assist member tribes to improve their health status and quality of life. The EpiCenter was one of four centers originally funded following advocacy from tribal leaders who felt that having Tribal access to accurate data, would help public health planning, advocacy and ultimately increase knowledge that can lead to the elimination of health disparities.

The mission of the Northwest Tribal Epidemiology Center (The EpiCenter) is to collaborate with Northwest American Indian Tribes to provide health-related research, surveillance, and training to improve the quality of life of American Indians and Alaska Natives (AI/ANS).

Over the years the EpiCenter has generated seminal reports that have allowed our member tribes to have enhanced health information for those living in the NW. Key among those have been the tribal specific BRFSS, and data linkage project, which began with cancer linkages, but has broadened significantly in the past five years.

The EpiCenter has also developed a strong surveillance and research portfolio, which has funding from not only Indian Health Services, but the National Institutes of Health, the Substance Abuse and Mental Health Services Administration, and the Centers for Disease Control and Prevention. Funding is also gathered from other non-governmental organizations.

Projects have also been an important focus for the EpiCenter, including the activities of Project Red Talon, which has grown from an HIV/AIDS prevention program to a sweeping program engaging adolescents in enhancing health behaviors.

Finally, the EpiCenter has assisted in the training and education of many native public health professionals and researchers through the Native American Research Centers for Health (NARCH). The NARCH Summer Institute is offered each summer to enhance career development for those working at tribal Epidemiology Centers, Tribes and students. Topics are broad reaching and cover many aspects of public health, grant writing and data management.

I am proud of the contributions of the Northwest Tribal Epidemiology Center. I envision a bright future for the Center, as the staff works to continually enhance their commitment to the tribes of the Northwest.

Sincerely,

Joe Finkbonner, MHA, RPh,  
Executive Director,  
Northwest Portland Area Indian Health Board

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Portland, OR 97201  
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Oklahoma City Area Inter-Tribal Health Board (OCAITHB) Tribal Epidemiology  
Center (TEC)







## **Oklahoma City Area Inter-Tribal Health Board (OCAITHB) Tribal Epidemiology Center (TEC)**

PO Box 5826

Edmond, OK 73083

Phone: (405) 652-9200

Fax: (405) 840-7052

[www.ocaithb.org/SPIEC2.htm](http://www.ocaithb.org/SPIEC2.htm)

*Street address:* 9705 N. Broadway Ext., Suite 150,  
Oklahoma City, OK 73114

### **American Indian/Alaska Native Population in the Oklahoma City Area**

The Indian Health Service Oklahoma City Area (IHS-OCA) includes tribal members residing in Oklahoma, Kansas, and Texas. The area is subdivided into twelve service units. The American Indian and Alaska Native (AI/AN) population is estimated at 857,154 (U S Census 2010) identifying themselves as AI/AN alone or in combination with one or more races accounting for 16.5% of the nation's AI/AN population. Of forty-three federally recognized tribes situated in the three state area, 38 tribes have tribal headquarters in Oklahoma, four (4) in Kansas, and one (1) in Texas. The IHS user population of the IHS-OCA area is 335,579 (IHS Area Report, 2011). There is a combination IHS, Tribal, and Urban health care facilities (I/T/Us) located throughout the area. There are six hospitals, four of which are tribally operated and 55 outpatient care health centers including four urban clinics, one health station, and one school health center. IHS-OCA is home to some of the largest federally recognized tribes in the nation [Cherokee, Choctaw, and Muscogee (Creek)] as well as tribes whose membership total is less than 1,000. The Tribes are diverse in culture as they are in size.

Approximately fifty-percent of the health care delivery system is provided directly to tribal patients by the Indian Health Service, while the other approximately fifty-percent of health care is provided utilizing Public Law 93-638 through contracts/compacts.

### **Parent Organization**

The Oklahoma City Area Inter-Tribal Health Board (OCAITHB) established in 1972, is a tribal organization and recognized by the Internal Revenue Service as a 501 (c) (3) non-profit organization. OCAITHB serves 43 federally recognized American Indian tribes of Kansas, Oklahoma, and Texas, and four (4) Urban

Health clinics. The OCAITHB membership composition is representatives from the area Indian Health Service, Tribes and Tribal Health programs, and Urban Centers. OCAITHB maintains oversight of the Tribal-Epidemiology Center (TEC) and the Dental Support Center (DSC). The OCAITHB region is aligned as one of the twelve (12) Indian Health Service units in the United States. One goal of the organization is to provide a tribal perspective toward the development of health policy and health program operations impacting tribes. While OCAITHB does not directly operate health care facilities, it serves the Indian Health Service, Tribal and Urban programs (I/T/Us) as an advocate by representing the interests of the area at the State and National level. OCAITHB is centrally located in Oklahoma City.

### **OCAITHB Tribal Epidemiology Center (TEC)**

The TEC functions as a subdivision under the legal authority of the Oklahoma City Inter Tribal Health Board (OCAITHB). Oversight and guidance is provided by the TEC Advisory Council and by OCAITHB. The TEC Advisory Council is composed of OCAITHB board of directors, tribal health representatives, IHS representatives, and academia. Day to day program oversight is under the direction of a TEC manager. The TEC received funding through an IHS cooperative agreement in 2004 and began operating in early 2005. The TEC serves the largest IHS user population area in the U.S. (IHS, 2011). The TEC's mission is to improve the health of American Indian/Alaskan Natives (AI/AN) in Kansas, Oklahoma and Texas by providing public health services in epidemiology, data management and analysis, training, evaluation, health promotion/disease prevention and research through outreach and creative partnerships.

The center collaborates with tribal health representatives and American Indian communities to collect, analyze, identify, and interpret health related data to prioritize health care objectives. TEC staff disseminates valuable health research and information regionally and nationally amplifying awareness of AI/AN health disparities. The TEC also appraises tribal partners of funding sources and potential grant opportunities.

### **TEC Staff**

The TEC employs eight staff: a manager; four epidemiologists; a public health training coordinator; a project grant coordinator; and an administrative assistant.

## **Selected TEC Project Summary**

A partial listing of selected projects or programs being administered by TEC staff includes:

### ***AI/AN Health Disparities Project***

The primary objective for the Office of Minority Health AI/AN Health Disparities project is to reduce health disparities in the AI/AN population. The TEC completed a linkage project between the Oklahoma Central Cancer Registry and the Indian Health Service. A similar linkage project was conducted using communicable disease data from the Oklahoma State Department of Health. The TEC also developed a cultural competency curriculum and hosted several trainings with the new material; an online version of the training is being developed for tribal health care professionals. The grant award allows the TEC to sponsor a graduate internship program for AI/AN students or students interested in working with AI/AN communities working toward obtaining a Master of Public Health degree.

### ***Tribal Community Health Profiles Project***

One objective of the project is to obtain tribal area specific health information to create community health profiles (CHP) for tribal communities to assist with determining health priorities. The TEC created community health profiles for all 43 tribes in Oklahoma, Kansas, and Texas. Health data for the profiles were obtained from reputable sources yet considered secondary data. The TEC worked closely with the Oklahoma State Department of Health on the project. The profiles indicate health status, outcomes, and trends based on county specific data. The TEC used designated tribal jurisdictional areas aligned them at the county level data to reflect a snapshot of the tribe's health. The second phase of this project is underway and shall include additional tribal specific data for a more accurate representation of each tribe's health.

### ***Tribal Epidemiology Center Consortium (TECC)***

Through collaborative effort between the Northwest Portland Epi Center, OCAITHB TEC and California Rural Indian Health Board's Epi Center, a tribal Injury Prevention Toolkit was created. The Injury Prevention Tool Kit material included current trends, fact sheets of the more common types of injury for the AI/AN population, social media (flyers, etc.) that can be duplicated for dissemination, and printed material identifying specific ways to avoid and prevent injuries. Distribution of the toolkits was by hard copy and in electronic format (CD's). The

collaboration also provided car seat safety events where children's car seats were provided to families in need and free children's car seat safety inspections to parents with car seats. The car seats were inspected for safety and checked for being properly installed by a nationally licensed car seat safety technician. Education and installation instructions were offered to parents. Smoke and carbon monoxide detectors were also distributed to any AI/AN with a need.

### ***Methamphetamine and Suicide Prevention Initiative (MSPI)***

The Oklahoma City Area Inter-Tribal Health Board's role in the Methamphetamine and Suicide Prevention Initiative (MSPI) is to provide training and technical assistance regarding implementation and data collection, as well as to assist MSPI programs with the evaluation in the Oklahoma City Indian Health Service Area. The TEC gives oversight to 23 different tribal programs in the Oklahoma City Area.

### ***Strategic Prevention Framework State Incentive Grant (SPF SIG)***

The Oklahoma City Area Inter-Tribal Health Board TEC partnered with four area tribes to form the Oklahoma Inter-Tribal Consortium (ITC) to apply and receive a substance abuse prevention grant from the Substance Abuse and Mental Health Services Administration (SAMHSA). Objectives of the SPF SIG are to prevent the onset and reduce the progression of substance abuse including underage drinking, reduce substance abuse-related problems, and build prevention capacity and infrastructure at the tribal and community levels. Since tribal reservations are absent in Oklahoma, 15 Oklahoma counties were selected to be targeted with the cooperative agreement correlating somewhat with original tribal jurisdiction boundary areas.

### **Partnerships**

The TEC collaborates with a wide array of partners to implement its projects and obtain additional funding. For funding opportunities, the TEC works with Indian Health Service (IHS), Office of Minority Health (OMH), and the Substance Abuse and Mental Health Services Administration (SAMHSA). TEC stakeholders and technical advisors for various projects include the National Institute of Health (NIH), Center for Disease Control (CDC), Indian Health Service (IHS), National Association of Public Health Statistics and Information Systems, the Oklahoma and Kansas State Department of Health, and the University of Oklahoma, College of Public Health. Other coalition activities the TEC is involved include Oklahoma Inter-Tribal Emergency Management Coalition, Methamphetamine

Suicide Prevention Initiative, Native American Injury Prevention Coalition, Oklahoma Central Cancer Registry, Oklahoma Healthy Mothers Healthy Babies Advocacy Coalition, Oklahoma Healthy Mothers Healthy Babies Awareness Coalition, Oklahoma State Department of Health Infant Safe Sleep Workgroup, Oklahoma Inter-Tribal Diabetes Coalition, Oklahoma Toddler Survey Steering Committee, Oklahoma Maternal Mortality Review Board, Oklahoma Pregnancy Risk Assessment Monitoring System Steering Committee, Oklahoma University American Indian Diabetes Prevention Center Research Committee, and others.



# OKLAHOMA CITY AREA INTER-TRIBAL HEALTH BOARD

P.O. Box 5826 • Edmond, OK 73083 • [www.ocaithb.org](http://www.ocaithb.org) • (405) 951-6005 • Fax (405) 951-3902

August 20, 2013

Dear Tribal Epidemiology Center Director:

The Oklahoma City Area Inter-Tribal Health Board (OCAITHB) was established in 1972 to provide a unified voice for tribes in the states of Kansas, Oklahoma, and Texas. I would like to submit this letter of support for the Tribal Epidemiology Center (TEC).

The mission of the OCAITHB and the TEC is to improve the health and quality of life of Native American communities through advocacy and education with federal, state and local entities while maintaining tribal sovereign rights.

Since it began in 2005, the TEC has provided the 43 tribes in our area with much needed epidemiologic services. These services include developing local community health profiles, providing health education and training, data analysis, program evaluation, survey development and implementation, and much more. Through these services, the tribes in our area have enjoyed having access to quality health information and better health outcomes. The TEC also works closely with many of the state and local agencies to provide consultation on how best to respect tribal values and ideals when working with tribal communities.

The staff at the TEC have shown great commitment to the tribes in our area and I look forward to their continued progress and accomplishments. It is for these reasons that I wish to show my support for the TEC and all the amazing work that they are doing for our tribes.

Sincerely,

Diddy Nelson  
Executive Director  
Oklahoma City Area Inter-Tribal Health Board

Absentee Shawnee Tribe

Alabama Quassarte Tribal Town

Apache Tribe of Oklahoma

Caddo Tribe of Oklahoma

Cherokee Nation of Oklahoma

Cheyenne & Arapaho Tribes

Chickasaw Nation

Choctaw Nation of Oklahoma

Citizen Potawatomi Nation

Comanche Nation

Delaware Nation

Delaware Tribe of Indians

Eastern Shawnee Tribe

Fort Sill Apache Tribe

Iowa Tribe of KS & NB

Iowa Tribe of Oklahoma

Kaw Nation

Kialegee Tribal Town

Kickapoo Tribe in Kansas

Kickapoo Tribe of Oklahoma

Kickapoo Tribe of Texas

Kiowa Tribe of Oklahoma

Miami Tribe of Oklahoma

Modoc Tribal Council

Muscogee (Creek) Nation

Osage Nation

Otoe-Missouria Tribe

Ottawa Tribe

Pawnee Nation

Peoria Tribe

Ponca Tribe of Oklahoma

Prairie Band Potawatomi Nation

Quapaw Tribe of Oklahoma

Sac & Fox Tribe of Missouri

Sac & Fox Nation of Oklahoma

Seminole Nation of Oklahoma

Seneca-Cayuga Tribe

Shawnee Tribe of Oklahoma

Thlopthlocco Tribal Town

Tonkawa Tribe of Oklahoma

United Keetoowah Band of Cherokee

Wichita & Affiliated Tribes

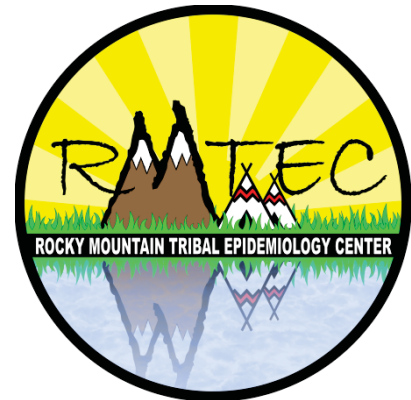
Wyandotte Nation

## Rocky Mountain Tribal Epidemiology Center (RMTEC)





**Rocky Mountain Tribal Epidemiology Center (RMTEC)**  
Montana Wyoming Tribal Leaders Council (MTWYTLC)  
175 North 27th ST. Suite 1003  
Billings, MT 59101  
Phone: 406-252-2550  
Fax: 406-254-6355



[www.rmtec.org](http://www.rmtec.org)

### **American Indian/Alaska Native Population in the Billings Area**

The Billings Area includes the Montana and Wyoming Tribes: Tribes on 8 Reservations in Montana and Wyoming with an American Indian (AI) population of approximately 75,891 (US Census, 2010).

### **Parent Organization**

Montana Wyoming Tribal Leaders Council (MTWYTLC), the parent organization of RMTEC, provides RMTEC a link to all Tribes in the region.

### **Rocky Mountain Tribal Epidemiology Center (RMTEC)**

RMTEC started in the fall of 2005 in collaboration with multiple stakeholders. A 5-year cooperative agreement with Indian Health Services (IHS) to support RMTEC was awarded in 2006 and provides the current core funding for RMTEC activities. All RMTEC projects were developed through a Community Based Participatory Research (CBPR) approach, with Community Health Priorities presented by RMTEC advisory group. RMTEC's advisory group includes Montana and Wyoming Tribal Leaders and Tribal Health Directors, which represents all of the Tribes and Reservations served by Billings Area Office – Indian Health Service (BAO-IHS). The Advisory Council provides guidance and assistance to RMTEC and also serves on the MTWYTLC Board's Committee on Health. RMTEC Mission is to empower American Indian Tribes in Montana & Wyoming in the development of Public Health services and systems and epidemiological data in order for Tribes to have resources and express their authority in response to Public Health concerns.

RMTEC staff members travel several times a year for various projects and as a team (RMTEC Round Trip) at least once a year to present Reservation Specific Community Health Profile data and emerging projects to each Tribal Health Director (the Community Health Gate Keeper of the Reservations) and their staff on each Reservation.

### ***RMTEC Goals***

1. Strengthen Individual Tribes' Public Health Infrastructure and Capacity.
2. Improve Surveillance Data for Health Conditions and Diseases.
3. Provide Data and Technical Assistance to Support Health Promotion, Disease Prevention (HP/DP) Objectives and Behavioral Health Strategies.
4. Implement Pilot Projects and Specific Studies to Address Tribally Identified Health Priorities and Support Tribal Community Based Participatory Epidemiological Studies.
5. Develop Tribal/Urban Indian Community Health Profiles and Tribe Specific Data Collection Initiatives.

### ***RMTEC 5 Focus Areas***

- Capacity Building
- Infectious Disease/Chronic Disease and Public Health Ethics
- Healthy Lifestyles
- Environmental Health and Disease Prevention
- Community Health Profiles and Emerging Projects

### ***RMTEC Staff***

RMTEC has a staffing capacity of 12, which currently includes a Senior Epidemiologist/Acting Director (MD, MPH); an MPH Statistician; an MSPH Infectious disease and Emergency preparedness Epidemiologist; four (4) Project Coordinators; an Administrative Assistant; an AmeriCorps VISTA member; and a local Tribal Research Assistant (Montana Wyoming Native Youth Development Project Intern).

### ***RMTEC Projects***

#### ***Strengthening Tribal Public Health Infrastructure for Improved Health Outcomes***

Strengthening Tribal Public Health Infrastructure for Improved Health Outcomes project is funded by the Center for Disease Control and Prevention (CDC). The project goal is to systematically increase performance management capacity of Tribal Health Departments in Montana and Wyoming in order to ensure Tribal Health Departments have access to resources needed to express their public health authority.

RMTEC implements the National Public Health Performance Standards Programs (NPHPSP) and Mobilizing for Action through Planning and Partnerships (MAPP) process among Montana and Wyoming Tribes, strategizing on ways to

strengthen public health infrastructure; develop work plans based on community need assessments, health data; and prioritize prevention and wellness initiatives, through Performance improvement including Workforce Development. RMTEC also hopes to improve the Tribal Public Health System and Policy development, encouraging Public Health Best/Promising Practices among Montana and Wyoming Tribes.

### ***Community Health Profiles***

In order to address health and public health disparities, data is needed for all population groups including hard to reach population such as American Indians living on rural Reservations. Numerous Healthy People 2010 & 2020 indicators speak to the need for public health infrastructure. This includes public health data that is essential to provide effective public health services for data for all population groups; data for Leading Health Indicators, Health Status Indicators, and Priority Data Needs at Tribal, State, and Local levels and National Tracking of Healthy People 2010 & 2020 objectives.

RMTEC continues to work with Wyoming Department of Health, Montana Department of Health and Human Services, IHS and Montana KIDS Count (University of Montana-Missoula), to develop Community Health Profiles for each Reservation in the Billing IHS Area based on county and American Indian population group census data. The data is used to help drive decision making and health priorities of each of the Montana and Wyoming Reservation.

### ***Suicide Data Tracking Project***

Suicide data is crucial in understanding and preventing suicides on the Montana and Wyoming Reservations, however, suicide data on Montana/Wyoming Reservations are severely underreported. There are only a few agencies/departments in the community that collect suicide data and these data are not shared between agencies/departments offering treatment or other services to suicidal individuals and/or their family members. The Suicide Data Tracking Project augments the current IHS suicide tracking database (augmented by IHS staff as needed). The qualitative pilot study on three Reservations in Montana and Wyoming improved the process of collaboration between the Indian Health Service (IHS) and all other Tribal agencies/departments with a responsibility towards suicidal patients. Multi-institutional collaboration and agreements were developed and implemented. Community integration and trust and a lot of negotiation for resolutions and

Memorandum of Understanding (MOU) were important. Without any of these, the Suicide Data Tracking Project will not succeed on any Reservation. Because of the trust the community had in the project and the coordinators, the coordinators received references from various community members and institutions even before the medical team or law enforcement were notified; the process of data collection on each case reported was documented with a detailed account of the obstacles faced by the data collector. Both conventional and non-conventional method was allowed in obtaining more complete Tribal data on suicide attempts and completions. "One Tribal Form" was completed for each case and referrals were made to Behavioral Health Professionals by the coordinators. The more complete Tribal data was used to understand suicide and suicide attempts and initiate intervention plans on Reservations. IHS Behavioral Health Personnel were Principle Investigators (PI) for this project.

### ***Child Health Measures***

Native Americans have one of the highest prevalence of obesity among North American youth. Overweight and obesity among youth is associated with the increased risk for pre-diabetes, metabolic syndrome; type 2 diabetes (with insulin resistance) and heart disease. The purpose of the project is to help inform participating Tribes on health measures associated with the risks for childhood obesity, diabetes, and heart disease among participating Tribe's children. The project screens children in kindergarten through high school with the following measurements: Weight/Height (BMI), Blood Pressure, presence of Acanthosis, Asthma diagnosis and family history of disease annually. Trained Tribal field workers and school teachers/nurses (over 50 per year) who volunteer to help with the project measurements from participating Reservations work with RMTEC staff to implement the project. Currently Seven (7) out of Eight (8) Reservations measure their school children annually. Over the past five years there has been over 13,000 measurements.

### ***Montana-Wyoming Native Child and Youth Project***

A major benefit of providing safe play areas for children is the social skills that children gain on the playground that become lifelong skill sets that are carried forward into their adulthood. Independent research concludes that playgrounds are among the most important environments for children outside the home. Most forms of play are essential for healthy development, but free, spontaneous play—the kind that occurs on playgrounds—is the most beneficial type of play.

Unfortunately, many low-income communities do not have developmentally-appropriate, well-designed, safe playgrounds: this limits options for incorporating active play into the child's day, and contributes to inequitable health outcomes.

The purpose of the MT-WY Native Child and Youth project is to promote the body, mind and spiritual well-being of Montana and Wyoming American Indian School age children and youth, ages 5 to 19 years by refurbishing safe and accessible play places for children in the Reservation Communities, encouraging healthy traditional foods and culturally appropriate emotional well-being and social skills development.

The project process includes, outreach, community mobilization, community project planning, playground refurbishment, recreation aid training and program evaluation. The project also provides funding for Staff Recreation Guides to ensure child safety and supervision via the S.A.F.E. Playground Assessment Training & Certification.

## **Partnerships**

RMTEC partners with several institutions including academic institutions and research organizations (i.e. Avera Research Institute/Sanford School of Medicine, University of South Dakota) to implement its projects and seek supplemental funding opportunities and grants. RMTEC's relationships with academic and other research organizations are fostered, in part, by the partnerships that the parent organization, MTWYTLC has in place. RMTEC also partners with Montana and Wyoming State Health Departments, various county health departments including the Yellowstone County Health Department also known as Riverstone. RMTEC also partners with the Tribes, Tribal Health Departments, Tribal Chemical Dependency programs, Tribal Behavioral Health Departments, Tribal Social Services, and the BIA. RMTEC stakeholders and team of technical advisors for various projects include the National Institute of Health (NIH), Center for Disease Control (CDC), Indian Health Service (IHS) and Prevention and the Performance Standards and Accreditation National Association of Local Boards of Health (NALBOH). In order to address all Community Health Priorities, RMTEC has with the help of its parent body; MTWYTLC pursued other sources of funding to augment its core funding from IHS. Other RMTEC funding agencies include: Agency for Healthcare Research and Quality (AHRQ); Robert Wood Johnson Foundation (RWJ); Office of Minority

Health (OMH); American Legacy Foundation; OMH American Indian Physician Association (AAIP); Native American Management Services; CDC and Public Health Law - Georgetown University. Some Cancer stakeholders and partners include: Crow-Northern Cheyenne; Montana Department of Health and Human Services, Montana Comprehensive Cancer Control (MTCCC); Participating Montana Cancer Control Programs; Montana Cancer Institute Foundation, American Cancer Society; American Indian Tobacco Prevention Specialists; Benefis-Sletten; Cancer Institute; Billings Clinic; Bozeman Deaconess; Indian Family Health Clinic; Montana American Indian Women's Health Coalition (MAIWHC); Montana Family Planning Clinics; Montana Tobacco Use Prevention Program (MTUPP); Northwest Healthcare; Planned Parenthood; Respecting the Tobacco Way; Shodair; St. Peters Hospital; St. Vincents Hospital and Susan Komen for the Cure Foundation.

***Disclaimer:*** *The results presented in this report are for your review only and are not to be referenced or duplicated without permission from the Montana Wyoming Tribal Leaders Council. For clarifications, please contact Folorunso Akintan at MTWYTLC/RMTEC, 175 North 27<sup>th</sup> Street Suite 1003, Billings MT 59101, or call (406) 252-2550; e-mail: [fakintan@mtwytlc.com](mailto:fakintan@mtwytlc.com)*





## Montana & Wyoming Tribal Leaders Council

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### Executive Letter

JUN 07 2013



Dear Colleagues:

We are pleased to present the Rocky Mountain Tribal Epidemiology Center. The Rocky Mountain Tribal Epidemiology Center fulfills the Indian Health Service Tribal Epidemiology Center core funding epidemiology grant for Montana and Wyoming Tribes. The Rocky Mountain Tribal Epidemiology Center was established in 2005 and is the designated Tribal Epidemiology Center for Montana and Wyoming Tribes, with Resolutions from all Tribes in support of its activities.

The mission of the Rocky Mountain Tribal Epidemiology Center is to empower American Indian Tribes in Montana and Wyoming in the development of Public Health services and systems and epidemiological data in order for Tribes to have resources and express their authority in response to Public Health concerns.

All Montana and Wyoming Tribal Health Departments participate in the Rocky Mountain Tribal Epidemiology Center projects which is based on Local Tribal Health priorities; a community participatory approach.

The Rocky Mountain Tribal Epidemiology Center activities include Surveillance, Capacity Building and Epidemiological Intervention activities, presented in this report.

We fully support our epidemiology center and are proud of it. We appreciate the epidemiological work accomplished by the center over the years.

Sincerely,

Gordon Belcourt,  
Executive Director  
Montana Wyoming Tribal Leaders Council



## United South and Eastern Tribes, Inc. (USET) Tribal Epidemiology Center



**United South and Eastern Tribes, Inc. (USET) Tribal Epidemiology Center**

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<http://www.usetinc.org/Programs/USET-THPS/TribalEpiCenter.aspx>



**American Indian/Alaska Native Population in the Nashville Area**

Current estimates put the American Indian/Alaska Native (AI/AN) population in the service area at approximately 135,000, with 60,000 residing on or near reservations and an additional 75,000 residing in non-reservation communities.

**Parent Organization**

The United South and Eastern Tribes, Inc. (USET) is a non-profit, inter-Tribal organization comprised of 26 federally recognized Tribes in 12 eastern and southern states. USET is dedicated to promoting Indian leadership through Indian involvement and responsibility at all levels of Indian affairs, including improving the quality of life for Indians through health, education, social services and housing opportunities; promoting better understanding of the issues involving Indian Tribes; and protecting Indian rights and natural resources on Tribal lands.

USET serves American Indian/Alaska Native (AI/AN) people in the 22-state region known as the Indian Health Service (IHS) Nashville Area which spans from Maine to southern Florida to eastern Texas. Within this region there are 28 Tribes and two Urban Indian Health Organizations, with 26 of these Tribes comprising the USET organization. USET provides the structure for multiple AI/AN public health activities that are integrated with the Indian Health Care Delivery system of each of the Tribes. The USET member Tribes have a variety of healthcare facilities, including hospitals, ambulatory care centers, rural health clinics, health stations, alcohol and substance abuse programs, and/or contract health services only sites. Three of the USET Tribes receive services at healthcare facilities operated by the IHS and the remaining Tribes receive services at Tribally operated health care facilities.

Because USET's guiding principle is unity, USET plays a major role in the self-determination of the member Tribes in promoting better Tribal health through its Tribal Health Program Support office (THPS). The USET THPS includes the Health Information Office, Tribal Epidemiology Center, the Nashville Area Diabetes Program, the Dental Support Center and the Tribal Data Quality Support Program. The USET THPS team also facilitates the operation of the USET Tribal Health Directors' Committee, which represent the management of each Tribe's health care program

### **USET TEC**

The mission of the USET TEC is to help the USET Tribes monitor and communicate community health status and build public health infrastructure. This regional center has been in operation since the year 2000. Among the 26 Tribes served by USET TEC, 23 currently obtain health care services through 638 contract arrangements, and three of the Tribes still receive direct IHS service delivery. USET was awarded its first TEC cooperative agreement in 2000. Initially, the USET TEC operation was located at Johns Hopkins University in Baltimore, Maryland. In 2004, USET moved its TEC operations to its headquarters office in Nashville, TN.

### **USET TEC Staffing**

At the present time, USET TEC has 5 full-time employees with epidemiological and statistical backgrounds. Additional program oversight is provided by the USET Tribal Health Program Support Assistant Director.

### **USET TEC Projects**

A sample of projects the USET TEC staff members have developed are highlighted below:

#### **Domestic Violence Audit Project (DVAP)**

The objective DVAP is to pilot Tribal use of the Praxis Safety and Accountability Audit (Safety Audit) to improve domestic violence identification, documentation, treatment and prevention. The Safety Audit is based on the idea of a coordinated community response to domestic violence from the standpoint of people in their everyday lives. Safety Audits are meant to be conducted by an interagency team of advocates and practitioners by utilizing interviews, observations, and text analysis to examine the ways in which institutions standardize and coordinate workers' actions to produce interventions that enhance or diminish safety for battered women and their children. Safety

Audits serve as tools to identify gaps in services and form problem-solving teams to improve the safety of victims of domestic violence.

### **Maternal and Child Health Certificate Program**

The Maternal and Child Health Certificate Program is a joint effort between the University of Arizona, University of Kentucky, and USET. The goal of the program is to assist workers serving women and children in rural, medically-underserved Tribal regions to develop epidemiological skills. The two-year curriculum is comprised of 15 graduate credit hours that can be applied towards a Master in Public Health degree. The USET TEC assists with promoting and evaluating the success of the program.

### **Native American Research Center for Health (NARCH)**

In collaboration with Vanderbilt University, the mission of USET's NARCH project is to foster training of AI/AN scientists and research focused on improving AI/AN health. To date this program has supported AI/AN STEM education for high school and undergraduate students and research about promising diabetes interventions. Newly proposed activities currently under review include training about Community Based Participatory Research and research about Historical Trauma.

### **Passing on Healthy Traditions through Breastfeeding**

For some mothers, breastfeeding is easy. For others, breastfeeding is a challenge and needs the support of all family members and relatives to be successful. This program shared the latest breastfeeding information by training Peer Counselors. The TEC staff worked with the Tribal program to demonstrate its successful impacts.

### **Population Health Data Portal**

In 2012 USET began developing a Data Portal that would include a Data Center, a secure web based portal that can be accessed by appointed Tribal officials. The Data Portal contains two sections of data retrieval: data queries (i.e. Mortality and Birth) and selected indicators (i.e. Tobacco Use, Immunizations, and Obesity). The data queries section allows the user to run customized reports based upon certain criteria; whereas the selected indicators contains only statistics that have already been calculated and compared to Government and Performance and Results Act (GPRA) indicators and Healthy People 2020



goals. This project will replace the past written Community Health Profiles. The Data Portal site will go live by the end of 2013.

### **Tribal and Area Aggregate Diabetes Report**

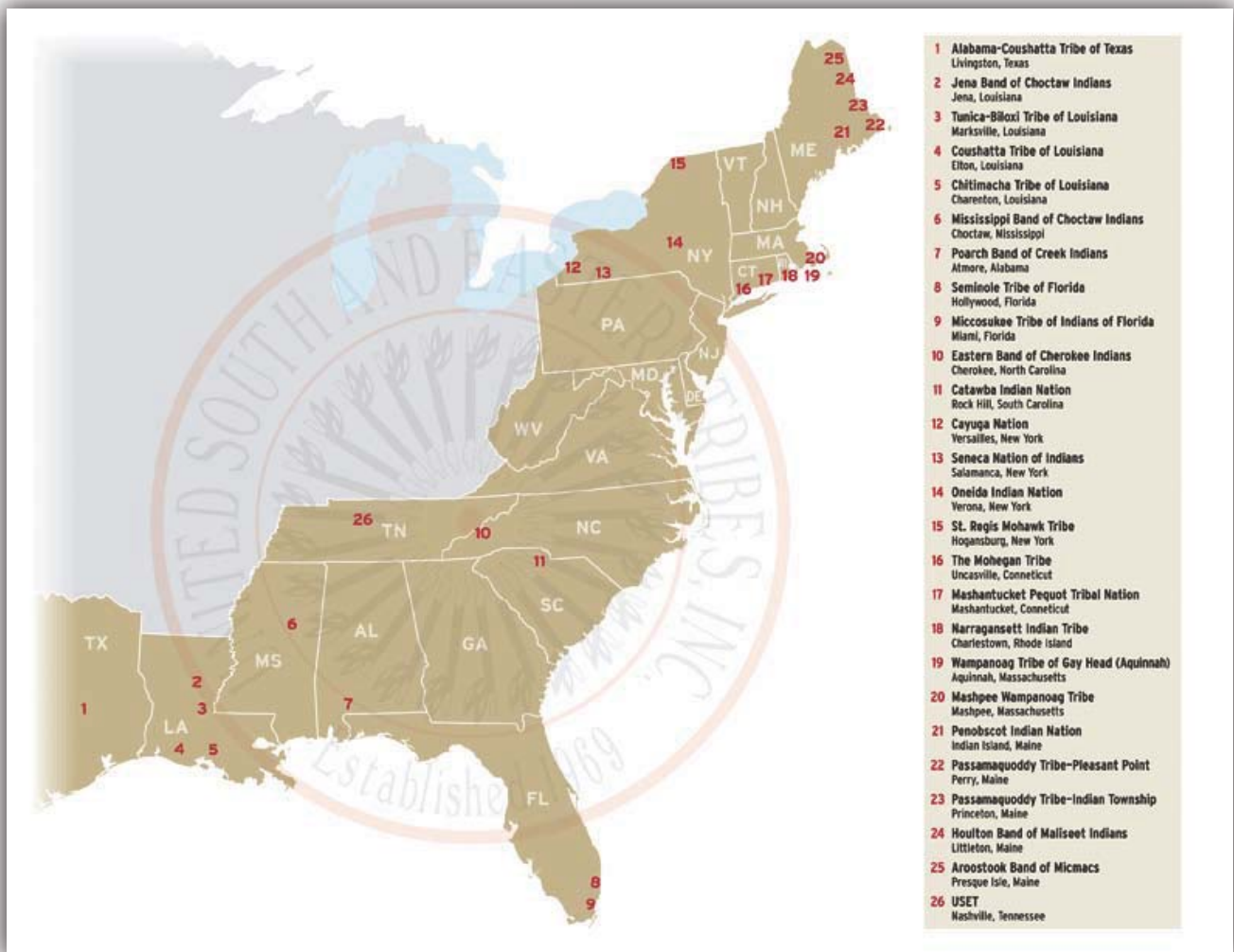
USET TEC continues to develop, produce, and distribute Tribal-specific and area aggregate diabetes reports on an annual basis. These reports include analyses of community-specific diabetes prevalence, the health status of persons with diabetes being treated at a particular Tribal health care system, and how well the local diabetes program is meeting the IHS standards of care for persons with diabetes based on the annual IHS diabetes audit data. These reports are in support of the USET-run diabetes prevention and intervention initiative.

### **Other Reports**

In addition to the diabetes reports, the USET TEC has prepared: Community Health Profiles, Elder Health, Mortality, Hypertension and Social Determinants of Health reports.

### **Partnerships**

USET TEC has collaborated with faculty from D'Youville College in New York, Middle Tennessee State University, State University of New York at Buffalo, University of Arizona, University of Kentucky, University of Tennessee in Knoxville, University of New Mexico, and Vanderbilt University. The USET TEC also collaborates and serves as a resource to the USET and IHS Area Office Behavioral Services, Diabetes, Dental and Environmental Health Programs.





## United South and Eastern Tribes, Inc.

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September 27, 2013

Dear Tribal Epidemiology Community Health Profile Workgroup,

On behalf of the United South and Eastern Tribes, Inc. (USET) I write to reaffirm USET's support of Tribal Epidemiology Centers (TEC). Since 2000, the USET TEC has served a vital role in the services that USET provides to its member Tribes by: 1) working with Tribal Health Directors to identify priorities; 2) developing and distributing meaningful health reports; 3) supporting local responses to outbreaks; 4) working with member Tribes to develop ways to identify and evaluate health risks; 5) supporting data sharing to enhance the understanding of Tribal health and 6) supporting initiatives to improve the overall health of Tribal communities.

USET is dedicated to building capacity at the Tribal level by providing Tribes with quality information and services. The USET TEC has a team of well qualified epidemiologists and statisticians, trusted by our membership and experienced in working with Tribes on a wide variety of health projects. USET believes that to improve the health status of AI/ANs takes a multifaceted approach, therefore, the USET TEC team also collaborates with internal health programs (i.e. USET Diabetes Program, Dental Support Center and the Health Information Technology – Regional Extension Center, and Meaningful Use Programs) as well as other health professionals that have in-depth knowledge of Tribal communities. Together through these collaborations USET is able to address critical areas of need for which the USET TEC is an essential contributor.

Again, as one of twelve TECs within Indian country, USET fully supports the work completed by TECs for the betterment of the Tribal Nations we serve. Our member Tribes greatly benefit from this valuable resource, and we stand together in our collective efforts to eliminate health disparities which persist among AI/AN people throughout the nation.

Sincerely,

Kitcki A. Carroll  
Executive Director

*"Because there is strength in Unity"*

## Urban Indian Health Institute Tribal Epidemiology Center (UIHI TEC)





**Urban Indian Health Institute Tribal  
Epidemiology Center (UIHI TEC)**

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**American Indian/Alaska Native Population in the Urban Areas**

American Indians and Alaska Natives are a diverse and growing population. Over the past half-century, AI/AN have increasingly moved from rural communities to urban areas throughout the United States. In 2000, approximately 61% of self-identified AI/AN resided in urban areas in the United States—a 23% increase from 1970 (2000 U.S. Census). The reasons for such relocation are varied including better educational, employment, or housing opportunities in urban areas, as well as forced relocation due to the 1950s federal relocation and termination policies (Castor, Smyser et al. 2006). According to the 2010 Census, the majority of AI/AN who identify as AI/AN alone or in combination with another race lived outside of an AI/AN area of residence and are outside the jurisdiction of a federally-recognized Indian tribe (2010 Census). Therefore, they may not have access to tribal or Indian Health Service health care.

Urban Indian Health Organizations (UIHOs) are private, non-profit, corporations that serve AI/AN people in select cities with a range of health and social services, from outreach and referral to full ambulatory care. UIHOs are located in 19 states serving individuals in approximately 100 US counties, in which over 1.2 million AI/ANs now reside.<sup>1</sup> The UIHO provide unique services to the urban AI/AN population and facilitate the following: (1) overcoming of cultural barriers when many AI/AN are reluctant to go to health care providers who are unfamiliar with and insensitive to AI/AN cultures; (2) cost saving and improvement in care by encouraging AI/AN to seek medical attention earlier; (3) identification of health issues particular to urban AI/AN; (4) addressing through first-hand knowledge the impact of mobility (between the reservation and urban areas) on health care



quality; and (5) provision of care to the large population of uninsured AI/AN who might not seek care elsewhere.

### **Parent Organization**

The UIHI's parent agency, the SIHB has 40 years of experience addressing urban AI/AN health care needs in the Seattle area with programs/services, external linkages/affiliations, and management expertise in public health, information systems, community organization, and fiscal-related issues. The mission of SIHB is to assist American Indians and Alaska Natives in achieving the highest possible physical, mental, emotional, social and spiritual well-being through the provision of culturally appropriate services, and to advocate for the needs of all Indian people, especially the most vulnerable members of their community. The SIHB manages over \$6,000,000 in Federal funds annually and receives multiple city, county and state funds. The Urban Indian Health Institute (UIHI) was created by the Seattle Indian Health Board (SIHB) in response to Healthy People (HP) 2010 and suspected urban American Indian and Alaska Native (AI/AN) health disparities.

### **Urban Indian Health Institute (UIHI)**

The Urban Indian Health Institute (UIHI) was created as a division of the Seattle Indian Health Board in 2000 to quantify and address health disparities affecting urban AI/ANs. UIHI serves the national network of 34<sup>1</sup> Urban Indian Health Organizations (UIHOs) with the mission to support the health and well-being of urban AI/AN communities through information, scientific inquiry and technology. The UIHI is a part of the network of 12 IHS-funded Tribal Epidemiology Centers (TEC). While the other eleven TECs act as a local Department of Health for tribes in a regional area, the UIHI's target population are AI/AN living in urban areas nationally. Since UIHI's target population typically exists in urban areas already under local/state DOH jurisdictions, UIHI's activities focus on collaboration with existing public health entities and filling gaps in the public health system where urban AI/AN needs might otherwise go unnoticed. UIHI maintains collaborative relationships with the TECs to address the health issues of urban AI/AN in various regions across the United States.

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<sup>1</sup> UIHI recognizes that there are currently only 33 active UIHO; however, for the purposes of this report, UIHI will continue to refer to the network of 34 UIHO that are designated to receive contracts under Title V of the Indian Health Care Improvement Act.



## UIHI Staffing

UIHI staffing includes 13 professional and support staff, with student interns and temporary staff sometimes added to support additional activities. Program staff include: Associate Director, Scientific Director, five Project Coordinators, Database Developer, a Project Associate, three Project Assistants, and an Administrative Coordinator.

## UIHI Projects

Since its inception, the UIHI has developed and delivered technical assistance to UIHO nationwide for a variety of projects focused on improving the health of the urban AI/AN population. Over the past 5 years, some of the major outcomes of projects include: improvement in the overall availability of urban AI/AN data; community health profiles specific for each of the 34 UIHO areas nationwide; development of an interactive web-based smoking cessation intervention adapted for urban AI/AN youth; creation of a family health history toolkit focused on urban AI/AN; onsite viral hepatitis integration training at 19 UIHO sites; AI/AN health needs assessment conducted at 6 Bemidji area urban sites; maternal and child health capacity needs assessment with information from 21 UIHO; correction of AI/AN misclassification in one state for cancer, mortality and hospitalizations data; reports on reproductive health, behavioral risk and youth risk factors for urban AI/AN; and an annual report summarizing data for all urban programs collected through the IHS Diabetes Program. Through the current OMH-funded Demystifying Data project, we have worked to promote epidemiologic means for identifying health priorities by building UIHI capacity for public data access, collection, management, and analysis and working with UIHO to identify and address their top health priorities through epidemiology data and community surveillance. Finally, through the WEAVING Resources for Urban Indian Women's Wellness Project funded by CDC, we provided technical assistance to UIHO and state breast and cervical cancer programs with **the primary goal of increasing the number of urban AI/AN women receiving breast and cervical cancer screening services**. The WEAVING Project worked directly with the 34 UIHO as well as the 19 states with an UIHO, providing onsite training/technical assistance, online resources (toolkits, culturally appropriate outreach and education materials), reports on best practices/models of success, networking and training opportunities. Using an innovative health data surveillance system, the UIHI responds to data requests to enhance access and usability of urban AI/AN population-specific information. In summary, the UIHI

has vast experience working on projects that address health disparities to improve the health of the urban AI/AN population.

### ***Health Disparities in Urban AI/AN Communities***

The UIHI produced a seminal report on the health disparities of urban Indians in its 2004 “Health Status of Urban American Indians/Alaska Natives” report. This report validated the suspected disparities in morbidity and mortality by analyzing vital statistics and Behavioral Risk Factor Surveillance System data for all 34 UIHO areas. It also highlighted misclassification that occurs in death certificate data for urban AI/AN people, suggesting that true mortality disparities are greater than what the data shows. Building upon the 2004 report, the UIHI produces 34 individual community health profiles and one aggregate report every two years describing the health status of the urban AI/AN population. This report is distributed to the 34 UIHO to identify health priorities, allocate resources, guide the development of new programs, identify gaps in data and needs for new data collection, plan analyses to examine indicators among clinic patients and provide statistics and figures to use in grant applications requiring supporting data.

### ***Promoting Health Equity***

The UIHI seeks to reduce health disparities by conducting projects that promote health equity. The UIHI is working to identify best and promising practices in the UIHO and to disseminate such practices across the UIHO network. Building upon the recommendations of the Urban Indian Health Commission, the UIHI will increase delivery of quality care specifically for urban AI/AN focused on CVD, depression, and a third community-determined health topic in order to make strides toward reaching HP 2012 goals and achieving health equity for AI/AN people.

### ***Limitations in National Data***

While all national data sources have limitations, especially when attempting to describe the health of such a diverse and dispersed population as urban AI/AN, the UIHI recognize that these data sources can also be a common language among the public health community. UIHI continues its exploration of national data sets in order to assess the limitations and gaps in data that exist. UIHI also continues to advocate for the improvement in urban AI/AN data collection to achieve a more complete picture of AI/AN health status. Historically the UIHI has been a leader in highlighting the need for improved data collection,

analysis and reporting, especially in regard to the paucity of urban AI/AN “Best Practices”. Due to the lack of evidence based practices and the empirical connotations ascribed to urban AI/AN “Best Practices” terminology, UIHI has opted to employ the term “Promising Practices” to more accurately represent UIHI’s urban AI/AN health care research and results.

### **Partnerships**

The UIHI has an extensive network of partnerships that includes academic institutions, state, national, state and local partners, in addition to other TECs. For example, the UIHI partners with the University of Washington, Fred Hutchison Cancer Center, and Johns Hopkins Bloomberg School of Public Health. Partners also include the National Council of Urban Indians, the Indian Health Service Office of Urban Programs, and the state-based California Consortium of Urban Indian Health Programs. For support of its data surveillance system, the UIHI partners with Public Health Seattle and King County, the local public health department. The UIHI also partners with other TECS, such as the Northwest, Great Lakes and California TECs.



## Data Challenges and Strategies

Challenges exist in the collection, analysis, interpretation and sharing of AI/AN health data. These challenges make up a set of issues relating to data collection, access, utilization and quality. Individual TECs have developed strategic initiative to address challenges in their respective areas. This section of the report highlights work commissioned under contract between the U.S. Department of Health and Human Services, Office of the Assistant Secretary for Planning and Evaluation and Westat, Contract No. 233-02-0087 entitled, "Gaps and Strategies for Improving AI/AN/NA Data", January, 2007. In addition, the section will focus on the TECs' unique roles, functions and strategies that address data challenges identified.

### Issue 1: Data Access

**Issue Description:** Data are the foundation for good decision making. Health data has the potential of transforming personal and population based health behavior and disease conditions into science-based treatment and prevention strategies. Yet, population health data remains largely inaccessible, although by law it is considered "public".

The "open" government philosophy proclaimed in 2008 has begun to address public access: "Building on the success of efforts to further mobilize the data and information through the Health Data Initiative, new avenues of focused activity on data and information services across HHS will be integrated as a flagship initiative for 2012-2014. The amalgam of programs, strategies, and policies at the heart of many components of HHS are yielding new opportunities for Open Government through better understanding of data and information services derived from them. While our efforts will continue to produce more data and data service technical capabilities, a major thrust of our Open Government plan will be to enhance the quality and usability of the data we publish. The ability to integrate, analyze, and interpret data into useful information services is growing in demand across government and the private sector."<sup>2</sup>

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<sup>2</sup> <http://www.hhs.gov/open/plan/planv2/usability.html>

In order to fully access public AI/AN population health data to support local, state and national decision making, agencies possessing public health authority face multiple and varied state and regional data release practices. Some states respond promptly to data requests, easily facilitate data sharing agreements to protect misuse of public data and do not charge a fee. Other states are limited in response and/or charge expensive fees to acquire public data. Access to AI/AN data across the U.S. is highly variable from one region to another.

Many datasets, both federal and state, are in formats that may require expensive software or a specialized skill set to operate. Many AI/AN communities do not have funding to acquire the software or staff who are proficient in the use of statistical analysis programs. In addition, staff turnover may limit the capacity to establish experience working with data systems, and thus hinder the ability of AI/AN communities to utilize the data.

**Broad National Strategies:** The U.S. Department of Health and Human Services Region V, consisting of the states of Minnesota, Wisconsin, Michigan, Illinois, Indiana and Ohio, has brought together state and Tribal representatives who share a commitment to explore and document variation in state vital statistics and state disease registry data collection practices. When complete, the group intends to work toward standardization of data access, collection, reporting and disease surveillance activities region wide.

**Local, Community Based Strategies:** Primary data originating from the Tribal health programs is more representative of AI/AN health than many national and state data sets. Perfecting the collection, analysis and use of local data is empowering for local community leaders and health care providers. With effective, functional data use agreements grounded in trusting established relationships, TECs have been able to collaborate with communities to best utilize local data sources. TECs respond to data access issues in the following ways:

1. **TECs actively pursue relationships** with their state and regional health departments to secure data access, implementing data sharing agreements to confirm appropriate data security and data use. TEC staff serve on state level health committees working on topics including immunization practices, Healthy People 2020, infant mortality, pre-natal risk assessment and drug abuse prevention. These strengthen working and trusting relationships.

2. **TECs establish** ongoing relationships with Tribal and Urban Indian health programs in their region, ensuring that TEC staff are known and trusted. TEC commitment to “presence” in AI/AN communities, diligent compliance with Tribal protocol, respect and cultural humility creates pathways for data access.
3. **TECs collaborate with AI/AN communities** in a manner that ensures that all data collection, analysis and evaluation activities directly benefit the community as a whole as well as its members.
4. **TECs build community capacity** to collect primary data providing data collection and analysis methodology technical assistance and support.
5. **TECs provide AI/AN communities** access to staff with public health backgrounds and data collection and analysis skills. This allows Tribal and urban communities greater access to needed data.

## Issue 2: Framework and Measures used to Record Race and Ethnicity

**Issue Description:** A number of structural problems and historical legacies prevent accurate and complete data collection on race. Some data collection systems collect race inconsistently or routinely lack racial data collection, such as the Social Security Administration’s social security number application data, affecting the Medicare Enrollment Database downstream. At least one major national survey, the National Health and Nutrition Examination Survey (NHANES), purposefully does not sample for zip codes located on reservations, though they oversample for other population subgroups.<sup>3</sup>

Some data collection systems or questionnaires do not provide a sufficient number of racial or ethnic categories for respondents to choose from; often these categories consist only of White, Black, Hispanic, and Other. In addition to this conflation of race and ethnicity, this structure of response options collapses multiple racial groups (American Indian or Alaska Native, Asian, and Native Hawaiian or Other Pacific Islander) into one category, making any useful analysis by race impossible for these different groups. Though some data systems collect all the OMB minimum categories for race and ethnicity, only a few categories’ results will be reported, with the remainder excluded outright or combined into “other.” Not all surveys may follow the OMB guidelines which state that when self-identification is used, respondents should be able to select

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<sup>3</sup> [http://www.cdc.gov/nchs/tutorials/nhanes/surveydesign/SampleDesign/intro\\_i.htm](http://www.cdc.gov/nchs/tutorials/nhanes/surveydesign/SampleDesign/intro_i.htm)



more than one race category- and the options should not include a “multiracial” category.<sup>4</sup>

There are 566 federally recognized AI/AN tribes in the U.S.<sup>5</sup> Though they are nearly always grouped together as a homogenous population, each tribe is unique with its own history and culture, which in combination with other factors can create disparate health status. AI/AN communities often request data that is meaningful to their member population and not be forced to rely on state or national estimates. Collecting data on tribal affiliation may be as important as race data, due to the federal government’s treaty obligations.

Data collection systems also may have difficulty reaching AI/AN populations. AI/AN people are more mobile than the general population, often moving between reservations and urban areas, or moving residences within a geographic area. They also are less likely to have telephone service. Consequently, it is more difficult to make contact with them, leading to lower response rates. Literacy and, in some regions, language barriers also hinder data collection.

**Broad National Strategies:** Combining multiple years of data for some, but not all surveys will increase sample size providing a cost effective way to improve data availability for small populations. An example of a federal survey appropriate for analysis of multiple years of data are consumer expenditure surveys to permit a wider range of issues at a higher level of precision. However, issues that may be disposed to changing rapidly or cyclically limit the accuracy of this methodology. New approaches to using small samples for estimating AI/AN issues of health and well-being must be sought and funded to be more informed about level and degree of health disparity between population groups. Continuation of educational strategies regarding the value of using standardized OMB racial identification categories in federal, academic and state data collection activities will improve the quality of sample estimates. There must be development and implementation of new methods for cost-effective identification of AI/AN who reside off reservation lands and are dispersed in rural and metropolitan areas.

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<sup>4</sup> [http://www.whitehouse.gov/omb/fedreg\\_1997standards/](http://www.whitehouse.gov/omb/fedreg_1997standards/)

<sup>5</sup>

[http://www.ihs.gov/MedicalPrograms/Diabetes/HomeDocs/Resources/FactSheets/2012/Fact\\_sheet\\_AIAN\\_508c.pdf](http://www.ihs.gov/MedicalPrograms/Diabetes/HomeDocs/Resources/FactSheets/2012/Fact_sheet_AIAN_508c.pdf)

**Local, Community Based Strategies:** Routine national and state data collection practices do not generally allow for the identification of Tribal affiliation and membership. Yet, Tribal communities vary in geographic location, traditional food gathering and selection, medicinal and spiritual practices to name a few. This population feature can influence risk factors that impact health and disease. Therefore, to improve the definition of health disparities:

1. **TECs collaborate and partner** with area Tribal communities to conduct local area versions that identify and document the unique disease and risk factors that can inform local leaders and health care providers.
2. **TECs adapt data gathering practices to local needs** resulting in improved response rates, increased sample size and essentially serves as an “oversample” that is difficult to obtain otherwise.
3. **TECs ongoing relationship** with Tribal communities aids in understanding population migration patterns to more effectively locate Tribal members for data inclusion.

### Issue 3: Racial Misclassification

**Issue Description:** Racial misclassification affects population health data quality. AI/ANs are more likely to be misclassified than individuals of other races<sup>6,7</sup>. The net result of racial misclassification for AI/ANs is under-counting the number of individuals in a population and health events, and underestimated disease and mortality rates. In one study, without misclassification accounted for, AI/AN initially had the lowest mortality rates from major cardiovascular disease, but with misclassification corrected, their rates were the highest.<sup>8</sup> The reasons why these data are misclassified vary.

Systems that do not allow people to self-identify their race create inaccurate data. The Office of Management and Budget (OMB) recommends that in respect for individual dignity, whenever possible respondents should be allowed to self-identify their race and ethnicity. In addition to affording people the right

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<sup>6</sup> Boehmer U, Kressin NR, Berlowitz DR, Christiansen CL, Kazis LE, Jones JA. Self-Reported vs Administrative Race/Ethnicity Data and Study Results, *AJPH* 2002;92(9):1471-1473.

<sup>7</sup> Noymer A, Penner M, Saperstein A. Cause of Death Affects Racial Classification on Death Certificates. *PLoS ONE* 2011;6(1): e15812. doi:10.1371/journal.pone.0015812

<sup>8</sup> *Circulation*, 2005 American Heart Assoc. Dorothy Rhoades, MD, MPH

to proclaim the group they most identify with, when individuals are not allowed to choose for themselves how they would like to be recorded in data collection systems, they often may be misidentified. Though third parties may accurately judge whether an individual is black or white, mistakes are often made with regard to multiracial or Hispanic individuals.<sup>9</sup>

Observers may perceive race based on appearance, name, or other characteristics, and report data based on their assumption. This is especially true in regard to vital statistics mortality data. Death certificate data is often recorded by coroners, funeral directors or medical examiners that may make assumptions about the decedent's race. Even if the person completing the form asks the next-of-kin, they may not answer as their relative would have. Racial misidentification on death certificates is common and varies regionally for AI/AN, though estimates of this frequency varies. One investigation by the IHS, comparing death records with IHS patient records, estimated that AI/AN with inconsistent race identification ranged from 1.2% in the Navajo Area to 30.4% in the California Area; overall misclassification was found to be 10.9% across the country.<sup>10</sup> Another estimate states that American Indians in general are undercounted by 38%.<sup>11</sup>

In administrative data systems, staff may not ask the client to self-identify and rely on their perceptions to fill the race field. Changes in individual's racial identity may occur over time, resulting in a change in the way they self-report. Errors can compound when systems interact; for example, cancer and other disease registries often rely on death records for demographic data.

National Center for Health Statistics (NCHS) guidelines for establishing a child's race at birth is to assign her or him the race of the mother. Though this simplifies analysis and may make some sense in light of the possible infrequency of the father's race field being complete, it also reduces the number of infants that may be included in some racial groups than using an "any mention" approach

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<sup>9</sup> <http://www.ncbi.nlm.nih.gov/pmc/articles/PMC1797091/>

<sup>10</sup> Indian Health Service. (1996). "Adjusting for miscoding of Indian race on state death certificates" U.S. Department of Health and Human Services, Public Health Service, Indian Health Service, Office of Planning, Evaluation, and Legislation, Division of Program Statistics.

<sup>11</sup> Sondik E, Director of the National Center for Health Statistics of the Centers for Disease Control and Prevention.(1999). Proceedings from the Intercultural Cancer Council. Washington, DC.

would, and thus may obscure or dilute some differences when comparing racial groups.

**Broad National Strategies:** The Westat report recommended the development of new requirements and guidelines for the reporting of race/ethnicity on vital statistics records and administrative databases with the provision of training for those responsible for reporting. A national agenda to systematically implement standardized data collection methods across states would improve misclassification rates and reach further to validate rates of disease disparity among all U.S. populations. A national approach to periodically match Indian Health Service death certificate files with state vital statistics or cancer registry records can further identify misclassification, although this is a costly approach compared to accurate racial identification upon data gathering.

**Local, Community Based Strategies:** Performing a data linkage is a reliable method to document and correct racial misclassification. In a study conducted by the Northwest Tribal Epidemiology Center, an evaluation of racial misidentification in two cancer registries in Washington State, using an urban AI/AN patient roster linked with a list of Indian Health Service (IHS) enrollees was conducted. In the two registries, 11 and 18% of the cases were originally coded as a race other than AI/AN.<sup>12</sup> Another linkage project conducted in Wisconsin in collaboration with the Great Lakes Inter-Tribal Epidemiology Center found that following correcting race miscoding led to a statistically significant increase in the all cancer incidence rate, from 386.3 per 100,000 to 471.7 per 100,000.<sup>13</sup>

1. **TECs actively partner** with federal and state partners to reduce racial misclassification in public health surveillance systems.
2. **TECs perform targeted data linkage studies** to identify regionalized misclassification rates to reduce under-counting of health events and underestimated disease and mortality rates.

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<sup>12</sup> Including self-reported race to improve cancer surveillance data for American Indians and Alaska Natives in Washington state. [Megan J Hoopes](#), [Maile Taualii](#), [Thomas M Weiser](#), [Rachel Brucker](#), [Thomas M Becker](#) Northwest Tribal Epidemiology Center, Northwest Portland Area Indian Health Board, Portland, OR 97201, USA. [J Registry Manag](#) 01/2010; 37(2):43-8.

<sup>13</sup> Improving cancer incidence estimates for American Indians in Wisconsin. Foote M, Matloub J, Strickland R, Stephenson L, Vaughan-Batten H. Wisconsin Medical Journal 2007 Volume 106, No. 4  
[http://www.wisconsinmedicalsociety.org/\\_WMS/publications/wmj/pdf/106/4/196.pdf](http://www.wisconsinmedicalsociety.org/_WMS/publications/wmj/pdf/106/4/196.pdf)

3. **TECs organize** local and area wide efforts to educate leaders and providers on the benefits of accurate race reporting.

#### Issue 4: Small Population Size

**Issue Description:** The AI/AN population comprises 1-2% of the overall population in the United States. While the 2010 U.S. Census revealed the AI/AN population increased at a faster rate than the total population, the percentage of AI/AN compared to the U.S. total population increased only slightly. AI/AN people, including those who identify as AI/AN and one or more other races, represent 1.7% of the U.S. population.<sup>14</sup> Due to the fact that AI/AN make up a small portion of the total United States population, they contribute very little to aggregate national data- they are considered statistically insignificant. Routine sampling methodologies used in national health surveys typically undercount and underreport AI/AN, often combining them with other small populations obscuring racial identification. To achieve a sufficient statistical power, often several years of AI/AN data is aggregated in the sample. Other times multiple geographical areas are combined. Pooling these data makes it impossible to determine trends over time or to determine geographical differences.

**Broad National Strategies:** Strategies that may be implemented nationally to improve data quality related to small sample sizes include increasing sample sizes and oversampling for specific racial/ethnic groups in national surveys to permit statistical analysis of small populations such as AI/AN. In order to compensate for the costly implementation of increasing sample size, statisticians often recommend stretching the sampling timeframe for small populations from annual or bi-annual data collection to every three to five years. However, in health surveys such as the Behavioral Risk Factor Surveillance Survey (BRFSS), implementation patterns are determined by each state and therefore highly varied.

In addition to the above national strategy, the federal Department of Health and Human Services (DHHS) convenes the National Data Council (NDC) to coordinate all health and human services data collection and analysis activities

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<sup>14</sup> Tina Norris, Paula L. Vines and Elizabeth M. Hoeffel. US Census Bureau. *The American Indian and Alaska Native Population: 2010*. January, 2012.  
<http://www.census.gov/prod/cen2010/briefs/c2010br-10.pdf>

for the Department. This includes an integrated data collection strategy, coordination of health data standards and health and human services and privacy policy activities.<sup>15</sup> The Council is seeking new scientific methodologies to apply appropriate statistics for small sample sizes.

**Local, Community Based Strategies:** The Westat report recommended developing partnerships with AI/AN communities to conduct local area versions of national surveys that could supplement national survey data or be used for comparison to national or state survey data. To address this:

1. **TECs actively engage** their respective IHS Area tribally-run health programs, IHS Service Units and Urban Indian Health Centers in trusting partnerships that identify health priorities and develop unique adaptations of national surveys.
2. **TECs innovatively develop** culturally-appropriate sampling methods that consider the geographic distribution and migration patterns of each Tribal community in order to obtain valid and reliable estimates.
3. **TECs work with Tribal community members** to further identify historical protocol and customary practices to appropriately sanction survey activity and generate community involvement.
4. **TECs assist in data translation** or facilitate local interpretation of data, transforming it into important program or policy decisions. TECs also prepare profile reports for the community that compare local data to available AI/AN data from other sources, as well as aggregate area reports to be utilized in state and regional program development, funding allocation and policy decisions.

## Issue 5: Other Data Quality Considerations

**Issue Description:** Many of the issues discussed as individual issues (small numbers, race/ethnicity measurement, and racial misclassification) actually fall under the broader umbrella of data quality. Several additional data quality issues are noted here, related to denominators, cultural appropriateness, trust and health research over-surveying.

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<sup>15</sup> <http://aspe.hhs.gov/datacncl/>

Understanding which AI/AN denominator to use can be complex. As discussed in terms of race/ethnicity measurement and racial misclassifications, there can be problems with miscounting the individuals as well as the frameworks used to collect them. Familiarity with these issues and the drawbacks and benefits for using each is key to choosing appropriately in terms of the study aim.

Additionally, there are varying statutory definitions of what constitutes an AI/AN.<sup>16</sup> There are many types of denominators that may be chosen: a few examples are numbers based upon census figures, enrolled members (of a particular tribe or tribes), enrolled members and descendants (of a particular tribe or tribes), or IHS user populations, based upon various levels of geography (states, counties, reservations, or census geographies such as census blocks or block groups).

Data collection instruments may not be culturally appropriate for AI/AN. A notable example has to do with tobacco. When non-American Indians refer to the “use of tobacco” they are actually referencing commercial tobacco use.<sup>17</sup> Unlike commercial tobacco, the tobacco plant is held sacred and is utilized with purpose: for prayer and healing; presented as a sign of respect; offered as a gift to the Creator by placing it on the ground; and used for purification. Using commercial tobacco by smoking cigarettes or chewing tobacco is “abuse of a plant meant for sacred use only.”<sup>18</sup> Surveys commonly used by federal and state agencies do not make this distinction, and thus any resulting data likely is inaccurate for AI/AN respondents.

AI/AN individuals and communities mistrust governmental actions and motivations.<sup>19 20</sup> The federal government’s actions, including the establishment of boarding schools, extensive removal and relocation policies, and termination initiatives have created a legacy of distrust. AI/AN people may be disinterested

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<sup>16</sup> <http://www.nihb.org/docs/08262011/NIHB%20WR%20Issue%2011-21%20August%2026%202011%20final.pdf>

<sup>17</sup> California Rural Health Board. Resource Guide for Assisting American Indian Smokers to Quit. Tobacco Education & Prevention Technical Support Center. 2010

<sup>18</sup> California Department of Public Health. Respect Traditional Tobacco: Protect Our Communities from Secondhand Smoke [Brochure]. Tobacco Education Clearinghouse of California. 2007

<sup>19</sup> Brendtro LK, Brokenleg M, Bockern SV. Reclaiming Youth at Risk. Bloomington, IN: National Educational Service; 1990.

<sup>20</sup> Brave Heart, MYH. The historical trauma response among Natives and its relationship to substance abuse: A Lakota illustration. In E. Nebelkopf & M. Phillips (Eds.), *Healing and Mental Health for Native Americans: Speaking in Red*. Walnut Creek: Alta Mira Press



in participating in government-sponsored or administered data collection efforts.

AI/AN populations are frequently a population of interest among researchers. Because the population is small and a larger proportion of the total population must be sampled to create a meaningful sample size, community members may experience fatigue due to being asked to participate in survey after survey. Additionally, the findings may not be reported back to the communities, or the information may not be provided in a meaningful way. As a result, communities and community members may feel taken advantage of or frustrated, leading to resistance to future good faith efforts. Additionally, grave contemporary abuses related to health research have been committed, such as the Barrow alcohol studies and Havasupi genetics research.<sup>21</sup> As a result of these traumas, AI/AN people and communities are distrustful and cautious of activities that are or are perceived as research.

**Broad National Strategies:** Efforts noted to address **Issue 3: Racial Misclassification** would assist in determining an accurate and consistent population denominator. As data omissions and misclassification is corrected, epidemiologic and research studies would benefit from greater reliance on the chosen denominator. Use of OMB directives to standardize race categories can facilitate consistent collection and recording of vital statistics that would improve denominator accuracy.

The Westat report recommends that in order to improve the quality of AI/AN survey participation and response rates in national surveys and/or federal and state agency funded research, sampling designs must be examined to identify their potential to include AI/AN representatively and develop approaches that increase representation. Survey designs that are more culturally appealing visually (Native art and graphics), contain appropriate language/literacy levels, consider population mobility and that contain culturally relevant questions and response options will enhance participation. The practice of cognitive testing of

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[https://docs.google.com/viewer?a=v&q=cache:EOYQ1Y8C2OQJ:www.sjsu.edu/people/peter.a.lee/courses/ScWk240/s1/Week%25203\\_ethics\\_Caldwell.pdf+&hl=en&gl=us&pid=bl&srcid=ADGEESgAYEcXEWq2UFZYMcfSuyTf3VXivDZLkz3VdY5cajyv\\_dXY2Oz535mtYzULPc5W6fb00ynM4Tawrgy8mXepm41q-ee3H-eSZdB-CL1CQd2FDSkmbNL3ojO2yVjRxDXB9-c54yG0&sig=AHIEtbSbVGMOcnU0mDjMkZvTAHg6fGLhtg&pli=1](https://docs.google.com/viewer?a=v&q=cache:EOYQ1Y8C2OQJ:www.sjsu.edu/people/peter.a.lee/courses/ScWk240/s1/Week%25203_ethics_Caldwell.pdf+&hl=en&gl=us&pid=bl&srcid=ADGEESgAYEcXEWq2UFZYMcfSuyTf3VXivDZLkz3VdY5cajyv_dXY2Oz535mtYzULPc5W6fb00ynM4Tawrgy8mXepm41q-ee3H-eSZdB-CL1CQd2FDSkmbNL3ojO2yVjRxDXB9-c54yG0&sig=AHIEtbSbVGMOcnU0mDjMkZvTAHg6fGLhtg&pli=1)

current and new survey instruments to assess the extent of cultural differences in question interpretation should be routine when implementing survey methodology in AI/AN communities.

An increasing number of federal and state agency funders are recognizing the importance of community involvement in research design, implementation, evaluation and translation. Strong community partnerships formed in the practice of community based participatory research (CBPR) increases trust and has been demonstrated to improve response rates.<sup>22</sup> Additional approaches that could increase AI/AN response rates should be tested and funded.

**Local, Community Based Strategies:** The data quality problems created by insufficient trust and culturally appropriate communication in public health and/or research activities can be overcome by cultural competence (otherwise termed cultural humility or congruence) training and continuing education in the health professions, augmented by relevant experiences in and around Tribal communities to learn cultural perspectives. While this can be viewed as a broad based strategy, it is one that is best implemented through local Tribal community involvement. To this end,

1. TECs establish a foundation of community based participatory process (CBPP) in all activities which engage Tribal communities.
2. TECs actively translate data into action.
3. TECs collaborate with their respective state/region, academic institutions and local Tribal communities to rigorously determine the most appropriate denominator for health status reports, data profiles, epidemiologic and research studies.
4. TECs seek culturally appropriate adaptations of national, state and academic research methodology and instrumentation to improve AI/AN survey participation response rates.

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<sup>22</sup> Nina Wallerstein, Dr. P. H., Tassy Parker, Ph.D., RN. "Community Based Participatory Research: A Foundation and Building Blocks for Academic Based Partners. University of New Mexico School of Medicine. [hsc.unm.edu/som/fcm/cpr/docs/CBPR\\_Intro.ppt](https://hsc.unm.edu/som/fcm/cpr/docs/CBPR_Intro.ppt)

## The Role of Health Inequity

TECs actively assist in efforts to reduce health inequities while also supporting the federal government in fulfilling its trust responsibility to AI/AN peoples. Data play an important role in understanding health inequities.<sup>23</sup> In particular, TECs robustly support several guidelines developed by the National Association of County and City Health Officials (NACCHO) in their document *Guidelines for Achieving Health Equity in Public Health Practice*:

1. Monitor health status and track the conditions that influence health issues facing the community
2. Give people information they need to act collectively in improving their health
3. Engage with the community to identify and eliminate health inequities

These modifications of the essential public health services parallel the distinctive pathways through which TECs operate to reduce the health inequities that AI/AN people have persistently faced. Whether through advocating for equal explanatory power within national or state data systems to produce equitable and high quality health statistics or collaborating with communities, TECs operate in a unique fashion to increase health equity.

Structural racism also plays a role in AI/AN data quality. Structural or institutional racism may be defined as “differential access to the goods, services, and opportunities of society by race.” It is built into how our society functions, so that no individual person may be consciously aware that certain customs, practices, or laws are racist, and no individual person is acting in a conscious manner to perpetuate them.<sup>24</sup> The capacity of communities to flourish is based on opportunity to access resources and services that contribute to stability and advancement.<sup>25</sup> TECs can be seen as an attempt to remedy inequitable access that AI/AN communities have to quality health data and data analysis, thereby reducing barriers that the communities face in improving the health of its people.

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<sup>23</sup> <http://content.healthaffairs.org/content/25/4/1053.full>

<sup>24</sup> <http://www.ncbi.nlm.nih.gov/pmc/articles/PMC1446334/pdf/10936998.pdf>

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[http://www.prrac.org/full\\_text.php?text\\_id=1095&item\\_id=10188&newsletter\\_id=90&header=Symposium:%20Structural%20Racism](http://www.prrac.org/full_text.php?text_id=1095&item_id=10188&newsletter_id=90&header=Symposium:%20Structural%20Racism)

A principle called “equal explanatory power,” arising to describe the principle that New Zealand’s indigenous population, the Māori, should have equal and equitable access to health data with as much depth and breadth as non-Māori health data. Equal explanatory power recognizes that Māori’s statistical needs are equally as important as those of the nation as a whole.<sup>26</sup>

These types of philosophical underpinnings must be adopted to enhance health equity in the United States.

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<sup>26</sup> Te Ropu Rangahau Hauora a Eru Pomare. Mana Whakamarama- Equal Explanatory Power: Maori and non-Maori sample size in national health surveys. 2002. Wellington School of Medicine and Health Sciences, Wellington South, New Zealand.

## **BEST PRACTICE EXAMPLES OF TEC WORK ON KEY HEALTH TOPICS**

This section provides specific examples of the work TECs are doing to improve data collection, analysis, reporting and use which is instrumental in eliminating health disparities throughout Indian Country.



## Adolescent Health: Southwest Tribal Youth Project

### PROJECT NAME

Southwest Tribal Youth Project - Youth Risk and Resiliency Survey (YRRS)

### REPORT TITLES

- Expanding the Utility of Youth Risk and Resiliency Survey (YRRS) Data for American Indian Communities in New Mexico
- 2009 New Mexico Youth Risk and Resiliency Survey (YRRS) High School (Grades 9 – 12) Aggregate Site Report
- 2009 New Mexico Youth Risk and Resiliency Survey (YRRS) Middle School (Grades 6 – 8) Aggregate Site Report

### TRIBAL EPIDEMIOLOGY CENTER

Albuquerque Area Southwest TEC (AASTEC)

### BACKGROUND

To address gaps in the availability, representativeness and usefulness of data for American Indian youth in the Albuquerque Area, AASTEC has partnered with the University of New Mexico, the State of New Mexico Department of Health and the New Mexico Public Education Department to increase the representation of American Indian youth in the biennial New Mexico Youth Risk and Resiliency (YRRS) survey. The YRRS is a classroom-based assessment tool that examines the health risk behaviors and resiliency (protective) factors of New Mexico high school and middle school students. The NM YRRS is part of the national CDC Youth Risk Behavior Surveillance System (YRBSS). This assessment includes a host of topics related to youth health risk behaviors such as alcohol and drug use, unintentional injury, violence, bullying, suicidal ideation and attempts, tobacco use, sexual activity, physical activity, and nutrition. The NM YRRS is unique in that it also includes measures of youth resiliency including relationships in the family, school, community, and with peers. The overarching aim of this AI youth oversampling approach is to gain a better understanding of the prevalence of risky health behaviors and resiliency factors among this underserved population.

### BEST PRACTICE APPROACHES

#### Targeting American Indian Schools

In 2009, AASTEC and its partners sampled an additional 23 high schools and middle schools located within or adjacent to tribal communities to participate in the NM YRRS in addition to the random sample generated by the state. The YRRS was administered to all classrooms in these supplemental schools, which



resulted in the inclusion of an additional 2,039 AI youth into the 2009 NM YRRS survey. This figure reflects a 74% response rate, the highest in the state. AASTEC provided invaluable support in identifying and recruiting schools with high AI enrollment to participate in the survey, educating teachers and school administrators about YRRS survey administration, coordinating survey administration, analyzing the data, and generating and disseminating school and tribal specific reports of the findings.

### **Community and School Engagement**

With a motto *“Together, we can fix things,”* the AASTEC partnered with the University of New Mexico, the New Mexico Public Education Department, and the New Mexico Department of Health to successfully oversample AI youth into the 2009 NM YRRS survey. Prior to administration of the survey, AASTEC staff met with staff at the supplemental schools and tribal leadership of the tribes affiliated with the schools. The AASTEC staff provided detailed information about the purpose, procedures and benefits of participating in the YRRS survey. AASTEC also provided on-site logistical support to participating schools on the day of the survey and provided school supplies to honor the time commitment of the participating schools. As a follow-up, AASTEC disseminated in-person results to the supplemental schools and tribes by providing an aggregate data booklet as well as a school or tribe specific data booklet. AASTEC has conducted a similar oversampling approach for the 2011 NM YRRS, where an additional 3,471 AI students were included in the state survey to monitor trends in health risk behaviors and protective factors over time. The response rate of 79% for 2011 in the AASTEC supplemental schools exceeds all previous targets in the state.

### **2009 NM YRRS Findings**

AASTEC staff and its partners conducted comprehensive analysis on YRRS data to identify key risk behaviors and protective factors experienced among AI youth, document health disparities witnessed among AI youth in New Mexico and monitor trends over time. For example, the data for 2009 demonstrated that the AI youth in New Mexico have not met Healthy People 2020 targets for several indicators, including:

- Tobacco use past month
- Rode with driver who had been drinking alcohol in the past 30 days
- Percentage who are obese
- View 2 or less hours of television on school day

- Suicide attempt in past 12 months
- Have a caring relationship with a parent or adult caregiver in their lives
- Participate in daily school physical education

This data has been reported back to the participating Tribal leadership bodies as well as school and health administrators in an effort to begin to address these critical health disparities observed among AI youth in New Mexico.

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## **Adolescent Health: Risk and Protective Factors for Tobacco Use**

### **PROJECT NAME/REPORT TITLE**

Risk and Protective Factors for Tobacco Use Among AI/AN Youth

### **TRIBAL EPIDEMIOLOGY CENTER**

Albuquerque Area Southwest Tribal Epidemiology Center (AASTEC)

### **BACKGROUND**

Measuring smoking-related behavior among Native American youth (grades 6-12) in New Mexico is a key component of the New Mexico Youth Risk and Resiliency Survey (YRRS). As previously noted, one of the main objectives of the Albuquerque Area Southwest Tribal Epidemiology Center is to increase the representation of American Indian youth in the New Mexico YRRS survey in order to gain a better understanding of the prevalence of risky health behaviors and resiliency factors among this underserved population. Data from the 2009 YRRS survey revealed that rates of tobacco use among American Indian high school students were significantly elevated compared to other populations in the state and nationally (31.3% AI compared to 24.0% NM all races and 19.5% nationally). This rate considerably exceeds the Healthy People 2020 Target of 16.0%.

### **BEST PRACTICE APPROACHES**

To better understand the elevated tobacco use rates witnessed among AI youth in New Mexico, AASTEC staff conducted in-depth analysis of 2009 NM YRRS data to explore key resiliency and risk factors that are linked to AI youth tobacco use. Similar reports were also developed for suicide, drug use and alcohol consumption among American Indian youth in New Mexico.

### **Assessing Protective and Warning Factors of Smoking**

As demonstrated in this report, a host of protective factors and risk behaviors were significantly associated with tobacco use among New Mexico AI youth in grades 6-12. For AI middle school students (grades 6-8), protective factors against current smoking included receiving mostly A's & B's, having parents that listen to the student, and having a parent that knows where their student is and with whom. Warning factors of cigarette smoking including the following: current marijuana use, current alcohol use, past or present cocaine use, inhalant or injection drug use, having friend(s) who get in a lot of trouble, having been in

a physical fight, receiving mostly D's and F's, and having seriously thought about suicide.

Among AI high school students (grades 9-12), protective factors against smoking included: receiving mostly A's and B's, involvement in extra-curricular activities, planning to attend college, and having parents that a) think it is wrong for student to smoke cigarettes, b) know where their student is and with whom, and c) expect student to follow the rules. Warning factors of smoking included drinking alcohol, current marijuana use, carrying weapon to school, past or present heroin use, ecstasy or methamphetamine use, having been in a physical fight, and receiving mostly D's and F's.

It is also important to note that the YRRS survey does not currently distinguish between occasional traditional/ceremonial tobacco use and habitual commercial tobacco abuse. Therefore, AASTEC has initiated a collaborative process in conjunction with the New Mexico YRRS steering committee and the Southwest Tribal Tobacco Coalition to explore potential revisions to the YRRS instrument that can better differentiate between these distinct forms of tobacco use. According to data from the 2009 NM YRRS survey, the prevalence of tobacco use among American Indian youth is significantly elevated compared to other populations in the state. Unfortunately, without better differentiation of the type of tobacco use disclosed by students on the YRRS survey instrument, it is not possible to determine if these elevated rates are due to occasional tobacco use in conjunction with adolescent participation in traditional ceremonies or increased habitual tobacco abuse among AI youth. If successful in this adaptation process, New Mexico will become the first state to include such measures within its YRRS/YRBS survey. We will also be able to serve as a model for other states with large Native American populations and can provide technical assistance in integrating these modification(s) into state YRRS/YRBS instruments.

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## Behavioral Health: Suicide Data Tracking Project

### PROJECT NAME/REPORT TITLE

Suicide Data Tracking Project

### TRIBAL EPIDEMIOLOGY CENTER

Rocky Mountain Tribal Epidemiology Center (RMTEC)

### BACKGROUND

The goal of the Suicide Data Tracking Project is to understand suicide and suicide attempts on reservations by using both conventional and non-conventional method to obtain more complete Tribal data on suicide attempts and completions.

### BEST PRACTICE APPROACHES

Project Coordinators from participating reservation's "Planting Seeds of Hope" Project, a Montana Wyoming Tribal Leaders Council Youth Suicide Project, were trained on both conventional and un-conventional methods of suicide data collection.

The project coordinators gained the community's trust as local Suicide Field Workers. The trust the community had in the project and the coordinators, helped with the references the coordinators received from various community members and community departments/institutions even before the medical team or law enforcement were notified, usually at a later time in the course of the event.

The coordinators developed or adapted databases in excel spread sheets and data collection on each case reported was documented. A conventional form, "One Tribal Form" was completed for each case and referrals were made to Indian Health Service Behavioral Health Professionals by the coordinators.

Indian Health Service - IHS Behavioral Health Personnel were Principle Investigators (PI) for the project and the data collected was reported to the Indian Health Service PI to augment the current IHS suicide tracking database (augmented by IHS staff as needed).

The qualitative pilot study on three Reservations in Montana and Wyoming improved the process of collaboration between the Indian Health Service (IHS) and all other Tribal agencies/departments with a responsibility towards suicidal patients. The more complete Tribal data was used to understand suicide and suicide attempts and initiate intervention plans on Reservations.

Multi-institutional collaboration and agreements were developed and implemented; and a lot of negotiation for Resolutions and Memorandum of Understanding (MOU). Project Coordinator community integration and trust was important in the successful implementation of the Suicide Data Tracking Project.

During a public health crisis on one of the reservations, the data collected by the project coordinator helped direct the community (with technical support from RMTEC) to the root cause if the suicides in the community which were seen more among the female youth in middle schools, an unconventional pattern. This led to anti-bullying interventions, further resolutions, and a more critical look into the school staff background in the Tribal communities.

**For more information on the project, please contact:**

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## Behavioral Health: Mental Health and Wellness

### PROJECT NAME/REPORT TITLE

Mental Health and Wellness – Data Indicators and Reports

- Excellence in Health Surveillance and Research Regarding the Health Status Deficiencies Affecting Urban Indians
- Community Health Profile: National Aggregate of UIHO Service Areas

### TRIBAL EPIDEMIOLOGY CENTER

Urban Indian Health Institute (UIHI)

### BACKGROUND

The UIHI uses national-level data sources to track mental health and wellness indicators and present the information in reports. Previous and current data sources utilized by UIHI include Vital Statistics, the Centers for Disease Control and Prevention's Behavioral Risk Factor Surveillance System (BRFSS) and Youth Risk Behavior Survey (YRBS). The UIHI continually investigates and assesses additional data sources regarding the potential for health status monitoring and secondary data analysis for American Indians and Alaska Natives. One example is the National Survey on Drug Use and Health (NSDUH), an initiative of the Substance Abuse and Mental Health Services Administration (SAMHSA). The NSDUH provides national and state-level data related to substances (tobacco, alcohol, illicit drugs, and prescription drugs) and mental health; many of the indicators compare racial and ethnic groups.

### PROMISING PRACTICE APPROACHES

#### Using Multiple Sources for Secondary Data Analysis of Urban Indian Populations

While the national-level data sources may not be ideal for all tribes, especially rural communities, the BRFSS and YRBS serve as stable data sources on mental health and wellness of American Indians on a national scale. The UIHI continues to identify data sources appropriate for Urban Indian populations and advocate for improving and expanding data collection efforts to include American Indians.



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CHP Report: <http://www.uihi.org/2011-community-health-profile-national-aggregate-of-uiho-service-areas/>

## Behavioral Health: Tobacco Wisconsin Native Youth Tobacco Survey

### PROJECT NAME/REPORT TITLE

Wisconsin Native Youth Tobacco Survey Report

### TRIBAL EPIDEMIOLOGY CENTER

Great Lakes Inter-Tribal Epidemiology Center (GLITEC)

### BACKGROUND

The Wisconsin Native American Tobacco Network (WNATN) invited the Great Lakes Inter-Tribal Epidemiology Center (GLITEC) to collaborate on a project with the goal of obtaining high quality data on American Indian youth and their commercial tobacco-related attitudes, knowledge, and behavior. Previously, little information regarding American Indian youth and tobacco-related risk behaviors existed; other surveys did not distinguish between commercial and ceremonial tobacco, and data about ceremonial tobacco use did not exist. No state had conducted a survey that included youth from all reservations.

### BEST PRACTICE APPROACHES

#### Targeting American Indian Youth

The Wisconsin Native Youth Tobacco Survey utilized a Census-based design. All middle and high schools (grades 6-12) located on Wisconsin reservations, as well as off-reservation schools serving students living on reservations, were selected to participate. In addition, the American Indian schools in Milwaukee participated. Through an extensive collaboration between Tribes, school districts, WNATN, and GLITEC, surveys were collected representing students from every reservation in Wisconsin and the urban Indian area of Milwaukee.

#### Using Culturally-specific Survey Questions

The Wisconsin Native Youth Tobacco Survey is a modified and culturally-specific version of the Centers for Disease Control and Prevention's (CDC) National Youth Tobacco Survey. Questions were also adapted from the American Indian Community Tobacco Project survey. The survey was piloted among local middle school and high school students.

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## Chronic Disease: Asthma Tribal Asthma Survey Project

### PROJECT NAME/ REPORT TITLE

Tribal Asthma Survey Project (TASP) Final Report

### TRIBAL EPIDEMIOLOGY CENTER

California Tribal Epidemiology Center (CTEC)

### BACKGROUND

The California Tribal Epidemiology Center in collaboration with the California Department of Public Health (CDPH), Environmental Health Investigations Branch, California Breathing implemented the comprehensive Tribal Asthma Survey Project (TASP). This survey gathered asthma and housing condition-specific data to determine the prevalence of self-reported asthma in AIANs in California and examine the association between housing conditions and asthma in California AIANs. Although the California Health Interview Survey (CHIS) and the California Behavioral Risk Factor Surveillance System (BRFSS) survey, have documented high prevalence of asthma among AIANs in California, these surveys have limitations that indicate that the survey findings may not be representative of AIAN populations in California. In addition, these surveys do not collect extensive information on the home environments of AIANs. The TASP survey questions were based upon previously developed surveys with an asthma related focus and included the following topics:

- Asthma
- Asthma symptoms for adults and children
- Allergens in the home
- Demographic variables
- Health conditions
- Housing conditions
- Perceptions of home and community health environments

### BEST PRACTICE APPROACHES

#### DEVELOPMENT OF A CULTURALLY APPROPRIATE SURVEY TOOL THROUGH A COLLABORATIVE PROCESS

The survey was created through collaboration between CTEC and staff at the California Breathing Asthma Program at the CDPH. Some survey questions were adapted for a tribal audience by CRIHB research staff. The survey was pilot-tested with AIAN persons before final administration.

## SEEKING AIAN PARTICIPATION BY TARGETING TRIBAL AND COMMUNITY EVENTS

Over the course of seven months, TASP staff attended ten different AIAN-specific events or events that were likely to have high proportions of AIANs in attendance to administer the surveys. These events included Big Times, Pow Wows, tribal health fairs, and community gatherings. This study had participants throughout California and included both rural and urban AIAN. Word of mouth was a key component in recruiting survey participants at the events.

### **Increasing awareness about asthma environmental triggers and morbidity**

A total of six different health education materials on asthma were available to all TASP participants at no cost. Two of the materials were adapted to be culturally-appropriate and Indian-specific. Notably, several participants shared their thoughts and experiences regarding asthma, barriers faced in receiving services, potential allergens and even tribal policies, and the free health education materials proved to be a well-appreciated component of the project.

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Summary report:

[http://www.crihb.org/files/TASP\\_Lay\\_Report\\_Final\\_E\\_VERSION.pdf](http://www.crihb.org/files/TASP_Lay_Report_Final_E_VERSION.pdf)

Technical report:

[http://www.crihb.org/files/Final%20Report\\_TASP\\_%208\\_30\\_10.pdf](http://www.crihb.org/files/Final%20Report_TASP_%208_30_10.pdf)

## Chronic Disease: Cancer Among the Navajo: 1995 - 2004

### PROJECT NAME/REPORT TITLE

Cancer Among the Navajo: 1995-2004

### TRIBAL EPIDEMIOLOGY CENTER

Navajo Epidemiology Center (NEC)

### BACKGROUND

Historically, cancer rates among the Navajo were low compared to whites (Reference in report). More recent reports revealed that mortality from all cancers remained lower among American Indians in the southwest United States, yet cancers of the liver, stomach, kidney and gallbladder were higher. At the time of the report, cancer was one of the leading causes of illness and death for the Navajo. The Navajo Cancer Workgroup used cancer data from the Arizona Cancer Registry, New Mexico Tumor Registry, National Cancer Institute's SEER program, and the Centers for Disease Control and Prevention's NPCR program to provide Navajo-specific cancer incidence, stage of cancer diagnosis, and cancer mortality. The burden of cancer among the Navajo was compared to non-Hispanic Whites of Arizona and New Mexico. The most common cancers identified were colorectal cancer, kidney cancer, pancreatic cancer, and liver cancer.

### BEST PRACTICE APPROACHES

#### Tribe-specific Data and Statistics

Previously, a number of cancer reports were available for estimating the cancer burden among the Navajo. However, the data from a number of Tribes were combined which did not allow for a true understanding of cancer on a tribal level. This report demonstrated how Navajo-specific cancer data were analyzed and presented along with comparisons to other populations. The cancer data analysis was intended to support the Navajo Nation to develop the Navajo Cancer Control Plan, solutions, interventions and relevant research for cancer and to have a better understanding of the occurrence and patterns of cancer among the people.

## **Recommendations**

As a result of the findings, recommendations for addressing the cancer burden in the Tribal population were developed. These recommendations encompassed a framework that public health professionals, health care providers, and communities could use to address cancer among the Navajo people. Five recommendations included in the report were as follows:

- 1) Expand collaboration among Navajo tribal health programs, Indian Health Service and tribally operated facilities and local communities in order to translate these data into targeted and culturally appropriate cancer prevention and intervention programs.
- 2) Continue meaningful partnership with state cancer registries to further utilize and improve population-based cancer surveillance data and maintain on-going surveillance of cancer in Navajo Area.
- 3) Promote research that examines risk factors for many of these cancers, potential causes behind later diagnoses for screenable cancers, and reasons for low cancer screening rates.
- 4) Increased targeted and culturally appropriate education and awareness about cancer and cancer risk factors, cancer screening and prevention.
- 5) Increase education and training for health care providers regarding current cancer screening practices and guidelines.

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## Chronic Disease: Cancer Misclassification Oklahoma

### PROJECT NAME/REPORT TITLE

Final Report on Cancer Misclassification Oklahoma Central Cancer Registry  
1997-2006

Funded by the AI/AN Health Disparities (Office of Minority Health) and the  
OCAITHB

### TRIBAL EPIDEMIOLOGY CENTER

Oklahoma City Area Inter-Tribal Health Board (OCAITHB)

### BACKGROUND

Several studies document the notion that American Indian vital statistics data collected are prone to misclassify race especially for mortality records. Racial misclassification of American Indians is also at issue when analyzing data reported to cancer registries. The aims of this project were to: 1) determine the extent to which American Indians were correctly linked to the Oklahoma Central Cancer Registry using Indian Health Services (IHS) data sources, 2) explore associations between blood quantum of reported cases and misclassification, and 3) map the geographic distribution of misclassification since underreporting may vary by region.

### BEST PRACTICE APPROACHES

#### Investigating Misclassification through Linkage Studies

The linkage study explored the probability of misclassification of American Indians with confirmed medically diagnosed cancer in the Oklahoma Central Cancer Registry with IHS data sources. More than 10,000 individual cases/records were linked between the Cancer Registry and the Indian Health Service data sources. The linkages indicated forty five percent (45%) of the cases/records in the Oklahoma Central Cancer Registry were misclassified as some other race rather than American Indian. The end result is a lowering or underreporting of disease rates for American Indians. The study also explored associations between misclassification and various subject and disease characteristics including blood quantum, stage (of cancer), year of diagnosis, reporting source, insurance status, primary payer, and service unit. The data analysis suggested the odds of an American Indian being misclassified greatly increased as blood quantum decreased (realizing additional factors may have

modified the association). In other words, American Indian's with a lower blood quantum had a significantly higher probability of being racially misclassified with the disease versus an American Indian with a higher blood quantum. Again this may result in underreporting of the disease affecting American Indians.

### **Mapping the Geographic Distribution of Misclassification**

The TEC mapped the percentage of American Indians diagnosed with cancer and misclassified. Oklahoma Tribal Statistical Areas (OTSA) were used as geographic boundaries. The statistical areas are intended to represent former American Indian Reservation lands prior to Oklahoma statehood. The map provided a visual representation of the geographic distribution of racial misclassification of American Indian cancer cases in Oklahoma.

### **For more information on the project, please contact:**

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## Chronic Disease: Diabetes Annual USET Diabetes Report

### PROJECT NAME/ REPORT TITLE

Annual USET Diabetes Report

### TRIBAL EPIDEMIOLOGY CENTER

United South and Eastern Tribes, Inc. (USET) Tribal Epidemiology Center (TEC)

### BACKGROUND

American Indian/Alaska Native (AI/AN) adults are disproportionately affected by diabetes. AI/AN adults are twice as likely as white adults to have diabetes, and the Nashville Area is among the top three Indian Health Service (IHS) Areas with the highest prevalence of diabetes among AI/AN adults. USET operates an IHS contracted Area Diabetes Program which provides consultative support to IHS/Tribal/Urban (I/T/U) health facilities in the IHS Nashville Area. To describe the health status of the AI/AN communities in the IHS Nashville Area, the USET TEC analyzed data from each I/T/U's electronic patient management system, including data from their active diabetes patient registries. The annual USET Diabetes Report (IHS Nashville Area aggregate and Tribal specific) provides trends and comparisons for diabetes prevalence and other condition-related indicators. Selected indicators and distributions available in the reports are listed below:

- Age-adjusted diabetes prevalence
- Age and gender distributions
- Glycemic control
- Blood pressure control
- Weight status
- Nephropathy
- Depression active diagnosis
- Depression screen
- Tobacco use and cessation counseling
- Dental, eye, foot exam within past year
- Diet education provided
- Flu and Pneumovax vaccine

### BEST PRACTICE APPROACHES

#### Ongoing regional and site-specific technical support utilizing existing registries

The USET Diabetes Reports presented data from AI/ANs who received care through the Nashville Area Indian health care delivery system, which includes a network of 2 hospitals, 25 clinics, 17 health stations, 10 alcohol/substance abuse programs, and 4 wellness centers or Contract Health Service only programs. The

aggregate findings and site-specific information are utilized as a resource for Tribal leaders, health administrators and clinicians seeking improved and enhanced diabetes programs. Additionally, the USET Diabetes Report can be utilized to make data-informed decisions regarding the health needs of the Tribal communities such as resource allocation, health program planning, and prevention.

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## Chronic Disease: Obesity – Ojibwe SHIP survey

### PROJECT NAME/ REPORT TITLE

Ojibwe Statewide Health Improvement Program (SHIP) survey

### TRIBAL EPIDEMIOLOGY CENTER

Great Lakes Inter-Tribal Epidemiology Center (GLITEC)

### BACKGROUND

The Statewide Health Improvement Program (SHIP) is an initiative implemented by the Minnesota Department of Health. The goal of SHIP is to help Minnesota residents live longer and healthier lives by addressing tobacco use/exposure, physical inactivity, and poor nutrition, which are major contributors to illness and death. The seven Ojibwe Tribes in Minnesota (Bois Forte, Fond du Lac, Grand Portage, Leech Lake, Mille Lacs, Red Lake, and White Earth) collaborated on a SHIP project to implement policy, system, and environmental interventions. As part of SHIP, the Ojibwe Tribes conducted community surveys focusing on nutrition, physical inactivity, and tobacco abuse. As the case with many other AI/AN communities, Ojibwe Tribes in Minnesota did not have data based on sufficient survey numbers to draw meaningful conclusions for their communities.

### BEST PRACTICE APPROACHES

#### Community-based Surveys

The Ojibwe SHIP Survey was administered by seven Ojibwe Tribes; 2,009 surveys were collected. The self-administered survey consisted of five sections related to demographics, general health, tobacco, nutrition, and physical activity. Each Tribe sought to collect a large enough sample so that statistically significant results could be provided at the community level, rather than assume their data reflected that of the general Minnesota Ojibwe Tribal population. Though the same survey was used across the project, each Tribe recruited participants in ways which best fit community needs. Relying on local knowledge allowed coordinators to reach community members efficiently. The aggregate survey results provided an overview of the current state of seven Ojibwe communities; confidential Tribe-specific reports are forthcoming. Key findings provide the Ojibwe communities insight into strengths and concerns related to obesity and tobacco abuse, can serve as baseline data to track changes over time, and may be useful in community health planning.

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[www.glitc.org/epicenter](http://www.glitc.org/epicenter) [Chronic Disease: Obesity – Example 1](#)

## Chronic Disease: Obesity Prevention –Child Health Measures Project

### PROJECT NAME/REPORT TITLE

Child Health Measures: - ONGOING

### TRIBAL EPIDEMIOLOGY CENTER

Rocky Mountain Tribal Epidemiology Center (RMTEC)

### BACKGROUND

The Child Health Measures project has been implemented in seven (7) out of eight (8) reservations among school children and youth annually since 2006 (data collection started in 2007). The goal of the Child Health Measures project is to provide participating Tribes/ Reservations with information/ data on health measures associated with the risks for childhood obesity, diabetes, and heart disease.

Each Tribal community was encouraged to “*opt in*”/“*opt out*” in a time series fashion over the first five years of the project implementation, hence the time series fashion of increased participation.

### BEST PRACTICE APPROACHES

Measurements taken by over 50 trained Tribal field workers and community volunteers annually include: Weight/Height (BMI), Blood Pressure, presence of Acanthosis, Asthma diagnosis and family history of disease. Several steps are used to implement the project annually. These steps include: Obtaining School Participation; Informing the Community about the Project; Obtaining Parental Consent; Child Health Measurements (including 5 measurement stations and one survey station for grades 5 to grade 12); Data Entry; Child Referrals/Incident Reporting. Tribe specific Annual reports are generated and disseminated to participating Tribes.

Community project partners include Tribal Health Departments, Tribal Diabetes Departments, schools and parents. Annually, project community teams come together to discuss best practices, project protocols, intervention strategies, as well as conduct refresher trainings.

One of the interventions launched in 2009 based on the child health measures project is the *Montana Wyoming Native Child and Youth Health Project*. The intervention promotes body, mind and spiritual well-being of Montana and

Wyoming (MT/WY) American Indian school age children and youth, ages 5 to 19 years old by refurbishing safe play places and funding Staff Recreation Guides for child safety".

Less than half of the participating children had a normal weight for their age (45%). About 33% were overweight/Obese and over 20% of participating children were "at risk for overweight" suggesting that if more children go from being at risk for overweight to becoming overweight, a total of 54% of the children will be "high risk for heart disease and diabetes". The rest of the children were under weight. Pre-hypertension/hypertension was seen in about 15% of participants. There were however a higher percentage of male children in the "obese" category.

### Recommendations

More attention needs to be placed on Primary prevention, with children at risk for heart disease and diabetes like those in Montana and Wyoming. Funding is needed to at least equally intervene in both Primary and Tertiary Prevention (Example of Primary Prevention: Children with no signs of heart disease or diabetes; Example of Tertiary Prevention: those with complications of heart disease or diabetes currently undergoing specialist care).

Project Gaps: Child Health Measures are only performed in participating schools, so children who do not attend the participating schools are not included in this project. Montana High School diploma (GED) or higher for American Indians is 80% (compared to 90% for all races); and Wyoming High School diploma (GED) or higher for American Indians is 83% (compared to 91% for all races) (*2006-2008 American Community Survey, U.S. Census Bureau*).

Disclaimer: The results presented in this report are for your review only and are not to be referenced or duplicated without permission from the Montana Wyoming Tribal Leaders Council. For clarifications, please contact Folorunso Akintan at MTWYTLC/RMTEC, 175 North 27 th Street Suite 1003, Billings MT 59101, or call (406) 252-2550; e-mail: [fakintan@mtwytlc.com](mailto:fakintan@mtwytlc.com)

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## Immunization USET Immunization Program

### PROJECT NAME/ REPORT TITLE

United South and Eastern Tribes, Inc. Tribal Epidemiology Center Immunization Program

### TRIBAL EPIDEMIOLOGY CENTER

United South and Eastern Tribes, Inc. (USET) Tribal Epidemiology Center

### BACKGROUND

The USET TEC Immunization Program provides ongoing immunization coverage data analysis services and useful information to USET Member Tribes. Twenty-four sites within the Nashville Area report immunization coverage using Resource and Patient Management System (RPMS) or a commercial software. USET and Nashville Area of IHS have access to field-based Immunization Coordinators at the local Tribal and IHS health departments, all working to reduce the incidence of vaccine-preventable diseases among American Indian and Alaska Native (AI/AN) populations. The report includes information from the following sources and categories:

- "Two Year Old Reports, 19-35 Month Olds"
- "Quarterly Immunization Reports, 3-27 Month Olds"
- "Government Performance and Results Act (GPRA) Two Year Old Immunization Coverage"
- "Immunization Project Participation, Resource Patient Management System (RPMS) Use, RPMS Immunization Registry Use, and State Immunization Registry Use by Tribe"
- "Incidence of Vaccine-Preventable Diseases, RPMS Unconfirmed USET Cases"

USET collaborates with the IHS Division of Epidemiology and Disease Prevention using the National Immunization Reporting System (NIRS). NIRS is a web-based reporting tool used to collect quarterly immunization data from IHS/Tribal/Urban facilities nationwide. The NIRS was developed in partnership with the IHS Public Health Nursing Program to improve the quality and timeliness of immunization data.

## **BEST PRACTICE APPROACHES**

### **Capacity Building**

In the area of capacity building, USET has placed its focus on areas that accommodate Tribal immunization development and improvement. USET has arranged trainings for Tribal immunization coordinators and clinic personnel on RPMS immunization registry package. As a means to develop capacity building, the project has facilitated communication between Tribal personnel and state immunization programs for access to state immunization registries and to resolve vaccine supply issues.

### **Surveillance**

The project has maintained surveillance of immunization and vaccine-preventable disease through various means such as increasing the number of Tribes submitting quarterly childhood immunization reports and increasing the number of children ages 3-27 months tracked for immunization coverage. The project began surveillance using the RPMS Immunization Module Two Year Old report, which tracks how many 19-35 month old children are up-to-date on immunizations. It also obtained vaccine-preventable disease data from RPMS to compare tribal incidence with U.S. and state reported incidence. Utilizing the Government Performance and Results Act (GPRA) clinical measures initiative, USET has seen an increase in a measure of immunization coverage.

### **For more information on the project, please contact:**

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## Sexually Transmitted Diseases Viral Hepatitis and STI Prevention

### PROJECT NAME/ REPORT TITLE

Project Brief: Viral Hepatitis and STI Prevention Project

### TRIBAL EPIDEMIOLOGY CENTER

Urban Indian Health Institute (UIHI)

### BACKGROUND

The Seattle Indian Health Board's Urban Indian Health Institute (UIHI) recognized the need for integrated education and prevention efforts for Viral Hepatitis and Sexually Transmitted Infections (STIs). In 2011, the UIHI was awarded funding by the Office of Minority Health to address these health issues by providing technical assistance to Urban Indian Health Organizations (UIHO) and developing culturally appropriate health promotion materials.

### PROMISING PRACTICE APPROACHES

#### **Improving Access to Resources by Hosting Webinars and Through the Website**

Webinars were designed to serve as informational resources to support prevention, screening and treatment efforts for Viral Hepatitis, HIV and other sexually transmitted infections (STIs). All webinars were free, open to the public and are archived on the Project website for future viewing. Webinars focused on accessing and using Viral Hepatitis and STI surveillance data, funding opportunities and promising practices in prevention. The Project website contains information about these health issues, and is used to communicate with UIHO and other users. Native-specific and general health promotion materials such as postcards, posters, patient education materials and resources for providers are also available through the website.

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## **Injury: IDEA-NW Project and Injury Prevention**

### **PROJECT NAME**

IDEA-NW Project and Injury Prevention Program

### **REPORT TITLE**

Unintentional injury and motor vehicle crash mortality in the Northwest: With a focus on Washington data and trends, 1990-2009

### **TRIBAL EPIDEMIOLOGY CENTER**

Northwest Tribal EpiCenter, Northwest Portland Area Indian Health Board (NPAIHB)

### **BACKGROUND**

AI/ANs are often misclassified as another race on death certificates, and in the northwest AI/AN are usually classified as White. For that reason, mortality rates for AI/AN are often underestimated. The Improving Data & Enhancing Access (IDEA-NW) Project aimed to correct inaccurate race data at state level to provide improved health data for tribes in the northwest. Project staff linked Washington death certificate data with “Northwest Tribal Registry” clinic registration data from Indian Health Service (IHS), tribal and urban Indian facilities. When a match was found, the race on the death certificates were reclassified as AI/AN.

### **BEST PRACTICE APPROACHES**

#### **Data Linkage**

The data source for this linkage was Washington state death certificate data, 1990-2009 (Center for Health Statistics, Washington State Department of Health), which was linked with the Northwest Tribal Registry, which includes clinic registration data from IHS, tribal, and urban Indian facilities. Through this linkage, all records known to be AI/AN were identified, and any matches with death certificates reclassified as AI/AN race. Unintentional injury and motor vehicle collision (MVC) deaths were selected using ICD-9 and ICD-10 underlying cause of death codes. For the purposes of the analysis, AI/AN records were those which indicated AI/AN race on death certificate and/or which matched with the Northwest Tribal Registry. Data for non-Hispanic Whites were selected for comparison, and National Center for Health Statistics bridged-race population

estimates were used as population denominators. Rates were then age-adjusted and presented per 100,000 population.

The results of the linkage using 2000-2009 data showed about 9% of AI/AN were misclassified as another race on Washington death certificates. IDEA-NW analyzed the re-coded data, which showed that rates of unintentional injury death and motor vehicle crash related deaths were consistently higher than Whites. In addition, the gap between these two groups in motor vehicle crash deaths has grown in recent years; as death rates for non-Hispanic whites have dropped steadily since 1990, AI/AN rates have remained relatively constant.

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Report: [http://www.npaihb.org/images/epicenter\\_docs/NW-Idea/UI%20and%20MVC%20mortality%20data\\_Apr2012.pptx](http://www.npaihb.org/images/epicenter_docs/NW-Idea/UI%20and%20MVC%20mortality%20data_Apr2012.pptx)

## Maternal and Child Health: Alaska Native MCH

### PROJECT NAME/REPORT TITLES

- 1) Alaska Native Maternal and Child Health: Trends and Data (2008)
- 2) Alaska Native Maternal and Child Health Data Book 2011: Alaska Native edition (2011)
- 3) Healthy Native Families: Preventing Violence at All Ages (2012)

### TRIBAL EPIDEMIOLOGY CENTER

Alaska Native Epidemiology Center (ANEC)

### BACKGROUND

As part of its initiative to improve maternal and child health, the Alaska Native Tribal Health Consortium's Alaska Native Epidemiology Center (ANEC) has produced several reports and manuscripts. Although there are a variety of projects under this initiative, highlighted here are three data reports which are available on their website <http://www.anthctoday.org/epicenter>. The information provided in these reports is useful for planning and evaluation.

First, ANEC produced the *Alaska Native Maternal and Child Health: Trends and Data* in 2008. This reported provided information on:

- Birth Rates;
- Characteristics of Parents;
- Prenatal Risk Factors;
- Prenatal Health – Protective Factors;
- Birth Outcomes; and
- Infant and Child Mortality.

ANEC then collaborated with the Alaska Department of Health and Social Services, Division of Public Health to produce a data book based on survey data from the Pregnancy Risk Assessment Monitoring System (PRAMS) and the three-year follow-up survey called the Childhood Understanding Behaviors Survey (CUBS). This report, entitled *Alaska Native Maternal and Child Health Data Book 2011: Alaska Native edition* was published in 2011.

Information related to the following topics were included:

- Population Characteristics;
- Reproductive Health;

- Prenatal Health;
- Prenatal Substance Use;
- Maternal Health;
- Infant Health;
- Child Health; and
- Childhood Home Environment.

More recently, ANEC produced a bulletin ***Alaska Native Families: Preventing Violence At All Ages***. This report highlights what data is available and what data gaps exist for domestic violence, intimate partner violence, and sexual violence. This is the first time this information has been available for Alaska Native people in one document. This report was initially released in early 2012 and a revision was released in 2013.

## **BEST PRACTICE APPROACHES**

### **Reporting Indicators by Alaska Native Status and Tribal Health Regions**

Because health care through the Alaska Tribal Health System is delivered by regional tribal health entities and because there can be regional differences, it is helpful to tribal health programs to have their data analyzed and reported by the regions that closely align with their regional tribal health organization boundaries, in addition to the statewide rates. Thus, the reports noted above, as well as many other recent ANEC reports, provide regional estimates as well as statewide estimates.

By presenting the data for Alaska Native people and for tribal health regions, the data can assist in program design, implementation, and monitoring as well as in strategic planning and policy development. ANEC understands that data is critical to the decision-making process and that using data to improve health and wellness for Alaska Native and American Indian people in Alaska is our mission.

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## Maternal and Child Health: WIC and MCH Profile

### PROJECT NAME/ REPORT TITLE

Inter Tribal Council of Arizona, Inc.

Women, Infants, and Children (WIC) Program Maternal and Child Health Profile

### TRIBAL EPIDEMIOLOGY CENTER

Inter Tribal Council of Arizona, Inc. Tribal Epidemiology Center (ITCA TEC)

### BACKGROUND

The Inter Tribal Council of Arizona, Inc. (ITCA) Tribal Epidemiology Center (TEC) partners with the ITCA Special Supplemental Nutrition Program for Women, Infants, and Children (WIC) program that serves low to moderate-income women, infants and children at twelve local agencies, including eleven tribal agencies and one urban site. To assess the health status of the women and children enrolled in ITCA WIC clinics the ITCA TEC generates reports that compare site-specific data to ITCA WIC aggregate and national level data. The Centers for Disease Control and Prevention (CDC) national Pregnancy Nutrition Surveillance System (PNSS) and Pediatric Nutrition Surveillance System (PedNSS) are data sources for national level comparisons. These reports include health indicators for pregnant women, infants and children, a few are mentioned below:

### INDICATORS FOR WOMEN

- Age at birth
- Age at previous conception
- Pre-pregnancy BMI
- Weight gain
- Inter-pregnancy interval
- Gestational diabetes
- Hypertension
- Prenatal care
- WIC enrollment
- Smoking
- Breastfeeding by maternal WIC enrollment

### INDICATORS FOR CHILDREN AND INFANTS

- Age at WIC enrollment

- Birth weight
- Preterm & full term low birth weight
- Breastfeeding
- Low hemoglobin (Hgb)
- Stature
- Underweight
- Overweight
- Overweight by maternal BMI
- Preterm status by maternal age

## **BEST PRACTICE APPROACHES**

### **Provision of Information to Inform Policy and Program Planning**

The ITCA TEC develops the annual ITCA WIC Maternal and Child Health profiles and presents aggregate and site-specific results to the WIC program directors. The ITCA WIC Directors utilize the information from the annual reports by monitoring trends and as a resource to support health program planning for the local WIC sites. Annually, the TEC obtains feedback from the WIC directors regarding the profiles and modifications are made to best fit the needs of the users of the reports. For instance, the WIC program directors requested additional maternal and child indicators and available were included in the last iteration of profiles.

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## Maternal and Child Health: South Dakota PRAMS Surveillance

### **PROJECT NAME/ REPORT TITLE**

South Dakota Tribal Pregnancy Risk Assessment Monitoring System (PRAMS):  
Statewide Surveillance Report, 2009

### **TRIBAL EPIDEMIOLOGY CENTER**

Northern Plains Tribal Epidemiology Center (NPTEC)

### **BACKGROUND**

The South Dakota Tribal Pregnancy Risk Assessment Monitoring System (SD Tribal PRAMS) is a tribally-driven project led by the Yankton Sioux Tribe, and implemented in collaboration with all South Dakota tribes. The Northern Plains Tribal Epidemiology Center (NPTEC) of the Aberdeen Area Tribal Chairmen's Health Board (AATCHB) managed the project and collaborated with the Departments of Health in South Dakota and North Dakota, Indian Health Service and Centers for Disease Control and Prevention. The SD Tribal PRAMS Statewide Surveillance Report presented findings from a survey of women who gave birth to American Indian infants in the project period. The report included maternal and infant health indicators from the categories mentioned on the following page:

- Previous pregnancy outcomes and pregnancy intention
- Birth control use
- Nutrition and weight
- Medical risk factors
- Delivery
- Stressful life events
- Depressive symptoms
- Abuse by partner
- Tobacco
- Environmental tobacco smoke
- Alcohol
- Prenatal care
- Infant health after delivery
- Breastfeeding
- Infant preventative care
- Social support
- Services received
- Payer of health care
- Household income

## **BEST PRACTICE APPROACHES**

### **Implementing Tribally-managed surveys**

The SD Tribal PRAMS is the first tribally managed statewide survey of mothers of American Indian infants to capture information on health and their experiences before, during, and after pregnancy. Participation and input from tribal leaders and a Tribal Oversight committee ensured that the effort to improve AI health in South Dakota was tribally-driven and based on priorities identified by stakeholders. Stakeholders also played an integral role in the planning for analysis and utilization of the data.

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## Vital Statistics: Community Health Profile (CHP): Aggregate of Urban Indian Health

### REPORT

Community Health Profile (CHP): National Aggregate of Urban Indian Health Organization Service Areas  
Urban Indian Health Organization Community Health Profiles (UIHO-specific)

### TRIBAL EPIDEMIOLOGY CENTER

Urban Indian Health Institute (UIHI)

### BACKGROUND

The National Aggregate of Urban Indian Health Organization (UIHO) Service Areas Health Profile provides an overview of the health status of AI/AN populations living in select urban areas. In addition to the national aggregate report, UIHI developed local community level profiles for the Urban Indian Health Organizations located in 19 states across the nation. For both the aggregate and organization level Health Profiles, AI/AN populations were compared with the all race population, or the general population. Where possible, Healthy People 2020 objectives were reported with a relevant indicator to show the status of urban AI/AN populations with respect to current national goals. The selected health indicators provide reliable and relevant information about major health concerns of urban AI/AN communities. The following topics are covered in the 2011 UIHO Service Areas Health Profile:

- Socio-demographics
- Mortality
- Access to care
- Environmental health
- Heart Health
- Maternal Child health
- Alcohol use
- Mental health and wellness

## **PROMISING PRACTICE APPROACHES**

### **Monitoring of health status of urban AI/AN populations**

There are 34 not-for-profit UIHO or community health centers that play a vital role in providing culturally appropriate health care, outreach and referral services to urban AI/AN communities. These services are available to the more 1.2 million AI/AN residing in the service cities and counties. The UIHI routinely monitors the selected health indicators and develops the Health Profiles to support urban communities and UIHO to identify health priorities; allocate resources; guide new program development; identify gaps in data and needs for new data collection; and obtain supporting data for grant applications.

#### **For more information on the project, please contact:**

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**Aggregate Report:** [http://www.uihi.org/wp-content/uploads/2011/12/Combined-UIHO-CHP\\_Final.pdf](http://www.uihi.org/wp-content/uploads/2011/12/Combined-UIHO-CHP_Final.pdf)  
Urban Indian Health Organization Community Health Profiles:  
<http://www.uihi.org/urban-indian-health-organization-profiles/>

## Vital Statistics: ITCA Community Health Profiles

### PROJECT NAME/ REPORT TITLE

Tribal Community Health Profiles

### TRIBAL EPIDEMIOLOGY CENTER

Inter Tribal Council of Arizona, Inc. (ITCA) Tribal Epidemiology Center

### BACKGROUND

A tribal Community Health Profile (CHP) is a report that communicates the health status, or overall well-being, of a tribal community or population. The tribal CHP contains data and statistics on the well-being, morbidity (or illness), and mortality (or death) of the tribal members. Combined, these types of information provide an overview of the health status of the tribal community which is dynamic and influenced by a number of factors. A tribal CHP includes key characteristics of the tribal community such as demographic, socioeconomic status and health related information specific to the community. Demographic and socioeconomic status information is important because it details the basic characteristics of community members such as total number of tribal members, age, sex (gender), income, and educational attainment.

### BEST PRACTICE APPROACHES

#### Using Tribal and Federal Data Sources

In collaborative planning sessions, the ITCA TEC and the partner tribe determine which data sources are best for the demographic characteristics presented in the tribal CHP. Tribal data from enrollment or administrative departments are often the most current and reliable census of tribal members. If selected by the tribe, data from the U.S. Census are also included in the CHP. Tribes are then able to utilize both data sources and better understand the demographic and socio-economic characteristics of enrolled tribal members and also non-enrolled members living in the community.

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## **Future Directions/Next Steps**

The current report offers a snapshot of some of the important work TECs engage in to identify the actual health needs affecting AI/AN populations.

TECs were established with the purposes of: Identifying /understanding health and disease among AI/AN populations; expanding AI/AN capacity in public health; and, partnering in disease prevention and control with Tribal populations (1). In order to effectively carry out these critical public health actions, TECs need additional resources to conduct comprehensive surveillance work in order to get a timely and accurate understanding of health issues of impact in communities they serve.

States conduct ongoing surveillance efforts of a broader population, but their efforts alone have been repeatedly found to insufficiently capture the incidence of AI/AN health issues(2-4). TECs were established out of a concerns related to lack of public surveillance data and disease control in the AI/AN populations (5).

The insufficiencies of existing surveillance are of particular concern given that AI/ANs may be disproportionately impacted by health conditions for a variety of reasons. For instance, in a study of H1N1 mortality in 12 states, which involved collaborative efforts of State Health Departments and TECs, AI/AN were found to have a mortality rate four times higher than all other racial/ethnic populations combined(6).

### **Incorporate TEC surveillance efforts into larger surveillance systems**

AI/AN disease surveillance efforts by TECs are likely to succeed only if well-integrated into larger surveillance systems. The inconsistent quality and capture of public health surveillance data of the AI/AN populations underscores the need for better integration of TECs and health agencies serving AI/ANs to achieve improved integration into established public health networks (2). More comprehensive health data surveillance for AI/AN populations can serve as the basis for identifying issues amenable to strategies focused on disease control and prevention.

While large national surveys and databases offer perspective on U.S. population health in general, data from these national samples tends to be poor and under

representative of AI/AN and, may provide an inaccurate or incomplete picture of disease burden. There are several likely reasons for this deficiency: the relative small population numbers of AI/ANs decreases their representation in such data collection efforts as well as the tendency to clump AI/AN into a racial/ethnic "other" category for reporting; rural aggregation of AI/AN populations; misclassification of AI/ANs in surveillance systems such as cancer registries; and poor response rates from AI/AN (3, 7, 8). Appropriately including AI/ANs in national surveys is a major barrier but cannot be considered as an exemption from expanded efforts to improve the quality of these data.

Several methods have been proposed to address insufficiencies in large national datasets to fully capture the health status of AI/ANs. These methods include oversampling; aggregation of data across several years; partnerships between AI/AN and those conducting national surveys to conduct local versions with improved AI/AN capture(8).

Specific, continuous surveillance of the health status of minority populations including AI/ANs is critical in the implementation of community-specific, culturally-sensitive, and culturally-appropriate interventions (9).

### **Engage in Community Based Participatory Research (CBPR) to avoid continuation of historical mistrust**

Even with resources and infrastructure in place, the improvement of AI/AN health surveillance faces other barriers, including historical mistrust and legal issues related to sharing data.

Although AI/ANs are members of diverse sovereign nations and are not a homogeneous group, they share a common historical experience of population decimation, the loss of lands, destruction of language, religion and culture, and forced relocation(10). This history has left a legacy of mistrust among AI/AN(2), a critical factor that must be understood and accepted in order to engage in successful collaborations with existing public health systems. Certain approaches such as community-based participatory research are primed to acknowledge distrust, avoid a top-down approach to interaction and have been used to increase AI/AN surveillance(11). TECs have provided leadership in enhancing data sharing agreements, considering the tribal perspective, and suggesting strategies for professional interactions in Indian Country.

### **Collaborate with other public health entities**

TECs must also focus on collaboration with existing public health entities. In many cases, this collaboration fills gaps in the public health system where AI/AN needs might otherwise go unnoticed or where TECs are not engaged in state and local public health promotion efforts.

Successful collaboration between TECs and state and national surveillance efforts will depend on an open flow of data sharing between entities. TECs experience legal barriers to acquiring crucial data due to state public health privacy laws; some of these impediments may be based on legal misinterpretations of existing state laws(5). TECs might benefit from specifying their legal authority to acquire state and/or federal public health data(5). To improve the accuracy of surveillance, data linkages have been successfully employed to identify and correct racial/ethnic misclassification of AI/AN(12, 13), but such efforts are feasible only when potential data sharing issues are appropriately resolved (5).

As TEC's look toward the future to continue and expand their work, the Canadian health example should be explored. Although, Canada does not currently have aboriginal epidemiology centers, Canada has successful strategies for working with aboriginal and First Nations Peoples. Some of these strategies may be worth adapting. Some of these include Cancer Care Ontario's Aboriginal Program - a model program that ensures aboriginal peoples have access to cancer prevention, screening, and information; An Injury Surveillance Project conducted within aboriginal communities and a project focused in kidney disease in three First Nations communities was built upon partnership with local and regional health entities. Partnerships were considered focal to the success of these projects (15).

The success of the TECs to identify and respond to health issues of concern to the tribal communities they serve is evident in this report. Deficiencies in surveillance and capture in large national surveys motivate the need for an expanded role of TECs in surveillance, as well as more seamless and culturally-appropriate collaboration with local, state and federal health authorities. To carry out these tasks and comprehensively function as public health authorities, TECs need resources, including additional staff, and recognition for their role as public health authorities serving AI/AN.



## Concluding Summary

While it is clear that the TECs have made substantial progress, as illustrated in this document, much work remains to be done. TECs have demonstrable skills in providing Tribes, Tribal organizations and UIHOs with important data for advocacy and enhanced health equity. There have been substantial improvements in data quality and availability to the Tribes and UIHOs, since the Tribal Epidemiology Center Program's inception.

The TECs recommend the following actionable items to enhance the effectiveness of each of our centers and our collective effectiveness:

1. Under TECs authority as public health entities, equitable access to data should occur nationwide.
  - a. Each TEC embarks on work that is acceptable to its constituency. Once a particular project is endorsed, TECs should have equal ease of access to data, regardless of the State or States they are working with.
2. In order for TECs to optimize their performance, adequate funding of each center should occur.
  - a. For the majority of centers, adequate funding would be roughly two times the level of current funding.
  - b. Funding should be considered from other DHHS agencies, not only Indian Health Services. For example, the surveillance and tribal survey work that is done is very complementary to the work of the Centers for Disease Control and Prevention.
  - c. Inter-agency planning should consider ways to optimize funding to the Tribal Epidemiology Centers, thus ensuring a continuing, valuable service to the Tribes and UIHOs.

The aforementioned strategies would also facilitate the work of TECs on mutually agreed upon projects. Collaborative efforts such as this are key in providing constituents with a fuller picture of American Indian and Alaska Native health, nationwide.



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## GLOSSARY OF TERMS

AAIHB	Albuquerque Area Indian Health Board, Inc.
AAIP	Association of American Indian Physicians
AASTEC	Albuquerque Area Southwest Tribal Epidemiology Center
AI	American Indian
AI/AN	American Indian/Alaska Native
AI/AN/NA	American Indian/Alaska Native/Native American
AIAN	American Indian Alaska Native
AN/AI	Alaska Native/American Indian
ANEC	Alaska Native Epidemiology Center
ANMC	Alaska Native Medical Center
ANTHC	Alaska Native Tribal Health Consortium
ANTR	Alaska Native Tumor Registry
AODA	Alcohol and Other Drug Abuse
ATHS	Alaska Tribal Health System
BFA	Bachelors of Fine Arts
BMI	Body Mass Index Calculated at Weight in Kilograms divided by Height in Meters Squared
BRFSS	Behavioral Risk Factor Surveillance System
CBPR	Community Based Participatory Research
CDC	Centers for Disease Control & Prevention
CDPH	California Department of Public Health
CHA/Ps	Community Health Aides or Community Health Practitioners
CHIS	California Health Interview Survey
CHP	Community Health Profile
CHR	Community Health Representative
CRC	Colorectal Cancer
CRIHB	California Rural Indian Health Board
CSTE	The Council of State and Territorial Epidemiologist
CTEC	California Tribal Epidemiology Center
CTG	Community Transformation Grants
CTIP	Community Transformation Implementation Plan
DCHS	Division of Community Health Services
DEHE	Division of Environmental Health and Engineering
DHHS	Department of Health & Human Services
DSC	Doctor of Science
FOBT	Fecal Occult Blood Test

GED	General Educational Development
GLITC	Great Lakes Inter-Tribal Council
GLITEC	Great Lakes Inter-Tribal Epidemiology Center
GPRA	Government Performance & Results Act
GPTCHB	Great Plains Tribal Chairmen's Health Board
H1N1	A strain of flu virus
HGB	Hemoglobin
	Human Immunovirus/Acquired Immunodeficiency Syndrome/Sexually Transmitted Diseases/Sexually Transmitted Infections
HIV/AIDS/STD/STI	
HP/DP	Health Promotion Disease Prevention
HRSA	Health Resources & Services Administration
I/T/US	IHS/Tribal/Urban
IBIS	Interoperability in Business Information Systems
IDEA-NW	Improving Data & Enhancing Access - Northwest
I.H.S.	Indian Health Service
IHS-OCA	Indian Health Service Oklahoma City Area
IRB	Institutional Review Board
ITC	Inter-Tribal Consortium
ITCA	Inter Tribal Council of Arizona, Inc.
	Inter Tribal Council of Arizona, Inc. Tribal Epidemiology Center
ITCA TEC	
MAPP	Mobilizing for Action through Planning and Partnership
MCH	Material Child Health
MD	Physician
MIS	Management Information System
MOU	Memorandum of Understanding
MPH	Master's of Public Health
MSPH	Master of Science in Public Health
MSPI	Methamphetamine and Suicide Prevention Initiative
MT	Montana
MTWYTLC	Montana Wyoming Tribal Leaders Council
MTCCC	Montana Comprehensive Cancer Control Program
MVC	Motor Vehicle Collision
NACCHO	National Association of County and City Health Officials
NALBOH	National Association of Local Boards of Health
NATIVE CARS	Native Children Always Ride Safe Project
NBRFSS	Navajo Behavioral Risk Factor Surveillance Survey
NCHS	National Center for Health Statistics
NCI	National Cancer Institute

NCMHD	National Center on Minority Health and Health Disparities
NMDOH	New Mexico Department of Health
NEC	Navajo Epidemiology Center
NIH	National Institutes of Health
NIRS	National Immunization Reporting System
NPAIHB	Northwest Portland Area Indian Health Board
	National Public Health Performance Standards Program
NPHPSP	
NPTEC	Northern Plains Tribal Epidemiology Center
NTR	Northwest Tribal Registry
NWNARCH	Northwest Native American Research Center for Health
NWTEC	Northwest Tribal Epidemiology Center
OCAITHB	Oklahoma City Area Inter-Tribal Health Board
OMB	Office of Management and Budget
OMH	Office of Minority Health
OTSA	Oklahoma Tribal Statistical Area
PedNSS	The Pediatric Nutrition Surveillance System
PHI	Protected Health Information
PI	Principle Investigator
	Indian Self-Determination and Education Assistance Act
PL 93-638	
PNSS	Pregnancy Nutrition Surveillance System
PRAMS	Pregnancy Risk Assessment Monitoring System
RMTEC	Rocky Mountain Tribal Epidemiology Center
RPMS	Resource & Patient Management System
RWJ	Robert Wood Johnson Foundation
SAICN	Southwest American Indian Collaborative Network
SAMHSA	Substance Abuse & Mental Health Service Administration
SAS	Statistical Analysis System
	Surveillance, Epidemiology and End Results (SEER) Program, a premier source for cancer statistics in the United States
SEER	
SHIP	Statewide Health Improvement Program
SIHB	Seattle Indian Health Board
SPFSIG	Strategic Prevention Framework State Incentive Grant
	A general-purpose statistical software package created in 1985 by StataCorp
STATA	
TASP	Tribal Asthma Survey Project
TECs	Tribal Epidemiology Centers
THOS	Tribal Health Organizations
THPS	Tribal Health Programs

TMVCIPP	Tribal Motor Vehicle Crash Injury Prevention Project
UIHI	Urban Indian Health Institute
UIHO	Urban Indian Health Organization
USDA	U.S. Department of Agriculture
USET	United Southern & Eastern Tribes, Inc
	United Southern & Eastern Tribes Tribal
USET TEC	Epidemiology Center
VISTA	Volunteers in Service to America
WIC	Federally Funded Program for Women, Infants and Children
WNATN	Wisconsin Native American Tobacco Network
WNYTS	Wisconsin Native Youth Tobacco Survey

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