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Technical Assistance Report

Activities To Address HIV/AIDS In Native American Communities

March 2008

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INTRODUCTION

Thirty-five states have significant American Indian/Alaska Native (AI/AN) populations. Since state health departments are the focal point for public health services in each state, the National Alliance of State and Territorial AIDS Directors (NASTAD) understands the importance of building and establishing trust with these communities for successful HIV/AIDS programming.

Yet planning and implementing programs in Native American tribes and nations, tribal agencies, and urban programs requires a specific knowledge and understanding of the history and cultural background of the local tribes and how differing communication styles may impact intended outcomes. Equally important is an understanding of sovereignty issues and Indian health care policy and prevention and care delivery systems.

In November 2004, NASTAD published its Native American Report – *Native Americans and HIV/AIDS: Key Issues and Recommendations for Health Departments* to address these issues and foster increased understanding among health department staff about issues impacting HIV risk among Natives Americans. The report reviewed the historical underpinnings and key issues impacting HIV/AIDS risk among Native Americans and profiled several state programs addressing HIV/AIDS in Native American communities.

NASTAD's 2004 report emphasized that effective communication is essential for ensuring a successful partnership when working with Native communities. Effective communication can only be achieved when the following are present: trust, cultural sensitivity, accurate information about the community, an understanding of various communication styles, a thorough understanding of Native American health care utilization and a willingness to deal with competing health priorities. It is also important to acknowledge and accept that traditional methods of healing are important for many Native Americans.

Subsequent to publication of NASTAD's Native American Report, NASTAD convened a Native American Networking Group, composed of state health department staff and a Native American Stakeholders Group of Native Americans from local, regional and national programs and agencies, to further discuss issues impacting HIV/AIDS services for Native American communities. The groups served as a means to discuss strategies for health departments and Native American communities to work together to address issues impacting HIV/AIDS in Native American communities. These groups collectively identified the following issues to further explore:

- Strategies for building trust;
- Strategies for building cultural sensitivity and educating non-Native health providers;
- Strategies for dealing with data issues and quality;
- Strategies for dealing with competing priorities;
- Providing education, building capacity and mobilizing Native American clients and communities; and
- Strategies for supporting effective services in Native American communities.

This update to the 2004 report will briefly review the issues identified by NASTAD's Native American Networking and Stakeholder groups and the ways in which health departments and Native American tribes and urban organizations have worked to address these concerns. In addition, we hope to dispel some of the common

misconceptions about Native Americans, including eligibility for health services. In addition to discussing how specific issues are being addressed, this update also includes a list of several important resources: a description of how HIV/AIDS services for Native Americans are organized at the federal level; a list of pertinent U.S. laws related to Native Americans, and a glossary of important terms related to HIV/AIDS and Native Americans.

This update emphasizes strategies and approaches to consider for health departments and Native American advocates wishing to do more to address HIV/AIDS in Native American communities. As such, this update builds upon NASTAD's earlier work that reviewed historical underpinnings and other factors impacting Native Americans' HIV risk. In addition, this report is not exhaustive of all the work currently underway to address HIV/AIDS, viral hepatitis and other sexually transmitted diseases (STDs) in Native American communities. Rather, the report was developed by a convenience sampling technique; ten members of the Native American Networking Group and eight members of the Native American Stakeholders Group were interviewed for this update, and members of both the Networking and the Stakeholders groups provided additional input and guidance (see Respondents and Contributors section).

BACKGROUND

The 2004 NASTAD Native American Report pointed out that Native Americans face a multitude of challenges to their health and well-being. HIV/AIDS is only one of the many health issues being addressed by the different health systems providing services to these populations. The rates of poverty and disease morbidity and lack of higher education for Native Americans are well documented in the 2000 U. S. Census data and other reports. Those factors, combined with insufficient program funding, denial of the impact of HIV/AIDS in Native American communities, the ongoing impact of historical trauma, and inadequately trained primary health care professionals contribute to increased risk for HIV/AIDS in many Native American communities. In addition, surveillance data do not necessarily reflect the extent of HIV/AIDS morbidity among Native Americans due to data sharing issues, racial misclassification and/or misidentification and underreporting.

Furthermore, it can be challenging to ensure that health departments have a comprehensive understanding of the different health systems, including tribal programs that are "638" or "compacted," urban Indian health and Indian Health Service (IHS) facilities, and private facilities for those with insurance, due to the unique relationship tribes have with the U.S. federal and state governments. Building relationships and programs in some Native communities has proven challenging for some health departments. Many health department representatives have reported hitting a "glass wall" when trying to meet with tribes and tribal program staff to initiate programming. "What happened?" they might ask. "I thought I was getting through." Furthermore, both health department and Native American representatives report that significant turnover in state agencies and tribal/urban programs can hinder many advances that have been made in establishing the trust necessary for building a foundation for further programming. In some states, the state health department may not have direct ties to community based organizations or tribal entities, but rather, make allocations to local health departments/agencies to address local needs. This structure may allow only indirect support to Native American communities and populations.

These are only a few of the multiple issues that are important to understand when approaching HIV/AIDS programs in Native communities. In addition, in small, tight-knit communities, confidentiality is an overriding concern given how much stigma is still associated with HIV.

HIV/AIDS IMPACT IN NATIVE AMERICA

CDC's surveillance data indicates that:

- HIV/AIDS diagnoses among American Indians/Alaska Natives represented less than one percent of the total number of HIV/AIDS diagnoses reported in 2005 in the 33 states mature name-based HIV reporting.
  http://www.cdc.gov/hiv/topics/surveillance/resources/reports/2005report/default.htm

- "The rate (per 100,000 persons) of HIV/AIDS diagnosis for American Indians and Alaska Natives in 2005 was 10.4, compared with 71.3 for Blacks, 27.8 for Hispanics, 8.8 for Whites, and 7.4 for Asians and Pacific Islanders."
  http://www.cdc.gov/hiv/resources/factsheets/PDF/aian.pdf

- "Women accounted for 29 percent of the HIV/AIDS diagnoses among American Indians and Alaska Natives."
  http://www.cdc.gov/hiv/topics/surveillance/resources/reports/2005report/default.htm

- "The estimated rate (per 100,000) of AIDS diagnosis for American Indian and Alaska Native adults and adolescents in 2005 was 9.3, the third highest after the rates for Black adults and adolescents (68.7) and Hispanic adults and adolescents (24.0). The estimated AIDS diagnosis rate was 6.9 for White adults and adolescents and 4.3 for Asian and Pacific Islander adults and adolescents."
  http://www.cdc.gov/hiv/topics/surveillance/resources/reports/2005report/default.htm

- The survival time for Native Americans with AIDS is shorter than that for all other racial/ethnic groups except for Blacks. CDC reported: "Of persons who had received a diagnosis of AIDS during 1997– 2004, American Indians and Alaska Natives had survived for a shorter time than had Asians and Pacific Islanders, Whites, or Hispanics. After nine years from time of diagnosis, 67 percent of American Indians and Alaska Natives were alive, compared with 66 percent of Blacks, 74 percent of Hispanics, 75 percent of Whites, and 81 percent of Asians and Pacific Islanders."
  http://www.cdc.gov/hiv/topics/surveillance/resources/reports/2005report/default.htm

Note*: The HIV data only included data from the 33 states with a mature, confidential name-based HIV reporting system. Some states with high populations of Native Americans are not included in the HIV data because they have only recently adopted a name-reporting system, although the AIDS case data is for all states.*

Understanding how services work and what services Native Americans are eligible for and access are also crucial. Perhaps one of the most important and misunderstood issues in working with Native Americans is the concept of sovereignty. Each of these issues will be briefly outlined before presenting strategies and approaches for working successfully with Native Americans to address HIV/AIDS.

Understanding Sovereignty

Sovereignty is a complicated issue that may present barriers to effective working relationships between health departments and Native American tribes and programs. Simply put, tribal sovereignty refers to the inherent rights of Indian tribes to self-government and self-determination. Among other things, this includes the right to establish a form of government, to adopt legislation, to establish a law enforcement and court system, to define membership, and ultimately, to determine health policy for tribal members.

For most Native American tribes and nations, tribal sovereignty has been recognized by the United States Constitution, U.S. Supreme Court decisions, and federal legislation. Thus, the federal government must interact with the tribes on a government-to-government basis in all of its dealings with federally recognized Indian tribes (in New York State, the treaties are with England, and thus pre-date U.S. law). It follows that states must also deal with the tribes on a government-to-government basis. Note that sovereignty is not exercised by an individual, but rather by government entities. Only tribes have the governmental power to negotiate directly with federal and state governments. Because Native American non-profit organizations, such as urban Indian health programs, do not have the same relationship with the federal government, they must interact with governmental agencies through funding agreements such as contracts and cooperative agreements.

Sovereignty can affect contracting, data sharing, and communications. Because federally recognized tribes are considered sovereign nations, tribes may elect to make decisions about how health data can or cannot be shared. Establishing negotiations can begin to educate tribal leaders and program staff about the importance of sharing data for increased funding.

Furthermore, many Native American tribes and nations may be hesitant to "open the door" to contracting with state governments because they fear that their sovereignty may be threatened. These tribes and nations may perceive this as "a foot in the door," allowing the state the opportunity to begin assuming authority over the tribe. Such reluctance may lead to difficulties in contracting for services with the state governmental agencies. On the other hand, states, too, may be reluctant to contract with tribes because they do not have a comprehensive understanding of sovereignty. Strategic planning among tribal leaders, tribal program directors, state health department program/division heads and others with the authority to make decisions is necessary to initiate discussions about contract work between state governments and tribes. States may even have to resort to changing their procurement procedures or laws to make it possible to contract with tribes.

Finally, more than half of Native Americans overall live off reservations/nations, in urban settings and elsewhere. These Native Americans may access services in these settings, rather than at the tribal level. Yet only 30 percent of the IHS budget is allocated to urban centers, so state health departments should become aware of the needs of urban Native American populations and

how to identify and develop relationships with leaders in these communities, as well as at the tribal/nation level.

Confidentiality

Ensuring confidentiality for testing and treatment of HIV and other sexually transmitted diseases is central to the well-being of any community. Confidentiality is of particular concern for Native American individuals who seek testing at local tribal, IHS or urban Indian health clinics, especially in small and tight-knit Indian communities. The members of many Native American communities are often related through marriage, blood, clan membership, and/or adoption. Friends, relatives or neighbors may work at these clinics; thus, an individual may be concerned that a clinic staff member who knows him or her may have access to sensitive health information, elevating the importance for supporting adequate staff training about working with such sensitive data and information.

Additionally, a community's perception of HIV/AIDS and associated risk behaviors may heighten stigma, consequently hindering individuals from seeking HIV testing at local tribal/urban health facilities. Some individuals will instead travel to major urban cities to be tested at non-tribal facilities. In the larger cities, some Native Americans may seek out a clinic that has no

TRIBAL RECOGNITION

The 2000 U. S. Census reported 2.5 million people who self-identified as Native American/Alaska Native. Another 1.5 million self-identified as being Native American/Alaska Native in combination with one or more other races. In Federal Fiscal Year 2003, the IHS service population was 1.59 million. As part of its eligibility criteria, IHS requires documentation of tribal membership in a federally recognized tribe in order to receive IHS health care services. Since 1990, the IHS service population annual growth rate has been 1.6 percent. Members of state-recognized tribes that are not federally-recognized are not eligible for IHS health care services.

Federally Recognized Tribe – Tribes that have federal recognition from the federal government as a sovereign nation to govern its members and the issues impacting its members. Federally-recognized tribes are eligible for services through the Bureau of Indian Affairs, Department of the Interior and IHS. These tribes may have existing treaties with the United States federal government. There are over 500 federally recognized tribes and villages.

State Recognized Tribe – Tribes that have no direct government-to-government relationship with the United States federal government. The status and relationship between a state and tribal entity is determined by state statutes and may vary from state to state.

Non-Recognized/Currently Unrecognized Tribe – There are a number of indigenous groups that identify as American Indian and maintain a tribal form of government and practice a cultural heritage that are not recognized by either the federal or state governments at the present time. Additionally, through the Indian Reorganization Act, some tribes lost federal recognition (109 tribes lost this status), and over 100 tribes are now seeking to gain or regain federal recognition (http://www.ncai.org/Federal_Recognition.70.0.html?&type=123).

relationship to their tribe. They may choose not to disclose their Native American cultural identity in order to further protect their confidentiality or to avoid being referred to a tribal health facility, or they may avoid testing altogether. Testing delay is a major factor contributing to people being identified with HIV only when they present with an AIDS diagnosis. The perceived lack of confidentiality by Native American community members, even if this is not actually the case, can be a barrier to seeking health care services.

Services and Funding Issues

The legal responsibility for Native American health care and funding is not widely understood. In large measure, the lack of knowledge about Native Americans, and misperceptions about issues such as sovereignty, have contributed to a lack of knowledge about how the federal government funds and supports services for Native Americans and where Native Americans access services.

The IHS has no direct or 'line-item' for HIV/AIDS in its budget. Funding appropriated to IHS through the Hospital and Health Clinics (HH&C) component of the Labor, Health and Human Services, and Education Appropriations encompasses treatment and care for multiple diseases, and this funding could potentially be used for HIV prevention services if the tribes choose to utilize these tribal shares for those HIV services. If treatment is provided at one of the IHS centers, it will come from normal operating budgets within the hospital. In 2006, tribal shares for HIV totalled roughly $450,000 for all tribes. The amount each individual tribe receives varies greatly based on a number of elements, including size of tribe. The IHS is divided into twelve Area Offices for service administration and the HH&C funding is distributed to tribes through these Area Offices. Depending on how each tribe negotiates its tribal share and the size of the tribe itself, a tribe (for example) may receive up to $50,000 or less than $50 per year for HIV related services.

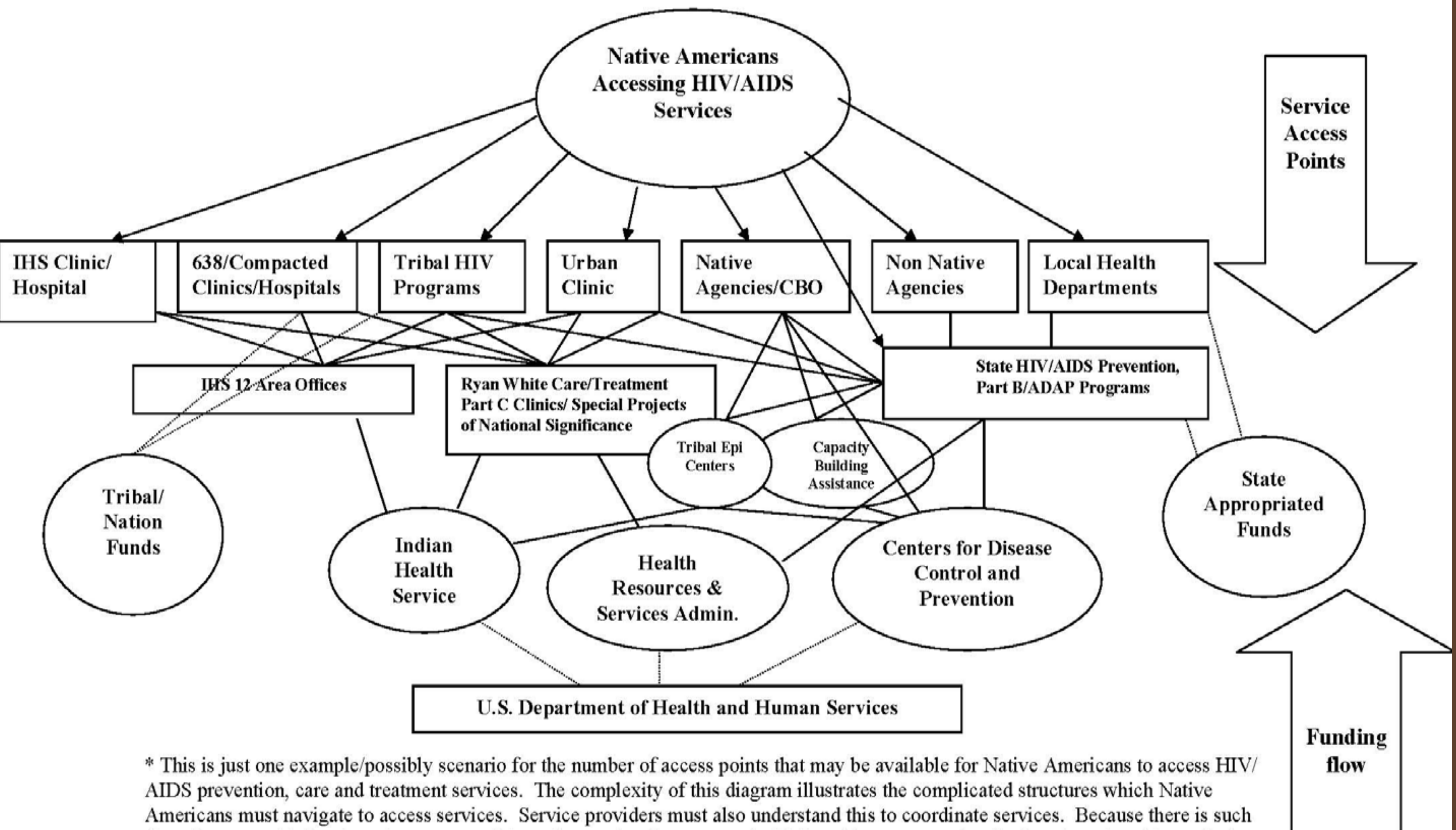
IHS also receives a portion of funding from the Office of HIV/AIDS Policy (OHAP) for additional national initiatives and has provided regional training on behavioral interventions, quality assurance, and telemedicine and epidemiology initiatives to name a few. These projects are based on annual proposals from IHS and funding is not guaranteed. Other than the portion of funds tribes elect to use for HIV/AIDS services through the HH&C budget, the IHS budget does not contain any direct funding for HIV/AIDS prevention or treatment.

Practically speaking, the IHS is mainly a primary care, community health system and not funded for tertiary or specialty care. A few major referral centers in Phoenix, Gallup, Anchorage, Tulsa, etc, have antiretroviral medications in their formularies; however, the capacity of the IHS to offer treatment services nationwide is very limited. The IHS also works to improve linkages for treatment and care with Ryan White facilities and other entities to care for seropositive AI/AN. In addition, the 2006 reauthorization of the Ryan White Program (http://hab.hrsa.gov/law/0701.htm) clarified that Native Americans are eligible for HIV/AIDS care and treatment services from this program, including Part B AIDS Drug Assistance Programs administered by state health departments.

Outside of the IHS, funding for HIV/AIDS programs for American Indians, Alaska Natives, and Native Hawaiians is distributed to state and local heath departments, CBOs and other service providers or tribes through the Centers for Disease Control and Prevention (CDC), the Health Resources and Services Administration (HRSA), and the Office of Minority Health (OMH) at the federal level, as well as the United States Conference of Mayors, private foundations, local AIDS agencies, and state and local health departments. Other than funding from the Federal government to state and local health departments, this funding is generally distributed through competitive RFP processes.

The following diagram demonstrates where Native Americans access services and cross-walks this with the flow of funding from federal and state governments.

Example of How Native Americans Access HIV/AIDS Prevention, Care and Treatment Services*



* This is just one example/possibly scenario for the number of access points that may be available for Native Americans to access HIV/AIDS prevention, care and treatment services. The complexity of this diagram illustrates the complicated structures which Native Americans must navigate to access services. Service providers must also understand this to coordinate services. Because there is such diversity across Native American communities, tribes and nations across the U.S. and between rural and urban America, this particular diagram may look different for each state, if not for each Native community.

STRATEGIES AND APPROACHES

Strategies for Building Trust

Building trust can be a difficult task when working with Native American tribes, agencies and communities. Native Americans' general lack of trust in the government stems from a number of factors, including the historical relationships between the tribes and the federal and state governments, non-Native people's lack of understanding about sovereignty, perceived conflict between Western-based medicine and Native American traditional healing practices, and myths and misconceptions about Native Americans.

Though Native Americans share many similarities with other minority populations, they are unique and represent a different experience as the indigenous peoples of the United States. Native Americans are themselves very different across tribes and nations. Yet a long, shared history of marginalization and disenfranchisement, including policies of "extermination," the decline of cultural traditions and language, land dispossession, genocide, broken treaties, forced sterilization of Indian women, compulsory placement of Indian children in boarding schools, and other experiences of oppression have established deep-rooted intergenerational anger, grief, and mistrust of government that persist to this day.

Health departments and Native American tribes, nations, and tribal and urban Native American community-based agencies face many barriers that hinder communications and programs. Some outreach to tribal entities remains ineffective or inappropriate, and denial by tribal leaders that HIV is a problem remains a roadblock in some places. Representatives from both health departments and Native American communities in several states have indicated that some tribal leaders have said, "We don't have any of that here." Clearly, any health department that seeks to provide services for Native Americans needs to understand these historical underpinnings, build cultural sensitivity among staff in their agencies, and undertake strategies to build trust with tribes and Native American agencies. NASTAD's work has found that there are potential strategies that can help build successful working relationships.

Potential Strategies:

Many health departments and Native American tribes, nations, agencies and programs have taken positive steps to build trust. A key facet of all the examples is the hard work and diligence of allies within health departments who champion these issues within their own agencies and tribal representatives who want to work with health departments. Since trust is usually initially built on relationships between individuals, regular staff turnover of contract managers, liaisons, and other key health department officials working with Native communities can often set back progress that has been made, making it imperative to focus on institutionalizing these relationships.

To address sovereignty concerns, states may use distinct systems or tools to interact fiscally with Native American tribes and nations. New Mexico has a number of types of contract tools that it uses for agreements with differing types of organizations and for various kinds of services (i.e. professional, clinical, support). When the New Mexico Department of Health contracts with other government entities, such as local governments or tribes, the usual contract is replaced with an intergovernmental agreement, known as a Joint Powers Agreement. A master Joint Powers Agreement (JPA) with the Navajo Nation is used to fund service delivery by that government entity, with various amendments to the main JPA to add funding or services for specific health issues.

The State of New York has a very different relationship with the sovereign nations within

their state borders. The Haudenosaunee or Six Nations have never signed a treaty with the United States government. Their treaties were with the King of England. Thus, they have a unique relationship with the State of New York. They do not recognize the border between the United States and Canada and some of the Six Nation tribes have nation territories that cross the U.S. – Canadian border, which allows tribal members to cross (without immigration processes) the border between the United States and Canada. The Haudenosaunee do not accept funding from the United States government but do have working relationships with the State of New York and their agencies. The New York State Department of Health AIDS Institute has developed some unique strategies to promote community mobilization among Native American programs in their state. In the early 1990s, agencies that could demonstrate strong indigenous connections to certain high need or traditionally underserved populations, strong leadership potential, and a commitment to providing HIV prevention and support services, were selected through a competitive process. Among the organizations selected was the American Indian Community House (AICH), which has used the funding to create the Native American Leadership Commission on Health and AIDS. This commission reaches Native persons on nation territories and in urban areas around New York State. Specific language is included in the state budget that exempts groups from automatic re-solicitation after five years as is the case with almost all other programs. This has enabled the AIDS Institute to maintain a contract with AICH for 14 years. This longstanding relationship has fostered trust, mutual respect and a strong sense of partnership that may not have otherwise been possible. Both AICH and another organization serving this community, Native American Community Services (NACS), have been successful in competing for additional HIV prevention funds through ongoing competitive solicitations. These efforts build on the foundation created by the longstanding relationships the health department has supported through this funding mechanism.

Because trust is initially built on relationships between individuals, it is important to ensure sustainability and diversity in public health programs. New Mexico has done this at the local level, where they fund regional public health offices and a CBO in each region. Staff for these offices is recruited by those local offices, to ensure that they are culturally competent for the populations served. Some public health offices, such as the ones serving areas near the Navajo Nation, have traditionally done well recruiting Native American staff. Developing a regular funding relationship with local providers in this way is a strategy New Mexico has used to ensure that local providers with an existing relationship and knowledge of the Native American community are the ones providing services in the community.

In Alaska, the Alaska Native Regional Corporations manage land and assets received under the Alaska Native Claims Settlement Act of 1971. A non-profit arm of each of these for-profit corporations manages health programs for their beneficiaries. The Indian Self Determination and Education Assistance Act of 1975 (P.L. 93-638) facilitated the gradual development of self-determination contracts with tribal organizations. In 1994, the Indian Self-Determination Contract Reform Act (P.L. 103-413) was signed to further facilitate tribal participation in the management of federal Indian programs. Alaska Native Health Corporations led the way in developing 638 contracts with the federal government to manage their own health and medical care programs. The Alaska Department of Health and Social Services (DHSS) worked closely with the Alaska Indian Health Service Area Office on public health matters during the time the IHS was a major service provider in Alaska. DHSS has also worked with the Alaska Native Health Board (ANHB), an organization that advocates for

Alaska Native issues, over the years, and funded ANHB for HIV prevention activities when ANHB was conducting project activities. The State DHSS currently works closely with the individual Regional Native Health Corporations and the Alaska Native Tribal Health Consortium (ANTHC) on health related matters. Several Regional Native Health Corporations and ANTHC are or have been State DHSS HIV prevention grantees and some have also received HIV prevention funding directly from CDC. Staff at ANTHC, DHSS and DHSS grantees/ contractors work closely together on HIV care under Ryan White Part B (ANTHC is one of two Ryan White Part C grantees in Alaska). State DHSS staff has additionally assisted ANTHC to pursue federal funds for STD prevention activities.

The California Department of Health Care Services, Indian Health Program's (CDHCS/IHP) mission is to improve the health status of American Indians/Alaska Natives living in urban, rural, and reservation/rancheria communities throughout California. Statute requires the California Department of Health Care Services to address the health status of American Indians through CDPH/IHP. CDHCS/IHP provides technical and financial assistance to 30 primary care clinics located in rural and urban areas throughout California. CDHCS/ IHP coordinates the American Indian Health Policy Panel which advises the department and is composed of members representing rural and urban areas. Previously, CDHCS/Office of AIDS (CDPH/OA) had an inter-departmental agreement with IHP to provide funds to support HIV testing and counseling at Indian health clinics and HIV testing and counselor training to Indian health clinic staff. Due to staff constraints, however, the CDPH/IHP has not renewed this agreement with CDPH/OA (the CDPH/OA does make allocations to local health jurisdictions to address HIV care and prevention needs at the local level).

Another way to address the specific issues of working with sovereign Native American tribes and nations is to specifically identify a mechanism within the state bureaucracy to facilitate this work. Wisconsin created a Tribal Affairs Office out of the Secretary of Health and Family Services office. The liaisons from this office help build bridges and understanding between the Wisconsin tribes and the state. This office serves as a resource to state staff and tribes and worked in collaboration with the Division of Disability and Elder Services to co-host training for state staff regarding tribal sovereignty. The training was conducted by Richard Monette (Turtle Mountain Chippewa) and Ada Deer (Menominee).

In Utah, Governor Huntsman signed a Tribal Consultation policy with five tribes in October of 2005 (see also, policy consultation flowchart). This policy consists of monthly Indian Health Advisory Board meetings and is also an interface between the Utah Department of Health and the tribes for all health promotion and disease prevention. In August 2006, the Governor and Lt. Governor held the first Annual Health Summit that began dialogue for state agencies to talk about disparities and narrow the gaps in services for Native Americans. The Department of Health also planned meetings with the monthly Indian Health Advisory Board in the summer of 2007 to develop cross-agency collaborations with the tribal representatives.

Across several states, successes have been reported in state programs that have contracts with tribes, villages and nations, providing invitations to key people and ensuring that tribal communities and representatives have a voice in community planning. Conferences, summits, community dinners and youth retreats have been used as outreach tools to build relationships and trust in Native communities. Many health department representatives have stressed the importance of becoming recognizable within these communities. This is especially important when large geographic distances are involved. Utah has found that having a state liaison for Native American health has been helpful to them. The liaison has worked with the Native American

population throughout Utah for over ten years and fully understands the culture, government, underpinnings, and the art of patience. In Oklahoma, an Indian Affairs Commission works with the state legislature on tribal issues. Additionally, state employee participation in Native coalitions and consortiums also serves to increase interest in the local communities.

Working with tribal Community Health Representatives (CHRs), state health departments have conducted HIV/AIDS 101 educational sessions, youth summits, and conferences, and have implemented HIV counseling and testing programs in Native communities. The array of programs is as varied as the sources of funding. Some states have funded advisory councils, and members of local communities have also worked to be included in the state planning process. For example, in Oklahoma, the HIV prevention community planning group is chaired by a Native American.

Other Things To Try

- Educate state health department staff about tribal sovereignty and convene tribal consultation meetings to address strategies to establish programming within the state for Native Americans.
- Coordinate efforts among various government departments to build and/or develop more successful relationships with tribal leadership. Consider supporting a minority coordinator within state government that includes responsibility for Native issues.
- Participate in local tribal health fairs.
- Establish a presence in Native American communities, including urban, rural and reservation or nation territories, as well as Native gay/lesbian/bisexual/transgender/questioning (GLBTQ) and Two Spirit people.
- Identify key stakeholders who can provide guidance as well as form partnerships with local Native communities.
- Collaborate with a liaison from within Indian communities.
- Develop routes of communication within agency departments to share information that will be mutually beneficial for all involved.
- Create a listserv of interested state HIV/AIDS programs and tribal key stakeholders to ask questions and share information about best practices.
- Contract with Native American consultants with experience in providing technical assistance to both state health departments and Native communities to begin collaborative efforts for advisory councils, planning councils, etc.

Strategies for Building Cultural Sensitivity and Educating Non-Native Providers

What is cultural sensitivity? How does one become culturally sensitive? One of the first steps in understanding the diversity of Native American communities is challenging assumptions and building an awareness of the complexities of Native American experiences. Becoming sensitive to other cultures is a continuous process that requires building knowledge among state agency staff regarding:

- Communication styles;
- Diversity among different tribes (i.e., not all tribes are alike even within a state or region);
- The history of tribes in the state;
- The number and names of tribes or nations and whether or not the tribes are federally or state recognized;

- Who the tribal leaders, elders and other key players are;
- The urban Native American communities and their leaders;
- What IHS programs exist in the state, if any, as well as any tribal health programs;
- The eligibility of Native Americans for services; and
- The overall breadth and scope of public health and social service programs serving Native American communities.

However, building knowledge alone is insufficient in becoming culturally sensitive or competent. One must also build relevant experience in working with Native American communities. This includes experiencing traditional culture and values, working through misunderstandings, and making and learning from mistakes.

Health departments that lack this knowledge-base and experience should seek avenues to gain it in order to begin to work with tribal and urban programs. For instance, differing communication styles may lead to misunderstandings. What may seem like unresponsiveness to some people, may actually be a culturally accepted way to translate, process and consider a question or issues for others. Also, acronyms and "government-ese" should be avoided when conversing with Native American communities. In many Native American communities, time is not measured by the clock, but by when people are ready or when everyone arrives. Native Americans call this "Indian Time," and misunderstanding this can lead to problems with contract language and deadlines. Conversely, knowing this, more time can be incorporated into program planning to allow time for these considerations to be addressed. Another very important aspect is to acknowledge and accept that many Indian people will integrate their tribal healing practices with their Western medical treatments.

Potential Strategies

An entire meeting of the New York State HIV Prevention Planning Group (PPG) included presentations and capacity building/education by its Native American members and other representatives from Native American communities to build the knowledge and understanding among the PPG about the issues impacting Native Americans in the state. Not only were there presentations about the programs, but there were optional evening sessions offering more in-depth contextual information about Native American culture and health issues impacting their communities.

The Wisconsin Division of Disability and Elder Services has provided culturally sensitive resources and training through activities such as the Sovereignty and Federal Policies training. In this training for state staff addressing sovereignty and federal policies, tribal experts from the University of Wisconsin-Madison Law School and American Indian Studies Program are invited to provide presentations. In addition, the state of Wisconsin and the tribes have a fifteen year history of co-hosting an annual conference, "Healing our Communities," for tribal communities, and state and county staff to address issues such as HIV/AIDS, STDs, talking with youth about HIV/AIDS, substance use including methamphetamine, Tribe/County relationships and the tribal history of the host tribe. (see Appendix 6 for conference agenda.)

In April 2007, the California Department of Public Health Office of AIDS (CDPH/OA) invited a Native American HIV capacity building specialist to present to management and staff on HIV/AIDS issues in Native American communities. This presentation was insightful and well received because the Native American specialist was well-versed on health disparities for Native populations, public health issues, IHS infrastructure, Native community and cultural issues, and the Ryan White program. CDPH/OA

successfully assisted the CDPH Director's Office to announce the first annual National Native American HIV/AIDS Awareness Day through a Director's message sent to all Department staff.

Other Things to Try:

- Attend or convene cultural sensitivity trainings specifically addressing Native Americans that are tailored to your jurisdiction.
- Include tribal leaders within the state boundaries to talk about their history.
- Access technical assistance for culturally appropriate interventions through services such as CDC's Capacity Building Assistance Program (see the "providing education and capacity section) and learning how to interact with the tribal government (see Appendix 5 for "Protocol for Working with Tribes").
- Co-host educational conferences and summits with participation from the tribal programs.

Strategies for Dealing with Data Issues and Data Quality

Many Native Americans are concerned about the quality of HIV/AIDS data for Native Americans. Information sharing among tribal programs, urban Indian health programs, IHS, the states and CDC can be problematic, despite the fact that IHS is "authorized to participate in communicable disease surveillance activities mandated by local or state regulation" and their funded clinics are required to report all HIV cases to state health departments. However, tribal programs are sometimes reluctant to share their data with outside agencies due to lack of trust and fear of being ostracized. A potential solution to this problem is to allow data to be shared after discussions with tribal leaders who are responsible for deciding what and how it can be shared.

Additionally, collecting complete HIV/AIDS data through IHS is challenging because Native Americans may seek healthcare services outside of IHS, tribal clinics or urban Indian health programs. To further compound the problem of incomplete data collection, not all of the aforementioned healthcare facilities use the IHS Registered Patient Management System (RPMS) for managing client information. The RPMS is the federal data system used in all IHS hospitals and clinics to register users, collect health statistics and bill for services. Most, but not all, tribal and urban Indian health clinics use RPMS for data retrieval and billing, but only about half of those who use it include HIV diagnoses in their electronic reports. Commander Scott Giberson, National HIV/AIDS Consultant with the IHS, stated that currently, an internal mechanism that would allow HIV/AIDS reporting by tribes currently does not exist through the IHS. Therefore, the data reported by IHS programs to state surveillance offices may not only be incomplete but are usually provided infrequently and often in aggregated format.

Another issue contributing to concern about data quality is the misidentification of race/ethnicity of Native Americans. For example, the Oklahoma State Department of Health collaborated with the Oklahoma Area IHS, and they discovered that physicians frequently rely on the patient's physical appearance or last name in the absence of family members to determine the patient's race or ethnicity when completing death certificates. Depending on a patient's last name or physical appearance when assigning race is problematic because most Native Americans from states such as New Mexico and Arizona have Hispanic last names or they have assumed Hispanic last names through marriage. Physical appearance or names are not reliable indicators of race.

Also, because the actual number of HIV/AIDS cases among Native Americans may be very low in some regions, the data are often aggregated in an "Other" category, partly to preserve patient confidentiality. Thus, the true HIV/AIDS burden among Native Americans becomes masked in the aggregated data. Not only does this preclude a

CHALLENGING ASSUMPTIONS ABOUT NATIVE AMERICAN COMMUNITIES:

Many people erroneously believe that most Native American tribes and individuals are wealthy from casino revenues. There are over 500 federally recognized Native American tribes across the United States, but there are only 367 gaming operations, with many tribes operating multiple sites. Indian gaming occurs in only 28 out of 50 states, with the majority of gaming located in California and Oklahoma. Most small tribes are not involved in gaming, and if they are, gaming is usually limited to local bingo halls and some gaming machines. Gaming revenue varies and the distribution of the funds is determined by each tribe. Gaming revenue is generally allocated to what is deemed a priority for that tribal membership determined through tribal elections. Tribal priorities may include elderly housing, Head Start, cultural activities (e.g., language programs), and health programs. A few tribes provide a per capita payment to individual tribal members, which vary annually from $1,000 per individual to $250,000 per individual (one small tribe). Only one or two tribes are able to afford large payments to their tribal members. Larger tribes also use funds for community projects. For instance, tribes with large populations in Oklahoma fund county and municipal projects, such as road improvements, water access, school construction and programming and other community needs in collaboration with the city and county governments.

Another popular myth is that "Indian people get everything free." Health care provided through federal and state governments has been 'pre-paid,' as a part of the trust relationship between Native American nations and the federal government, and/or as a part of agreements with states. Health care provisions for Native Americans have been made in *exchange* for vast amounts of land ceded to the federal and/or state governments. Of great frustration to many Native Americans is the realization that notwithstanding centuries of these treaties, legislation, and other obligations, Congress has never appropriated adequate resources to fund the necessary level of health care and educational needs in Native American communities. And per capita medical expenditures for Native Americans is lower than the general population – in 2003, $1914 per patient compared to $3545 for public sector financing for the general (non elderly) population overall, and this ratio is often even smaller for Native Americans in urban areas. Indeed, none of the treaties require the federal government to provide all of the services necessary or even deemed desirable by some. This is a bitter reality for many Native Americans.

thorough understanding of the extent of HIV/AIDS within Native American communities, it prevents an understanding of which Native populations are most affected by HIV (e.g., men who have sex with men, youth). These limitations of the surveillance data underscore the critical need for community-based needs assessments in Native American communities.

Another issue that should be addressed is that many of the states with large Native American populations, such as California, only recently implemented a name-based HIV reporting system in 2006. Consequently, their HIV data are not yet included in the CDC national HIV/AIDS surveillance report because CDC only includes HIV data from states that have a mature HIV reporting system and that has been in place for at least five years. California does issue its own surveillance report that includes this information, so there are differences between federal surveillance reports and the reports from states like California that have only recently switched to HIV reporting by name.

Data quality is also questioned when there are discrepancies between surveillance data and service utilization within jurisdictions. For example, in some states, respondents feel that, based on anecdotal information, there are more cases of HIV/AIDS in Native Americans than those documented, because more Native Americans are reported to be receiving Ryan White funded services than the number of Native Americans impacted with HIV/AIDS shown in surveillance reports.

Potential Strategies

Several states reported that they have taken steps to address concerns about surveillance and data, including developing a separate Native American Surveillance Report. The following examples highlight activities in different states aimed at improving HIV/AIDS surveillance among Native Americans.

The Alaska Native Tribal Health Consortium (ANTHC) was created in 1997 to provide statewide Native health services, including managing the Alaska Native Medical Center (the tertiary care center within the statewide Alaska Native health care system). At the time ANTHC was created, the Alaska DHSS and ANTHC established an MOA confirming ANTHC's participation in disease reporting to the state. At a subsequent meeting with the State DHSS and ANTHC, the Regional Native Health Corporations voted unanimously to confirm ongoing disease reporting to the state. The State DHSS, ANTHC, and the Regional Native Health Corporations regularly meet on a semiannual basis to share information and identify issues that need to be addressed. In addition, the State of Alaska has contractual agreements for Public Health Nursing Services with two of the Regional Native Health Corporations that compacted with the federal government under P.L. 93-638 for services formally provided by the Public Health Service.

In California, the University of California, Los Angeles was awarded a grant from CDC to partner with the Los Angeles County Department of Health Services to conduct HIV behavioral surveillance on Native Americans in Los Angeles County. And in San Francisco, the Native American AIDS Project has conducted a hepatitis B infection behavioral surveillance study to document the degree of risk among Native American men who have sex with men (MSM).

The Minneapolis Indigenous Peoples Task Force recently completed a survey with tribal leaders on surveillance, working with Peter Carr in the HIV Division in the Minnesota Department of Health and Allison Lapointe, epidemiologist with the Great Lakes Intertribal Council/Tribal Epi Center http://www.glitc.org/epicenter/index.html.

The New York State Department of Health AIDS Institute funded the first Native American community based HIV needs assessment in the state, released in 1995, and has subsequently funded ongoing needs assessment update activities in four regions of the state through its Capacity Development Initiative (CDI) program.

Wisconsin has presented workshops to educate tribal leaders about the high-risk behaviors shared between HIV/AIDS and other priority health concerns and the importance of sharing data with other agencies and its relation to justify increased funding.

Other Things to Try:

- The IHS Area Offices are located in 12 cities across the U.S. Each Area Office has a Tribal Advisory Health Board comprised of elected tribal leaders. Ask to be included on the quarterly agenda for a presentation on HIV/AIDS and data reporting issues. Work with the Area Office staff member with HIV/AIDS-related responsibilities.
- Develop coalitions of tribal programs to discuss the data collection issues relevant to them.
- Collaborate with the Native American Epidemiology Centers, including the IHS Division of Epidemiology and Disease Prevention.
- Support and encourage Native American community based efforts to conduct HIV related needs assessments.
- Ensure tribal leaders have a voice at the table to explore the issues and solutions relevant to them.
- Collaborate with the National Indian Health Board, a national policy making organization comprised of elected leaders and tribal health administrators, to discuss how data sharing can be accomplished to achieve comprehensive HIV/AIDS reporting among American Indians/Alaska Natives.
- Collaborate with the National Council of Urban Indian Health, a national organization that provides leadership development, education and support to Urban Native Americans.
- Collaborate with the National Congress of American Indians, a national policy-making board comprised of elected tribal leaders, to discuss how tribal leadership and health departments can collaborate to accurately record disease incidence to plan for HIV related prevention and treatment.
- Develop a more formal referral system to and from IHS/Tribal/Urban (I/T/U) facilities and state services.
- Provide workshops for clinic staff and HIV/AIDS program staff on confidentiality laws and the consequences of breaching confidentiality.

Strategies for Dealing with Competing Health Priorities

Native American communities have accomplished a multitude of tasks in building a health system that addresses primary health care, prevention, environmental issues and the challenges of diseases of epidemic proportions, such as diabetes and substance abuse, as well as unintentional injuries. However, HIV prevention continues to be a challenge for the many communities that start with a variety of deficits, such as inadequate funding, lack of culturally sensitive providers, and other major health challenges that also require immediate attention. Stigma associated with HIV/AIDS may also keep this health issue from being a priority. Furthermore, states report difficulty in getting tribes and tribal leaders to accept the importance of HIV/AIDS when there are few reported cases and other health issues have a higher priority. Programs addressing heart disease, diabetes, and substance use (including methamphetamine) are more generously funded, with funding for these issues specifically targeted for tribes. Comparatively, HIV/AIDS programs do not receive adequate funding.

In addition, funding is generally cyclic, and Congress may opt to fund the "disease of the season." For instance, diabetes seems to be the current focus in Congress, while heart disease and

environmental issues have been the focus of past targeted congressional funding. Mercurial funding from the federal level creates an added challenge when dealing with issues of denial and competing health priorities at the community level.

The new Centers for Disease Control and Prevention (CDC) HIV testing recommendations which call for increased testing in medical care settings also may present new challenges to those working in Native American communites, primarily because limited resources are available for implementation and follow-up services. Although Scott Giberson of the IHS believes expanded screening is a very appropriate public health measure, he expressed concern for the smaller IHS facilities and tribal and urban facilities that may not have the infrastructure to begin testing on such a widespread basis. Giberson stated, "Although there is community and system-wide support for implementing these recommendations in the Native American communities, and steps are currently being undertaken to expand screening opportunities, full implementation could stress systems, particularly at facilities within the Indian Health Service (IHS), Tribal and Urban health systems, which may not have the capacity for a substantial increase in screening or the capacity to treat newly diagnosed individuals. The IHS system does provide HIV treatment and care services at some of its major referral centers and not all of the diagnosed need to be referred out to other facilities and Ryan White centers administered by state and local health departments. However, the IHS is generally not resourced for specialty care or tertiary care (i.e., treatment of HIV/AIDS) and thus, many of its patients are linked to outside care for treatment."

While increasing recommendations for the provision of HIV/AIDS services in the face of limited resources present a specific set of challenges for those working in Native American communities, another great challenge facing most Native American communities is high rates of substance use, including alcohol, and most recently, the use of methamphetamine. Methamphetamine use is a growing threat across the country, not only in Native American communities and there are now many sources of funding for methamphetamine programming and funding to specifically address its use among Native Americans. Substance use in general has been shown to impair decision making and facilitate high-risk behavior, but many studies demonstrate a direct impact of methamphetamine use on HIV transmission. One strategy to address these dual problems is to incorporate HIV/AIDS prevention into methamphetamine programs.

Potential Strategies

In the Wisconsin *Healing Our Communities* conference discussed above, hepatitis C and methamphetamine use/abuse were two of the prominent issues addressed in the past few years. Methamphetamine has been a keynote and breakout session topic and methamphetamine use was a featured training topic at the statewide HIV case manager quarterly training in 2006.

The Center for Applied Studies in American Ethnicity (CASAE) at Colorado State University has integrated methamphetamine use and abuse into their HIV prevention posters and on their website. Since many tribes are in denial about HIV/AIDS, the link to HIV/AIDS with other health disparities is a strategy utilized by CASAE. http://www.colostate.edu/Depts/CASAE/

States have linked with other issues as well. In New Mexico, Gallup is the city closest to the Navajo Nation, and it provides a variety of core public health services. State, local and tribal organizations have a history of collaboration, such as through the Stamp Out Syphilis (SOS) collaborative outreach campaign that responded to a significant spike in cases of this sexually transmitted disease (STD). These relationships are aided by the close proximity of some key organizations, with the McKinley County Public Health Office (operated by the New Mexico Department of Health), Navajo Nation Social Hygiene Program, and Gallup Indian Hospital

"TRENDS IN INDIAN HEALTH 2000-2001" U.S. DHHS, IHS, OFFICE OF PUBLIC HEALTH, OFFICE OF PROGRAM SUPPORT, DIVISION OF PROGRAM STATISTICS

The top ten causes of death in the American Indian/Alaska Native populations are:

1. Diseases of the Heart
2. Malignant Neoplasm
3. Unintentional Injuries (motor vehicle, other)
4. Diabetes mellitus
5. Chronic Liver disease and cirrhosis
6. Cerebro-vascular diseases
7. Pneumonia and influenza
8. Suicide
9. Chronic Obstructive Pulmonary Diseases
10. Homicide

Of the top ten causes of death in the American Indian/Alaska Native populations, at least eight are preventable. Given these other health issues, HIV/AIDS is not a priority in many Native American communities, even though high rates of alcohol and substance use, STDs and unplanned pregnancies are indicators of risk factors that contribute to HIV transmission.

(operated by IHS) located on the same street. Collectively, these agencies provide an array of HIV/AIDS, STD and hepatitis outreach, screening, testing and vaccination services to a large area of the Navajo Nation. The New Mexico Department of Health's HIV Prevention Program funds staff at both the McKinley County Public Health Office and local community-based organizations that participate in these collaborative outreach efforts.

A collaborative of New Mexico agencies has received a number of HRSA Special Projects of National Significance (SPNS) grants for HIV prevention and testing on and near the Navajo Nation. The most recent grant, entitled the "Four Corners Collaborative (4CC)" provided support for a 5 year period (2002-2007) with an emphasis on at-risk clients with substance abuse issues. The Na'Nizhoozhi Center in Gallup, NM was the lead agency, and the University of New Mexico (UNM) Center for Native American Health (CNAH) served as the project evaluator. The project aimed to integrate HIV, substance abuse, case management and mental health services for Native Americans, primarily Navajo, by training local service providers in all of these fields. HIV counseling, testing and referral services, case management and support services were all provided through this project. Navajo AIDS Network (NAN), a community based agency that is part of 4CC, also receives direct support for HIV prevention from the New Mexico Department of Health.

Other Things to Try

- Integrate HIV prevention education into broader programs in Native American communities that already have infrastructure in place and where similar behaviors are addressed (e.g., combine HIV/AIDS education with STD, teen pregnancy education and prevention efforts or with substance abuse prevention and treatment activities).
- Take a high-risk based approach. With a large portion of the population potentially unaware of their serostatus, current prevalence data may not be accurate. Understanding the inter-relationships between HIV and other disproportionately high-risk factors (STDs, drug use, etc) may be more effective in allocating funding and resources.
- Provide educational materials on HIV/AIDS at local health fairs in Native American communities.
- Partner with Native health organizations that are not adequately funded to provide HIV/AIDS information to support the success of prevention and education efforts.

Providing Education, Building Capacity, and Mobilizing Native American Communities

Native Americans who provide HIV/AIDS-related services at the community level find it difficult to bring attention to the threat that HIV/AIDS is to their communities despite the high-risk behaviors. Capacity building is necessary for these communities to help them identify how they can build community acceptance for HIV/AIDS prevention and education in their local community. Representatives of the National Congress of American Indians and the Association of American Indian Physicians participated in the National Native HIV Conference in Alaska, marking a large step toward educating elected tribal leadership to notice the impact of HIV. The first National Native American HIV Awareness Day, held on March 21, 2007, also helped bring awareness.

Native and non-Native health care providers in Native American communities are in need of HIV/AIDS education and training. Basic HIV/AIDS 101 workshops need to be presented on a

regular basis with updated information. The comment, "I thought this wasn't a problem anymore, I haven't seen you in awhile," is heard by Native HIV/AIDS educators from their communities. Primary care providers are also reluctant to deal with HIV positive individuals because they lack proper knowledge and training of the latest treatment and care issues, or even basic HIV/AIDS information. Further, it is always important to continue to educate tribal leaders to understand how strategies addressing the other health priorities can also be applied to meet the HIV/AIDS prevention needs. Because tribal leaders change with elections, continuous education about health issues is especially critical.

Furthermore, a mechanism is also needed to support the dedicated workers in the field of HIV/AIDS to prevent burn-out. Frontline AIDS prevention and care providers face a daunting task to continue to provide services within a persistently low-resourced environment, constrained by ongoing stigma and denial. These dedicated workers continue to provide services with little recognition.

Potential Strategies

CDC funds three organizations to provide capacity building assistance (CBA) to Native communities and agencies that provide HIV/AIDS related services in Native communities: the National Native American AIDS Prevention Center (NNAAPC), the Inter-Tribal Council of Arizona (ITCA), and the Colorado State University Center for Applied Studies in American Ethnicity (CASAE).

- The National Native American AIDS Prevention Center (NNAAPC) provides CBA and technical assistance (TA) to improve the capacity of community-based organizations (CBOs) and tribes/nations to strengthen and sustain organizational infrastructure (CDC focus area #1), and to improve the capacity of CBOs and tribes/nations and health departments to design, develop, implement, and evaluate effective HIV prevention interventions (CDC focus area #2). Visit: www.nnaapc.org.
- Center for Applied Studies in American Ethnicity (CASAE) at Colorado State University found that most tribal communities know their own community strengths, concerns and resources quite well. Once they work with Community Readiness and utilize community readiness with CASAE or on their own, the strategies that work best emerge quickly and the smaller steps to achieve those strategies are identified with timelines. CASAE is funded by CDC to improve the capacity of CDC funded CBOs, and other stakeholders to implement strategies that increase access to and utilization of HIV prevention and risk-reduction and avoidance services (CDC focus area #3). Visit: www.colostate.edu/depts/CASAE.
- The Inter-Tribal Council of Arizona, Inc. (ITCA) provides CBA to Native Americans, CDC directly and indirectly funded CBOs, health departments and local community planning groups (CPGs) to increase parity, inclusion, and representation of AI/AN in HIV prevention community planning (CDC focus area #4). Visit: http://www.itcaonline.com/nshapp/communityplan.html.

In addition to the three CDC national CBA providers, states may offer capacity building assistance or support other local providers to do so. There are coalitions of Native American HIV/AIDS programs in Alaska, Montana, Utah, South Dakota and Michigan which have been supported by the states. These groups represent people who have skills in multiple areas (service provision, media campaigns, fund raising, and community organizations and education). The Oklahoma Native American AIDS Coalition is a group of volunteer community members with a concern of the incidence of HIV/AIDS in the Native American community. Members include representatives from the Oklahoma State Health

Department, IHS, and local Native American agency representatives as well as concerned community members. Activities center on providing education to other communities, sponsoring conferences, assisting in developing other coalitions and participating in local HIV/AIDS activities (i.e., AIDS Walk, gay pride and Native American AIDS Awareness Day).

Prevention and care community planning groups include representatives of communities affected by HIV. Participation in a planning group may provide individuals with opportunities to develop leadership skills, increase knowledge in multiple areas and help to shape HIV prevention programs. Working as paid or volunteer staff with HIV programs can provide similar opportunities. For example, Wisconsin had ongoing Native American member representation in the previous HIV Prevention Planning Council and has a Native American staff member who works in the care and treatment section. On the first Native American AIDS Awareness Day on March 21, 2007, a Wisconsin Tribal Chairperson addressed the HIV Community Planning Network and acknowledged that, "We can not afford to lose one more member of our community to this disease." Native Americans have consistently comprised approximately one third of the membership on Alaska statewide HIV Prevention Planning Groups and have been included among those serving as community co-chairs.

Other Things to Try

- Contact the national Native American CBA programs for capacity building and technical assistance, provided at no cost through their cooperative agreements.
- Helping tribes apply for federal and foundation funding opportunities.

Strategies For Effective Services In Native American Communities

Not unlike any other programs or populations, funders and providers want to ensure that the programs they support are effective in reducing HIV transmission and providing appropriate HIV/AIDS related care and treatment services. One of the chief challenges facing those working in Native American HIV/AIDS programs is the availability of interventions developed specifically for Native Americans that have been proven "effective." Native people frequently are expected to adapt other groups' work, instead of being given the opportunity to identify their own interventions. Some Native groups are using very effective interventions but some have not been able to "test" their effectiveness due to lack of resources. Anecdotally, the communities know the interventions are working and have seen the impact in their communities, but do not have the resources for formal evaluation.

It is difficult for some tribal programs to respond to very specific funding/contract requirements, such as those which require utilization of one of the CDC's Diffusion of Effective Behavioral Interventions (DEBIs). Another reason that the DEBIs are not widely implemented in Native communities is because they are not considered culturally relevant and would therefore need major revisions to be culturally appropriate for Native American communities. The DEBIs do not address the critical role of trauma and its relationship to community-wide risk behaviors in Native American communities. Furthermore, some tribal entities will only become familiar with the DEBIs when they respond to a request for proposals (RFP) and will not likely have had access to training required to successfully implement one of the DEBIs.

Another challenge is the competition for scarce resources. Even in jurisdictions that prioritize Native Americans, there may be multiple tribes and reservations/nations that do not/cannot access services in the same way and funding one agency will not necessarily ensure coverage for all Native Americans in that jurisdiction.

Potential Strategies

While the DEBIs have their limitations, and none thus far are Native-specific, at least six communities *have* implemented one or more of the DEBI interventions.

The Alaska Native Tribal Health Consortium (ANTHC) is currently funded by the State Department of Health to conduct two types of interventions: (1) to provide an adaptation of the MPowerment model for Alaska Native Men who Have Sex with Men (MSM) over age 29 in Anchorage and two rural regional hubs, and (2) HIV prevention in conjunction with medical care for PLWHIV in Native health system entities statewide (implemented through ANTHC's EIS program). ANTHC is directly funded by CDC to implement the Community PROMISE model. The Alaska Native Health Board formerly implemented a Popular Opinion Leaders (POL) intervention for MSM under a State HIV Prevention grant.

The Montana health department is in the process of finalizing the protocol for an adaptation of SISTA for Native American Women on the Blackfoot reservation. They worked with the Salish Kootenai College, a Native American Tribal College, to pilot the adaptation of the intervention and expected to have finalized protocols out by December 2007. One of the key things they have done is to not only adapt SISTA to make it culturally appropriate for Native Americans, but attend to different adaptations depending on the things that would make the messages culturally appropriate for a specific tribe, since they found that some messages resonated more for some tribes than for others.

The Oklahoma State Department of Health has funded two CBOs in Tulsa and Oklahoma City to implement Community PROMISE. The HIV/STD Prevention Intervention Center, University of Texas Southwestern in Dallas, Texas will provide PROMISE training to the HIV/AIDS program staff. The awards are for two years each. The target population is Native MSM and other MSM.

In 2007, Wisconsin recruited Tribal Advisory Councils for training as facilitators in the VOICES/VOCES which is a DEBI intervention using 45 minute sessions on condom negotiation and reducing sexual risk.

The Indigenous Peoples Task Force in Minneapolis, Minnesota, has been funded directly by CDC to adapt the DEBI POLs for pow-wows. They have trained Masters of Ceremonies (MCs), arena directors (ADs), drummers, singers and dancers to change the behaviors of 15 percent of the people who participate in pow-wows. Opportunities to further develop the intervention have come by way of educating drummers and dancers in an attempt to reduce high-risk activity that often occurs in the evening during "49s." To begin adapting this particular DEBI, the Indigenous Peoples Task Force first had the program staff review all of the DEBIs to determine which intervention would best fit their programs. They had focus group information to add to their planning process. The actual adaptation was to take the components and adapt them for use and acceptance by the local community. The goal was to change behavior and promote testing. This program is three years old and is of interest as a DEBI that might be replicable to other geographical regions, should they be able to obtain funding. They have also had a longstanding presence at pow-wows through their Two Spirit outreach program, where testing has been offered in past years, establishing a path for continuing work.

Other Funded Services

In addition to these state programs, the Native American International Caucus of the United Methodist Church (NAIC) was awarded a CDC Cooperative Agreement through the Division of Adolescent School Health (DASH) to develop and implement an abstinence-based HIV prevention program for youth. The concept of "Teen Empowerment" was to utilize Native American values and practices in presenting high risk behavior prevention messages. It introduced teens to the concept of "knowledge is power." The program recognized that Native American teens experience the dual stresses of being a teen and a Native American in today's society. Therefore, it began by addressing issues of self-esteem, exploring self identity, family, tribal and community values, gender roles, sexuality, healthy relationships, risk

behaviors, and abstinence. It also incorporated two sessions for parents and extended family members in the lives of Native American youth. Piloted in five faith communities that were geographically diverse as well as tribally diverse, it was well received and two of the five communities still use the program in their schools and communities. The three remaining sites are small and do not have the volunteers or funds to continue the program. The draft curriculum is available on CD through NAIC (deer4NAIC@aol.com).

CDC's Division of Adolescent and School Health (DASH) funded NNAAPC and the National American Indian Caucus of the United Methodist Church for prevention programs to youth. DASH funded NNAAPC to support American Indian/Alaska Native/ Native Hawaiian youth-serving, community-based agencies in their efforts to positively influence the behaviors of youth at high-risk to reduce HIV infection and transmission. One of the main strategies for accomplishing this goal is by improving the capacity of seven Native youth-serving organizations and providing technical assistance to them via their individual organizational activities with respect to differing youth population needs, staff, knowledge, skills, resources, culture and infrastructure. NNAAPC has also developed a Native Youth Media Curriculum which is designed to assist Native youth in designing and producing HIV/STD prevention messages and media. Through a grant from the Office of Minority Health, NNAAPC was able to provide funding for a Youth Media Project to three programs to pilot test the effectiveness of this intervention.

Other Things to Try

- Review DEBIs adapted by other states for use in Native American communities.
- Provide DEBI workshops at national Indian health conferences to introduce an overview of the DEBIs and the agencies available to provide the training.
- Develop a Native American Specific DEBI.
- Encourage CDC to support studies to evaluate and support effective interventions designed and implemented by Native American communities.
- Access technical assistance and/or capacity building assistance to evaluate and/or adapt Native-specific interventions.

CONCLUSION: THE WAY AHEAD

This report documents a variety of efforts that are underway to address HIV/AIDS in Native American communities. While it demonstrates that good work is being done, all contributors acknowledge that there is much more work to be done in Native American communities, and we cannot use a one-size-fits-all approach. Even a packaged intervention specifically geared for a Native American community would have to be adapted if it were to be utilized by a different tribe or nation or in a rural or urban setting.

This document also demonstrates that there is a lot to learn from the experiences in other state health departments, and from Native American HIV/AIDS service organizations. This document was produced as part of NASTAD's commitment to support peer-to-peer exchange and technical assistance. NASTAD remains committed to continue to share strategies for addressing racial/ethnic disparities in the HIV/AIDS and viral hepatitis epidemics. Lessons from this report clearly show that it is important to learn and build relationships, and that this work requires a term commitment.

In order to continue to share strategies like this, we need more examples! Please consider sharing strategies you have found successful with others and with NASTAD. Use the NASTAD Resource Bank (www.NASTAD.org) to find out about tools and approaches used by other states.

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APPENDIX 1:
HEALTH SERVICES AND SYSTEMS FOR NATIVE AMERICANS

Services via the Indian Health Service

Presently, the Indian Health Service (IHS) provides services to approximately 1.6 million American Indians/ Alaska Natives throughout the United States who reside in counties within or near reservations in 34 states, employing approximately 900 physicians who serve in 50 hospitals and several hundred clinics. IHS is a decentralized program in which the basic organizational structure is the local service unit. Service units are often, but not always, hospitals and may be a group of clinics without a hospital. Activities in service units are coordinated and directed through 12 Area Offices located throughout the United States. No other health delivery system attempts to integrate such a broad range of primary health care, preventive services and community services including sanitation, construction of facilities, health education, public health nursing, and community lay workers into a single program. See www.ihs.gov for more information.

Through the Indian Self-Determination Act and the Indian Health Care Improvement Act, tribes/nations and urban programs administer primary health care clinics. The 34 urban Indian health clinics are located in large metropolitan areas in response to "Relocation" when Indian people moved, with little support, to these metropolitan areas from their homelands. The tribal health clinics are those clinics which tribes have contracted (638) or "compacted" to administer and are housed in former IHS facilities or in facilities the tribe has built. See www.ncuih.org for more information on urban clinics and www.nihb.org for more information on tribal health systems.

Indian people may access services through IHS, an Urban Indian Health Clinic or a Tribal Health Clinic and they may travel back and forth between all of these clinics. If they are eligible for Medicare, Medicaid, Civilian Health and Medical Program of the Uniformed Services (CHAMPUS), or have private insurance, they are still eligible for services at any of the three IHS health systems mentioned as well as private facilities.

Although all Native Americans are entitled to certain health benefits, the use of "entitlement" in this case is quite different from that used to describe the Medicare program, for example. The "dual entitlement" rule simply states that Indian people, notwithstanding special arrangements between the federal government and their own tribe, cannot be denied any rights and privileges accorded to the general U.S. population. This means that Indian people cannot be denied services simply because they are available through the IHS.

The Twelve IHS Area Offices are located in:

- Aberdeen, South Dakota
- Anchorage, Alaska
- Albuquerque, New Mexico
- Bemidji, Minnesota
- Billings, Montana
- Sacramento, California
- Nashville, Tennessee
- Window Rock, Arizona
- Oklahoma City, Oklahoma
- Phoenix, Arizona
- Portland, Oregon
- Tucson, Arizona

See www.ihs.gov for more information on the Area Offices and their jurisdictions.

Tribal Epidemiology Centers (IHS Area Offices)

Twelve Tribal Epidemiology Centers are supported by HIS to conduct surveillance for disease conditions and epidemiological analysis, interpretation, and dissemination of surveillance data, as well as investigation of disease outbreaks, coordination with local public health, and development of special studies. The Epidemiology Centers are:

- Northern Plains Tribal Epi Center (Aberdeen Area)
- Alaska Native Tribal Health Consortium (Alaska Area)
- Albuquerque Area Southwest Tribal Epidemiology Center (Albuquerque Area)
- Great Lakes Inter-tribal Council (Bemidji Area)
- Montana/Wyoming Tribal Leaders Council (Billings, Mt Area)
- California Rural Indian Health Board (California Area)
- United South and Eastern Tribes, Inc. (Nashville Area)
- Navajo Nation Division of Health, Navajo Epi Center (Navajo Area)
- Oklahoma Area Inter-Tribal Health Board (OK City Area)
- Inter-tribal Council of Arizona (Phoenix Area)
- Seattle Indian Health Board (Portland Area)
- Northwest Portland Area Indian Health Board (Portland Area)

Link to these at: http://www.cdc.gov/omh/Populations/AIAN/AIANEpiCntrs.htm

HIV Care Services – The Ryan White Program

The Ryan White Comprehensive AIDS Resources Emergency (CARE) Act, or RWCA, was reauthorized (12/19/2006) as the "Ryan White HIV/AIDS Treatment Modernization Act of 2006 (RWMA)." The language contained within the reauthorized Ryan White Program establishes opportunity for more seamless access to HIV/AIDS care and treatment. Although the intent of previous RWCA language was to assist AI/AN in access and eligibility to treatment and care of HIV/AIDS, this specific language certainly aims and succeeds in augmenting that intent. It is the author's privilege to note that this revised language is due in large part to the hard work, diligence, and passion of community members and organizations that came from within our AI/AN communities.

The following provisions in the Ryan White reauthorization affect AI/AN populations, the IHS and Ryan White Programs:

1. AI/AN individuals are/were always eligible for Ryan White services if certain requirements were met (as any other person infected/affected by HIV/AIDS would need to meet various requirements - dependent upon the state of residence).
2. IHS federally operated Health Facilities will now be eligible to apply for services under Parts C and D (formerly called Titles III and IV) through the RWMA (in addition to previously authorized Urban Programs and 638 Tribal Facilities under Ryan White). Thus, the changes of eligibility as a grantee for Parts C and D affect IHS sites, but did not affect the eligibility that was already offered to Urban and 638 facilities. Here are links to services provided under Parts C and D:
3. IHS facilities are exempt from the "Payer of Last Resort" restriction for Parts A, B and C. Although Ryan White grantees are the payer of last resort, this amendment exempts Indian Tribal and Urban (I/T/U) facilities from reimbursement, regardless of referral. In the past, Ryan White grantees were asked to coordinate reimbursement of such funds with the tribes and with the IHS.

- http://www.hivta.org/
- http://hab.hrsa.gov/programs/PlanningGrant
- http://hab.hrsa.gov/programs/Early Intervention/
- http://hab.hrsa.gov/programs/women/.

4. The new legislature supports access for all AI/AN under Ryan White, regardless of I/T/U utilization/affiliation or geographic location. Previously, HRSA Policy 00-01 stated that AI/AN could not be turned away from Ryan White services, but still held Ryan White grantees as Payers of Last Resort. So, if patients were referred from IHS, Ryan White grantees could technically go back to IHS for funding. The reauthorized RWMA includes explicit language that exempts IHS from the Payer of Last Resort restriction.

5. Planning council representation should include members from federally recognized Indian tribes as represented in the population.

Language surrounding AIDS Education and Training Centers (AETCs) now specifically names "Native Americans" as person(s) to be trained. Previous language did not include this stipulation; however, collaboration with the AETC leads at IHS headquarters have been ongoing for quite some time and will continue through the renewal of a formal collaborative agreement.

IHS has been working diligently with leadership from the Health Resources and Services Administration (HRSA) to discuss the potential outcomes and implementation of the changes to the Ryan White Program and to disseminate information regarding these changes to increase care for AI/ANs at risk for or living with HIV/AIDS. Additionally, IHS hopes to focus current and future initiatives and collaborations with HRSA around efficient models and linkages of care between IHS clients, I/T/U facilities, and Ryan White grantees, service providers, and services (e.g., Ryan White Program Parts, which includes the AIDS Drug Assistance Program)

Although I/T/U sites are eligible for Parts C and D, this does not translate to automatic grantee status for the I/T/U sites. They are required to go through the application and approval process.

It is imperative that all AI/AN clients and facilities eligible for these new provisions become aware of the changes and receive assistance with removing any barriers to effective and seamless access and care. Health care facilities may wish to contact a Ryan White grantee in their respective area/state to translate the new changes into an action plan and discuss potential linkages and/or improve existing one.

HIV Prevention Services

CDC distributes approximately $9 million for HIV/AIDS prevention services for AI/AN/Native Hawaiian populations. They fund several Native American agencies for direct HIV prevention service provision. These agencies include the Indigenous Peoples Task Force in Minnesota, the Native American Health Center in San Francisco, the Native American Community Health Center in Phoenix, Arizona, the Missoula AIDS Council in Montana, and the Alaska Native Tribal Health Consortium, as well as the Life Foundation in Hawaii for Native Hawaiians. Each organization has designed their prevention activities to meet the needs of their target population. The Alaska Native Tribal Health Consortium's grant is to implement the Community PROMISE intervention in Anchorage for Alaska Native women, ages 21- 35.

APPENDIX 2:
RESOURCES AND AGENCIES

Association of American Indian Physicians (AAIP):
www.aaip.org

AAIP, in collaboration with NIWHRC is in the last year of capacity building and has developed three coalitions in Oklahoma. AAIP is located in Western Oklahoma, Anadarko, OK; Central Oklahoma, Pawnee, OK; and Eastern OK, Miami, OK and address the high-risk behaviors of the youth and HIV/AIDS prevention activities in their regions.

Bureau of Indian Affairs:
www.bia.gov

Center for Applied Studies in American Ethnicity (CASAE):
Colorado State University
www.colostate.edu/depts/CASAE

Centers for Disease Control and Prevention: www.cdc.gov

CDC National Center for HIV/AIDS Viral Hepatitis, STD and TB Prevention (NCHHSTP)
http://www.cdc.gov/nchhstp/

Department of Health and Human Service, Office of Intergovernmental Affairs, **Office of Tribal Affairs**
http://www.hhs.gov/ofta/

Health Resources and Services Administration, HIV/AIDS Bureau
http://hab.hrsa.gov/aboutus.htm

HRSA/HAB, Special Projects of National Significance (SPNS)
http://hab.hrsa.gov/special/evaluation2g.htm

Indian Health Service
www.ihs.gov

Inter-Tribal Council of Arizona, Inc.
http://www.itcaonline.com

National Council of Urban Indian Health
http://www.ncuih.org/

National Congress of American Indians
www.ncai.org

National Indian Health Board
www.nihb.org

National Indian Women's Health Resource Center
(NIWHRC)
www.niwhrc.org

NIWHRC provides technical assistance in culturally sensitive and HIV programming. OMH, OWH, and CDC provide funding for these activities.

National Minority AIDS Council (NMAC)
www.nmac.org

National Native American AIDS Prevention Center
www.nnaapc.org

National STD/HIV Prevention Training Centers (PTCs)
http://depts.washington.edu/nnptc/

CDC funds the PTCs, which provide training on CDC's Diffusion of Effective Behavioral Interventions (DEBIs) via their Behavioral Intervention Centers, located in:

- Denver STD/HIV Prevention Training Center
- Dallas STD/HIV Prevention Training Center
- California (Oakland) STD/HIV Prevention Training Center
- Region III (Rochester, NY) STD/HIV Prevention Training Center in Rochester, NY

Office on Minority Health
http://www.omhrc.gov/

Be Safe" A cultural competency model for American Indians, Alaska Natives and Native Hawaiians Toward the Prevention and Treatment of HIV/AIDS, National Minority AIDS Education and Training Center
http://aidsetc.org/pdf/p02-et/et-17-00/be_safe_natam.pdf

Office on Women's Health
http://www.4women.gov/OWH/

APPENDIX 3:
GLOSSARY

Acculturation - The process of becoming adapted to a new or different culture.

Alaska Native - A member of any of the indigenous tribes in Alaska. The major cultural groups of Alaska's indigenous population are called Alaska Natives and include Aleuts, Alutiiq, Yup'ik, Inupiat, Athabascans, Eyak, Tlingit, Haida, and Tsimpshian.

American Indian - A member of any of the people native to the Americas, except Alaskan Natives and Native Hawaiians.

Assimilation - total identification with mainstream culture

BIA – Bureau of Indian Affairs. Located in the Department of the Interior. Responsible for the trust lands of the federally recognized tribes and for providing social and educational services.

Ceremony – A formal act or set of acts performed as prescribed by ritual or custom.

Chief – Also known as an elected tribal leader. In Native communities, an individual is/or individuals are elected by that tribe to make decisions based on present community realities and past experiences. Different tribes or villages may refer to their elected leader as Governor, Principal Chief, Chief, Chairman or President.

Colonization – Extension of political, social and economic controls over an area by a state whose nationals have occupied the area and usually possess organization or technological superiority over the native population.

Compact – is the result of the amendments to the Self-Determination Act of 1975, which allows the tribes to contract directly with the federal government by the tribes. The process is referred to as "compacting" and allows for self governance of the funds received.

Culturally sensitive – to hold and demonstrate accepting attitudes that enable effective work in cross-cultural situations among people from diverse backgrounds.

Cultural genocide – A term used to describe the deliberate destruction of the cultural heritage of a people or nation for political or military reasons.

Culture – Distinct beliefs, behavior and language/communication that are held in common and accepted by members of a distinct group of people.

Ecocentric – Taking into account physical processes that support life, without sole focus on human activity. The aim of an ecocentric outlook is to be more consistent with the reality of life on earth as defined by ecology.

Environment – Physically external, objective factors that influence a person's behavior.

Federally Recognized Tribe – A tribe that is recognized by the federal government as a sovereign nation with its own government to govern its members and the issues impacting their members. Federally recognized tribes are eligible for health, social and educational services through the Bureau of Indian Affairs, Department of the Interior and IHS. These tribes may have existing treaties with the U.S. Government. (See also State Recognized Tribes)

Genocide - A term used to describe the deliberate destruction of the cultural heritage of a people or nation for political or military reasons (see also, Cultural Genocide).

Historical trauma – Physical and cultural harms inflicted on Native people during the colonization process. (For example, the impact of the relocation of children to boarding schools, which destroyed families, and led to loss of language and culture.)

IHS – Presently, the Indian Health Service (IHS) provides services to approximately 1.6 million Indians throughout the United States who reside in counties within or near reservations in 35 states extending from Alaska to Florida, and Maine to California, employing approximately 900 physicians who serve in 50 hospitals and several hundred clinics. IHS is a decentralized program in which the basic organizational structure is the local service unit. Service units are often hospitals with outlying clinics, but not always, and may be a group of clinics without a hospital. Activities in service units are coordinated and directed through 12 Area Offices located throughout the United States. No other health delivery system attempts to integrate such a broad range of primary health care and preventive services and community services, including sanitation, construction of facilities, health education, public health nursing, and community lay workers into a single program.

Indian – Many Native Americans refer to themselves as "Indian" as opposed to Native American. In addition, when speaking with other Native Americans/Indians, many will refer to themselves by their tribal name. Upon introductions, tribal name, family and/or clan will often be included.

Indian Country – Used by many Indian people to describe their homelands or to speak of the area, 35 states, that have a large American Indian/Alaska Native population.

Matrilineal – relating to, based on, or tracing ancestral descent thought the maternal line (e.g., Mother's side of the family).

Medicine man/woman – Among Native Americans and other traditional indigenous peoples as far back as Paleolithic times, a person believed to possess extraordinary healing powers. Different tribes have different customs; some only accept men as medicine people, while others accept women. Also, medicine men/women utilize native roots and medicines, prayers and ceremonies. When performing a blessing, many medicine men/women may use feathers and cedar or sage smoke as Catholic priests use incense and holy water. Medicine people may use roots and other natural plants and herbs from which much of modern medicine is made. Medicine people may be viewed as herbalists, counselors, psychiatrists, ministers and physicians.

NDN – A new acronym for "Indian" coined by Native American youth.

Native American – is a term coined in the late '60s or early 70s, during the American Indian Movement. Some Native American activists refused to identify as "Indian" because they considered it an imposed term that was a misnomer. Instead they identified themselves as natives of this land, hence, Native Americans. Then during the 1980 Census, some non-Indians identified themselves as Native Americans because their ancestors had been living in the United States for generations and believed they, too, were natives of this land. The multiple terms – Native American, Indian, Indigenous, Natives – has led to confusion as to which is politically correct. Some tribes do not want to be identified as any of the above, but to be called by their tribal name. Many still refer to themselves as Indians, but the term Native American has stood the test of time and is acceptable. However, consider that most of the legal language in Congressional Law uses the term American Indian/Alaska Native.

Native Hawaiian – A member or descendant of the indigenous peoples of the Hawaiian Islands.

Patrilineal – Relating to, based on, or tracing ancestral descent through the paternal line, (e.g., father's side of the family).

Pow-wow – A gathering of Native Americans. Pow-wows are now a specific type of event held by Native Americans, consisting of one night or a weekend of dancing, singing and socialization. It is an occasion to celebrate and also a holdover from the days when the clans of the tribes would come together annually to celebrate planting or harvesting seasons.

Reservation – As part of the Federal Trust Relationship, the U.S. Government has reserved, or allocated, lands for federally recognized tribes (approximately 56.2 million acres). The Allotment land is still in "Trust" under the Bureau of Indian Affairs, Department of the Interior.

Rural – Of, relating to, or characteristic of the country, non-urban. Of or relating to people who live in the country, relating to farming/agricultural or subsistence activities.

State Recognized Tribes – This status implies that the tribe has no direct government-to-government relationship with the U.S. government. The status and relationship between a state and tribal entity is determined by state statutes and may vary from state to state. Additionally, there are a number of indigenous groups who identify as American Indian who do not have either federal or state recognition, but continue to maintain a tribal form of government and practice a cultural heritage.

Sovereignty – Refers to the idea of right of authority for governance. As a federal appellate court stated in 2002: "Indian tribes are neither states, nor part of the federal government, or subdivision of either. Rather, they are sovereign political entities possessed of sovereign authority not derived from the United States, which they predate. Indian tribes are qualified to exercise powers of self government by reason of their original tribal sovereignty." Sovereignty is assumed by the governments of the tribes and is not an individual designation.

Stereotyping – Generalizing or characterizing a person or a group of individuals.

Tradition – Passing down elements of a culture from generation to generation, especially by oral communication, a mode of thought or behavior followed by a people continuously from generation to generation, a custom or practice. A set of such customs and practices viewed as a coherent body or precedents influencing the present followed family tradition in dress and manners, a body of unwritten religious precepts or a time-honored practice or set of such practices.

Traditional Medicine – Traditional medicine refers to health practices, approaches, knowledge and beliefs incorporating plant, animal and mineral based medicines, spiritual therapies, manual techniques, and exercises applied singularly or in combination to diagnose, treat and prevent illnesses or maintain well-being.

Tribal Shares – Tribal Shares are distributed to those tribes who compact or contract with Indian Health Service and are dependent upon the methodology used for administrative dollars and direct services dollars. The methodology is dependent upon historical workload and size of tribal population.

Tribe – Native Americans organized by band, nation, or other type of organized group or community, including Alaska Native village or Native Hawaiian communities.

Two Spirit – A term referring to third gender people (e.g., living neither as man or as woman, but an another distinct gender) who are among many, if not most, Native American tribes. It usually implies a masculine spirit and a feminine spirit living in the same body. It is also used by gay, lesbian bisexual, transgender and intersex Native Americans to describe themselves. There are also other Native terms for these individuals in the various Native American languages. The term was coined in urban areas, and therefore may not be acknowledged in traditional terminology.

Urban – Of, relating to, or located in a city, characteristic of the city or city life.

Village – A small group of dwellings in a rural area, usually ranking in size between a hamlet and a town.

APPENDIX 4:
U.S. LAWS AND POLICIES IMPACTING NATIVE AMERICANS

1830—The Indian Removal Act was endorsed by Congress to force the tribes remaining east of the Mississippi to be moved west of the Mississippi.

1834—The Indian Intercourse Act was to set aside land within the United States for the use by Native Americans. Indian Territory was a tract of land larger than the present state of Oklahoma.

1889—The Allotment Act, provided that each enrolled member of tribes in Indian Territory was individually "given" 160 acres. The land that was not allotted was then opened to settlers.

1924—Indian Citizenship Act provided allowed for Native Americans to vote.

1934—Indian Reorganization Act attempted to reorganize tribal government based on a Western, democratic model.

1950s—Public Law 280 "terminated" federal recognition of tribes in California, Oregon, Minnesota, Wisconsin and Nebraska. Since then many tribes have re-gained their federal recognition and trust status of their tribal lands.

California was not part of the public health model for Native Americans through the Indian Health Service until they filed a class action suit known as the Rincon Decision (1974).

The Bureau of Indian Affairs, Urban Relocation Program began in the 1950s and offered Native Americans the opportunity to leave their tribes and relocate to major cities with promises of better jobs and housing.

1975—Indian Self-Determination and Education Assistance Act, Public Law 93-638, gave Indian tribes the authority to contract with the Federal government to operate programs serving their tribal members and other eligible persons, to be self-governing. Tribes that have "638" programs indicates that they have contracted with the federal government to administer programs previously administered by the government, schools, social programs, higher education, and health programs.

1976—Congress passed the first Indian Health Care Improvement Act, Public Law 93-437 and Title V allowed that urban health programs that administered volunteer clinics to access funding to complete community health needs assessments and implement health care services.

1988—The Indian Health Care Act (IHCA) Amendments revised the Act to increase tribal participation in the management of Federal Indian programs and to help ensure long-term financial stability for tribally-run programs. The 1988 Amendments also intended to remove many of the administrative and practical barriers that seem to persist under the original Act. Thus you will hear of "compacted" programming which means that the tribes have an equal partnership with the federal government in administering the programs.

1994—Amendments provided for direct tribal participation in the promulgation of regulations using the Negotiated Rulemaking Act of 1990. Thus you will hear "Tribal Consultation" which refers to a process beginning with IHS and has extended to other government agencies, such as CDC, HRSA, OMH, etc.

APPENDIX 5:
PROTOCOL FOR WORKING WITH TRIBES

The following information has been presented in a workshop by the National Indian Women's Health Resource Center to federal and state agencies. Information available at: www.niwhrc.org. Used by permission from Pamela E Iron, Executive Director, National Indian Women's Health Resource Center, Tahlequah, Oklahoma.

Preparation:

- Learn the history of the tribe, (Knowing the history provides the context for this unique relationship)
- Learn how to correctly pronounce names of tribe, tribal headquarters, leaders and the names of the towns or villages of the tribe

Two Scenarios:

- You are invited to attend a meeting that someone else has organized
- You are organizing a meeting

  Scenario 1: You are an invited guest

  - Use formal titles when speaking to elected officials
  - When you are introduced to people, shake hands with them
  - When you first speak, thank your hosts for inviting you
  - When you leave, shake hands with everyone

  Scenario 2: You are organizing the meeting

  - Check with tribe about date, time, place
  - Have some discussions with tribe about what they want on the agenda
  - Arrange to have food at the meeting (Socialization is a strong cultural characteristic in Indian communities)
  - Send written invitations (Address "The Honorable (Title) (Name")
  - Telephone reminder the day before

Whom do you invite?

- Consider status – yours and theirs
- Consider who has authority in this matter
- Elected tribal leaders vs. tribal employees (Do you want buy-in or do you want action)
- Do not assume that one tribe or tribal leaders speaks for all tribes in your state. Take time to identify key players.
- Assume people will bring staff with them
- Discuss invitation list with tribe

Meeting may include a prayer

- Prayer can be at the beginning, before a meal and/or at the end
- Consult with tribal member about appropriateness of including prayer
- Usually a tribal elder or spiritual leader offers the prayer (Ask the person privately if they would like to offer a prayer prior to asking them publicly)

Styles of Communication

- Honesty and integrity are highly valued
- Humor is used to relieve tension, and to make a point
- Several issues may be discussed simultaneously, rather than sequentially
- Anger may be expressed
- They may not answer questions immediately, they may need to translate, or think about it or consult with others

If you Encounter Hostility

- Be prepared to encounter conflict
- Try not to take it personally, recognize that it is not a personal attack rather than being upset with historical actions or inactions on the part of the federal/state government.
- Listen intently. Try to understand the issues
- Don't make excuses
- Ask if anyone else would like to talk about the subject
- Ask what they want you to do
- Summarize what you have heard
- Be open to solutions that include negotiating new ways to getting to goals that you hold in common

Personal Conduct

- Respect tribal council officials, they are elected officials of a government
- Always shake hands when introduced, meeting with someone or departing. It is customary to shake hands with everyone in the room
- Be prepared for suspicion from some of the group you may be meeting

After the Meeting

- Respond with follow-up information within 10 days
- Communicate verbally by telephone, not just in writing
- Make a repeat visit to the tribe
- Build a lasting relationship over time

APPENDIX 6:
STATE RESOURCES AND TOOLS

Link here for the Utah Department of Health Federally Recognized Tribes Consultation Policy.

Link here for the UDOH Consultation Policy Flow Chart.

Link here for the Utah Department of Health (UDOH) Indian Health Liaison/Health Policy Consultant.

Link here for the Wisconsin Department of Health and Family Services and American Indians Against Abuse "Healing Our Communites" 13th Conference Program.

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