

Tab 9: Healthy Disparity & Cultural Competence



Toolkit for Integrating HIV Services in
Native Health Settings

- 1. Building Bridges: Working with American Indian and Alaska Native Health Care Providers to Integrate Reproductive Health, STI & HIV Prevention Services**
- 2. Cultural Competence: What Is Needed in Working With Native Americans With HIV/AIDS?**
- 3. Working with High Risk Subpopulations in Native Communities**



*Building Bridges:
Working with American Indian and
Alaska Native Health Care Providers
to Integrate Reproductive Health,
STI & HIV Prevention Services*

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JSI has over 25 years experience in providing client-centered counseling training and 18 years of HIV integration training and technical assistance (TA) to health care providers. For the past twelve years, through CDC cooperative agreements, JSI has offered training on HIV integration, counseling and testing, and client-centered counseling to reproductive health care providers in Region VIII. Among those groups trained have been IHS, Tribal and Urban (I/T/U) American Indian/Alaska Native (AI/AN)¹ recipients (e.g., an Urban Indian Clinic in Colorado and a Tribal Health Facility in Montana).

JSI has gained considerable experience working with AI/AN populations through numerous projects, giving us the insight and understanding into socio/cultural issues that can impact working in Indian Country. Overall, JSI staff members have worked with tribal entities in Alaska, Washington, Michigan, Arizona, New Mexico, Mississippi, Montana, California, Utah, North Dakota, Oklahoma, and South Dakota through various projects.

This document is a toolkit and is intended to be used as a general resource for groups who are trying to partner with AI/AN communities to address HIV prevention integration in both urban and non-urban areas. Our work was concentrated within the Northern Plains tribal culture (tribes residing in Iowa, Minnesota, South Dakota, Wisconsin, Montana, North Dakota, and Wyoming). Please keep in mind that this work and its lessons may look differently within other regions and within other tribal communities and cultures. Cultural differences among American Indian, Alaska Natives, and Native Hawaiians must be considered, particularly regarding the impacts of geography, assimilation, colonization, and cultural histories.

JSI is not presenting this document as a piece of primary research. We are presenting it as a toolkit which brings together various tools, information and resources. JSI has not claimed any of the information or resources, particularly within the overview section as our own work; we have referenced all passages which were taken from other sources.

¹ This toolkit generally uses the term “American Indian/Alaska Native” to refer to all tribal/aboriginal groups within the US; in some places the term “Native American” is used as well and is intended to refer to the same racial/ethnic minority groups. The toolkit uses the term AI/AN, however, JSI does recognize that it is AI focused, specifically on the Northern Plains Tribes.

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INTRODUCTION

This toolkit provides a framework to assist organizations which are working in American Indian/Alaska Natives (AI/AN) communities to integrate HIV prevention services into their clinical services. It is intended to supplement the “Roadmap to Integration: HIV Prevention Is Reproductive Health” toolkit. The Roadmap toolkit is a technical assistance and training guide which may be used by Regional Training Center staff to facilitate integration of HIV services into reproductive health clinics and other settings. Assisted by the RTCs, clinics can discuss the desired level of HIV integration, assess the current level of integration, determine clinic proficiency at the current level, assess current clinic capacities, develop a training and technical assistance plan to build and enhance capacities and evaluation efforts in integrating HIV service into clinical practice.

With this toolkit addendum, we hope to enhance your knowledge, abilities, and understanding as they pertain to HIV/AIDS prevention integration among AI/AN populations. The toolkit is intended for the Regional Training Center Family Planning staff, program/project coordinators and managers, health educators, or clinicians working within Indian Health Service, Tribal or Urban Indian clinics (ITU).

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. This toolkit is intended to serve as a basic resource for organizations seeking to work with Native communities. However, owing to the limitations of the toolkit, there are additional resources listed within pertinent sections herein, as well as a section of resources at the end of the document.

The primary goals of this toolkit are to:

1. Provide a brief summary of key historical events and policies related to AI/AN communities; and
2. Provide tips about how to work effectively with AI/ANs.

WORKING IN INDIAN COUNTRY

Working with AI/AN communities to address HIV/AIDS is important and must be done sensitively and collaboratively with the community; however, there are challenges to organizations wishing to work with AI/AN communities in developing HIV/AIDS prevention programs. These challenges are grouped into two areas: historical underpinnings of working with AI/AN communities and cultural amplifiers which impact HIV/AIDS risk.

HISTORICAL UNDERPINNINGS OF WORKING WITH AI/AN COMMUNITIES

Historical events with lasting repercussions mean there are complex issues organizations must understand in their work with AI/AN communities. Historical relationships with the federal government and with the U.S. health care system have engendered a large degree of mistrust. Below are the key themes of these historical underpinnings¹:

1. There is a trust responsibility of the federal government toward Native Americans. The trust responsibility stems from sovereign tribes ceding lands to the U.S. government in exchange for certain protections, including health care, which constitute the “trust.” This is the basis for federal funding of health care and education programs for Native Americans; and
2. There have been many breaches of this trust responsibility throughout history and there are still unresolved issues about tribal sovereignty.

While the challenge of overcoming the historical underpinnings of working with AI/AN communities can be complex, JSI has identified some strategies that will help support a successful implementation of an HIV/AIDS prevention integration program. We seek to develop a collaborative, trusting, long-term relationship—not simply a project that will end in a few years. Because this particular project was not a community-driven intervention, it had to be introduced slowly in a culturally-appropriate and acceptable manner. Experience has shown that interventions done right tend to continue in the community long after funding and TA ceases. The following are a few principles that we follow when working with AI/AN communities:

1. Build trust and establish rapport with the tribal leaders and elders who are the gate-keepers for health issues in their communities;
2. Meet communities where they are;
3. Keep your word. Avoid making commitments that you cannot fulfill.

CULTURAL AMPLIFIERS WHICH IMPACT HIV/AIDS RISK

The following are some important concepts organizations should explore when talking with Native American communities about HIV/AIDS prevention programs. These should be considered along with the social/health issues and the impacts of historical underpinnings of Native American communities. However, it is important to note that there is great diversity among Native American and Alaska Native cultures which is not universal to all communities. Within communities, there are often differences between those who are more or less “traditional” in their approach to their Native American identity. For a more thorough discussion of both co-factors in HIV risk and key strengths of Native Americans, see pages 20-23.

Confidentiality: Native Americans as a whole have serious concerns about breaches of confidentiality within their communities. In general, many do not trust the Indian Health Service to protect their confidentiality. In addition, because communities can be very “small,” many people have relatives, friends or acquaintances working in a clinic, leading to the fear that those people will have access to confidential information and breach that confidentiality.²

Stigma and Denial: The stigma against HIV/AIDS in some Native American communities coincides with that found in the larger society, and for some, there is denial that HIV/AIDS is a significant problem. For Native Americans with HIV/AIDS, this stigma is so great that they are often unable to be “out” with their families and neighbors about their HIV/AIDS status. When there is not a perceived risk of HIV infection in the community, we strive to help them understand the potential co-factors of HIV risk such as other STD rates/sexual behavior, substance use, or unintended pregnancy rates.²

While there are many challenges facing Native American communities, there is also great strength and resiliency. Furthermore, family and community factors, spirituality, traditional practice, and other cultural strengths can and do offer opportunities to maximize the health and well-being of Native Americans. Incorporation of these factors will make programs and interventions more culturally relevant. Most models of prevention and intervention have been developed with a *Western biomedical worldview*, which can discourage interest.

The next section focuses on historical underpinnings and deals with the federal government ruining the relationships/trust. We felt that this background information is important for groups that have not partnered with AI/AN communities to understand that the historical relationship that AI/AN have had with “outside” groups trying to partner with them.

BRIEF HISTORY OF U.S.-TRIBAL RELATIONS³

Pre-Constitution Policy (1533-1789)

- Administrators of British and Spanish colonies negotiated treaties with Indian tribes. Treaties are agreements between two sovereign governments, and are considered to be the supreme law of the land.
- These treaties had the effect of according tribes an equivalent status to that of the colonial governments.

The Formative Years (1789-1871)

- The new U.S. government assumed the role of the British and Spanish governments in making treaties with Indian tribes. U.S.-tribal treaties are indexed in international law publications with treaties made by all other nations of the world.
- Federal policy instead of state policy dominated because the United States Constitution specified in Article 1, Section 8 (Commerce Clause) that "The Congress shall have the power [t]o regulate Commerce with foreign nations and among the several states, and with the Indian tribes."
- The Marshall Trilogy (*Johnson v. McIntosh* - 1823; *Cherokee Nation v. Georgia* - 1831; *Worcester v. Georgia* - 1832) handed down by the Supreme Court further defined the relationship tribes had with the U.S. government, and established the doctrine of federal trust responsibility. The Marshall Trilogy also established tribal sovereignty.

The Era of Allotment and Assimilation (1871-1928)

- The U.S. quit making treaties with tribes during this time. One of the reasons for this was that treaty-making was seen as an impediment to the assimilation of Indians into "white" society.
- To encourage assimilation, Congress passed the General Allotment Act of 1887 (also called the Dawes Act). This act changed the communal ownership of tribal lands to individual ownership. Each Indian male over 18 year old was given an allotment of acres and the rest of the tribal lands, considered to be "excess," were sold to non-Indians.
- The Indian Citizenship Act was passed in 1924. This granted Indians United States citizenship for the first time.

Reorganization Era (1928-1945)

- The Merriam Report of 1928 set the tone for reform. It declared allotment to be a complete disaster.
- The Indian Reorganization Act of 1934 set up Reservation Business Councils to govern tribes, and provided for the adoption of constitutions and the granting of federal charters.

Termination Era (1945-1961)

- Legislation passed that called for a reversal of the tribal self-government movement previously endorsed and called for an end to the trust relationship between federal and tribal governments.
- This resulted in the termination of more than 50 tribal governments. The federal government simply no longer recognized them as Indian nations.
- Public Law 280 passed in 1953, gave six states mandatory and substantial criminal and civil jurisdiction over Indian country. The states included were Alaska (except for Metlakatla Reservation), California, Minnesota (except Red Lake Reservation), Nebraska and Oregon (except Warm Springs Reservation). Ten other states also opted to accept some degree of P.L. 280 jurisdiction. They are: Arizona, Florida, Idaho, Iowa, Montana, Nevada, North Dakota, South Dakota, Utah and Washington.

Self-Determination Era (1961-present)

- The abuses of the termination era led to reforms. This period has been characterized by expanded recognition of the powers of tribal self-government.
- Important legislation includes: Indian Civil Rights Act of 1968, Indian Self-Determination and Education Assistance Act of 1975, Indian Child Welfare Act of 1978, American Indian Religious Freedoms Act of 1978 and Native American Graves Protection and Repatriation Act of 1990.

AMERICAN INDIAN POLICY AND LAW³

Indian tribes have a unique political and legal status that differentiates them from other minority groups. The history of political and legal relations between Indian tribes and the U.S. government is fundamental to understanding the situation of American Indians today. Relations between Indian tribes and the U.S. government are based upon three fundamental principles—sovereignty, treaty rights and trust responsibility. Below each of these principles are briefly described, as follows:

Sovereignty

The purpose of this section is to provide the reader with a basic understanding about the sovereign status of American Indian tribes.

What is Sovereignty?

Sovereignty is an internationally recognized concept. A basic tenet of sovereignty is the power of a people to govern themselves.

American Indian tribal powers originate with the history of tribes managing their own affairs. Case law has established that tribes reserve the rights they had never given away.⁴

Treaty Rights

Treaties formalize a nation-to-nation relationship between the federal government and the tribes. American Indian Tribes Possess a "Nation-within-a-Nation" Status. A common misconception is that the United States government, via treaties, granted special rights to Indian tribes. The fact is American Indian tribes retained their inherent sovereign status. In the process of treaty making, Indian tribes relinquished some of these inherent rights, but retained others; these were known as reserved rights.

Treaties detailed what land would be relinquished, how much the tribe would be compensated, and specifies the 'treaty area' of remaining Indian land.

Trust Responsibility

In treaties, Indians relinquished certain rights in exchange for promises from the federal government. Trust responsibility is the government's obligation to honor the trust inherent to these promises and to represent the best interests of the tribes and their members.

The U.S. Constitution recognizes Indian tribes as distinct governments. It authorizes Congress to regulate commerce with "foreign nations, among the several states, and with the Indian tribes."⁵

Johnson v. McIntosh concerned the validity of a tribal land grant made to private individuals.⁶ It:

- Provided that tribes' rights to sovereignty are impaired by colonialization but not disregarded.
- Held that the federal government alone has the right to negotiate for American Indian land.

Cherokee Nation v. Georgia involved an action brought against the state of Georgia by the Cherokee Nation which sought relief from state jurisdiction on tribal lands.⁷ It:

- Described Indian tribes as "domestic dependent nations."
- Maintained that the federal-tribal relationship "resembles that of a ward to his guardian."

Worcester v. Georgia concerned the application of Georgia state law within the Cherokee Nation.⁸ It:

- Held that tribes do not lose their sovereign powers by becoming subject to the power of the U.S.
- Maintained that only Congress has overriding power over Indian affairs.
- Established that state laws do not apply in Indian Country.

Some Modifications in the Nation-to-Nation Relationship

In 1953, congress modified the federal-tribal relationship in five states through the passage of Public Law 280. More recently, the relationship was modified by the Indian Child Welfare Act (1978) and the Indian Gaming Regulatory Act (1988).

Public Law 280⁹ (1953)

Provides for five states, including Minnesota (with the exception of the Red Lake reservation), to assume general criminal⁷ and some civil⁸ jurisdiction over Indian reservations within the state. Tribes retain limited criminal and general civil jurisdiction, but because of a lack of resources have generally not fully assumed these responsibilities.

Indian Child Welfare Act (1978)

Establishes procedures state agencies and courts must follow in handling Indian child custody matters. Creates dual jurisdiction between states and tribes that defers heavily to tribal governments.

"The trust relationship evolved judicially and survived occasional congressional attempts to terminate the government's obligations to Indians. In theory, the trust relationship exists to protect tribes and individual Indians. However, in practice, the federal trustee has at times not worked in the best interests of the intended beneficiaries," according to attorney Larry Leventhal, writing for the Hamline Law Review. "One way to conceptualize trust responsibility is to think of it as treaty responsibility," said Dennis King, an Oglala tribal council member. The federal government still has the responsibility to honor agreements and treaties, which is why it is important for Indians to be knowledgeable about the treaties that affect them.

Often the promises made by the United States in treaties are enforceable under the trust doctrine. In a 1983 decision, United States v. Mitchell, the Supreme Court developed a standard for determining liability arising from a breach of trust responsibility.

It's important to note that although federal trust responsibility arises out of the nationhood of tribes, the trust doctrine also applies to individual Indians. This is unlike sovereignty and sovereign immunity, which can only be applied to nations.

The American Indian Policy Review Commission (AIPRC), set up by Congress in 1975, called federal trust responsibility the most important as well as the most misunderstood concept in Federal-Indian relations.

Part of the misunderstanding may stem from actions of Congress. The federal government has often acted inconsistently with, and in opposition to, the principles of trust doctrine, leaving the public and many tribes confused.

The AIPRC defined the United States as a fiduciary whose actions were to be judged by the highest standards. Because the federal government has so much control over the resources of Indian nations and individual Indians, the trust doctrine is implied in dealings even if not implicitly stated.

Trust responsibility affects everything the federal government is involved in, from education and health care to trust lands and the Bureau of Indian Affairs.

Key Themes: Historical Issues and Perspective¹

- The Native American/U.S. government relationship is unique (unlike other racial/ethnic minorities in the U.S.).
- Because of treaty obligations and Supreme Court decisions, there is an established government-to-government relationship between federally recognized tribes and the federal government.
- There is also a trust responsibility of the federal government toward Native Americans. The trust responsibility stems from sovereign tribes ceding lands to the U.S. government in exchange for certain protections, including health care, which constitute the “trust.” This is the basis for federal funding of health care and education programs for Native Americans.
- There have been many breaches of this trust responsibility throughout history and there are still unresolved issues about tribal sovereignty.
- Similar to African-Americans’ distrust of the federal government stemming from the legacy of slavery and abuses, such as the Tuskegee syphilis study, Native Americans and Alaska Natives have experienced abuses at the hands of the Bureau of Indian Affairs and the Public Health Service that fuel mistrust of government health programs. This has implications for HIV/AIDS prevention and care/treatment programs.

TRIBAL RECOGNITION¹⁰

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.

Federally Recognized Tribes – 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 Tribes – 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 Tribes – There are a number of indigenous groups that identify as American Indian, which maintain a tribal form of government and practice a cultural heritage, but which 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.

~Please see Appendix A for a full list of Federally Recognized Tribes.

~Please see Appendix B for information on State-Tribal Relations.

OVERVIEW OF IHS, TRIBAL, AND URBAN ISSUES

Numerous governmental and tribal agencies exist that provide culturally-appropriate information, education, training, research and services to American Indian and Alaska Natives, and advocate for the needs of Indian people.

INDIAN HEALTH SERVICE (IHS)¹¹

The Indian Health Service (IHS), an agency within the Department of Health and Human Services, is responsible for providing federal health services to American Indians and Alaska Natives. The provision of health services to members of federally-recognized tribes grew out of the special government-to-government relationship between the federal government and Indian tribes. This relationship, established in 1787, is based on Article I, Section 8 of the Constitution, and has been given form and substance by numerous treaties, laws, Supreme Court decisions, and Executive Orders. The IHS is the principal federal health care provider and health advocate for Indian people, and its goal is to raise their health status to the highest possible level. The IHS currently provides health services to approximately 1.5 million American Indians and Alaska Natives who belong to more than 557 federally-recognized tribes in 35 states.

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.

There are 12 IHS area offices which serve various tribes and geographic areas of the United States. Please see a brief description of each area below:

The Aberdeen Area serves North Dakota, South Dakota, Iowa, and Nebraska.

The Aberdeen Area Office in Aberdeen, South Dakota, works in conjunction with its 13 Service Units to provide health care to approximately 94,000 Indians on reservations located in North Dakota, South Dakota, Nebraska, and Iowa. The Area Office's service units include nine hospitals, eight health centers, two school health stations, and several smaller health stations and satellite clinics.

Each facility incorporates a comprehensive health care delivery system. The hospitals, health centers, and satellite clinics provide inpatient and outpatient care and offer preventive and curative clinics. The Aberdeen Area also operates an active research effort through its Area Epidemiology Program. Research projects deal with diabetes, cardiovascular disease, cancer, and the application of health-risk appraisals in all communities.

The Alaska Area serves the State of Alaska.

The Alaska Area Native Health Service works in conjunction with nine tribally-operated service areas to provide comprehensive health services to 130,682 Alaska Natives (Eskimos, Aleuts, and Indians). Through the provisions of P.L. 93-638, there are 18 Title I contracts and one Title V compact with 22 annual funding agreements. Alaska tribes administer 99% of the Indian Health Service funds earmarked for Alaska. Tribal hospitals are located in the communities of Anchorage, Barrow, Bethel, Dillingham, Kotzebue, Nome, and Sitka. There are 25 tribal health centers and 176 tribal community health aide clinics operated throughout the State. The Alaska Native Medical Center (ANMC) in Anchorage serves as the Area's referral center and is gatekeeper for specialty care.

The Albuquerque Area serves New Mexico, Colorado, and Texas.

The Albuquerque Area is responsible for the provision of health services to a number of distinctly different tribal groups. In New Mexico, The tribes served are the 19 Pueblos, the Jicarilla and Mescalero Apaches, and the Alamo, Canonicito and Ramah Chapters of the Navajo Nation. In Southern Colorado are the Southern Utes, and the Ute Mountain Ute Reservation (extending into a small portion of southern Utah). In Texas, the Ysleta Del Sur Reservation is served. Additionally, numerous tribal members from throughout the United States who live, work, or go to school in the urban centers of the Albuquerque Area are provided services in health facilities operated by the Indian Health Service.

Bemidji Area serves Indiana, Minnesota, Michigan, and Wisconsin.

The Bemidji Area Office (BAO) of the Indian Health Service (IHS) is located in Bemidji, Minnesota. It provides health care and funding to support health services for American Indians and Alaska Natives residing in five states with tribal facilities in Minnesota, Wisconsin, Michigan, and Indiana; and urban centers in Minnesota, Wisconsin, Michigan, and Illinois. Currently, there are 34 federally-recognized tribes in the BAO geographical area, with more tribes seeking recognition by the federal government. Ojibwe (Chippewa) Indians are the most numerous of the 34 tribes served by the Bemidji Area. Still occupying areas today where they had earlier settled are the Ottawa, Potawatomi, Menominee, Ho-Chunk, and Sioux. Only the Oneida, a member of the Iroquois of upstate New York, and the Stockbridge-Munsee Mohican Band (originally from Massachusetts) were resettled in the area from greater distances. Some of the nation's record low temperatures and some of the record snowfalls are recorded in these northern places.

The total population served by the Bemidji Area IHS exceeds 90,000 individual patients. The population is based on the official 2001 Headquarters User Population data of federally-recognized Indians who use IHS services.

Billings Area serves Montana and Wyoming.

The Billings Area Indian Health Service (IHS) provides a comprehensive health services delivery system to more than 70,000 American Indian and Alaska Native (AI/AN) people in the states of Montana and Wyoming. There are six IHS service units, two Self-Governance service units, five urban programs, and an administrative office in Billings, Montana.

The Billings Area clinical staff consists of approximately 54 physicians, 179 nurses, 29 dentists, and 33 pharmacists delivering health care through 3 IHS hospitals, 9 health centers, 6 health stations and numerous health locations.

The Tribes of Montana and Wyoming, in partnership with the Billings Area Office of IHS, and the Urban Programs have engaged in a comprehensive planning process to define the Health Care needs of its population and the capacity to provide that care through The Billings Area Health Services Master Plan. The Master Plan is expected to forge referral partnerships to improve access care that is currently unavailable and to improve the overall health and spiritual well-being of its population served.

California Area serves California and Hawaii.

The primary goal of the California Area Indian Health Service is to raise the health status of American Indians to the highest possible level. To achieve this goal, the California Area Indian Health Service supports tribal governments and urban Indian communities in the development and administration of comprehensive health care delivery systems that meet the needs of Indian people.

Nashville Area serves Eastern United States and Texas.

No information provided on this IHS area office.

Navajo Area serves Arizona, New Mexico, and Utah.

The Navajo Area Indian Health Service (NAIHS) is responsible for the delivery of health services to American Indians in portions of the States of Arizona, New Mexico, and Utah (a region known as the Four Corners Area). NAIHS is primarily responsible for healthcare to members of the Navajo Nation and Southern Band of San Juan Paiutes, but care to other Native Americans (Zuni, Hopi) is also provided. The Navajo Nation is the largest Indian tribe in the United States and has the largest reservation, which encompasses more than 25,000 square miles in Northeast Arizona, Northwest New Mexico, Southern Utah and Colorado, with three satellite locations in central New Mexico.

Comprehensive health care is provided by NAIHS through inpatient, outpatient contract, and community health programs centered around 6 hospitals, 7 health centers, and 15 health stations. Six hospitals range in size from 32 beds in Crownpoint, New Mexico, to 99 beds at the Gallup Indian Medical Center in Gallup, New Mexico. Health Centers operate full-time clinics, some of which

provide emergency services. Smaller communities have health stations that operate only part-time.

Oklahoma City Area serves Oklahoma, Kansas, and Texas.

The Oklahoma City Area Indian Health Service serves the states of Oklahoma, Kansas, and portions of Texas. Oklahoma is home to more than 39 tribes and Tribal Organizations, a large number of which have opted to operate their own health programs (a unique characteristic of the Oklahoma City Area) including large scale hospitals to the smaller preventive care programs and behavioral health programs. The Area consists of eight Service Units with federally-operated hospitals, clinics, and smaller health stations.

The Oklahoma City Area is also home to Urban Clinics and Urban Demonstration Projects which operate similar to Service Units. All the Urban Clinic facilities are Federally Qualified Health Centers, which provide ambulatory outpatient health care to urban communities.

Phoenix Area serves Arizona, California, Nevada, and Utah.

The Phoenix Area Indian Health Service (PAIHS) Office in Phoenix, Arizona, oversees the delivery of health care to approximately 140,000 Native American users in the tri-state area of Arizona, Nevada, and Utah.

Services are comprehensive and range from primary care (inpatient & outpatient) to tertiary care and specialty services. In addition, dental services, behavioral health, public health nursing, health education, and environmental health services are provided. The services are provided through nine service units located throughout the tri-state area. The Phoenix Area works closely with the 40 tribes within the tri-state area in providing health care services.

Portland Area serves Idaho, Oregon, and Washington.

The Portland Area Indian Health Service provides access to health care for an estimated 158,000 Indian residents of 42 Tribes located in Idaho, Oregon and Washington. Health delivery services are provided by a mix of health centers, health stations, preventive health programs, and urban programs.

The Indian Health Service in Tucson works with the Tohono O'odham Nation (to.ho.no aah.tum), formerly known as the Papago, and the Pascua Yaqui Tribe (pah.skwah ya.ke) of Arizona. Health service for the Tohono O'odham is centered in Sells, Arizona, capital of the Tohono O'odham Reservation and hub of reservation life. Health centers are also located in the reservation communities of Santa Rosa and San Xavier. Health care in the Sells Service Unit is a combined effort of IHS and the Tohono O'odham Health Department, providing a comprehensive health program of inpatient services, ambulatory care, and community health services.

The Pascua Yaqui Service Unit is jointly managed by IHS and the Pascua Yaqui Tribe of Arizona. Services are rendered directly and indirectly through a non-traditional system of subcontracts.

TRIBAL HEALTH SERVICE

The National Indian Health Board (NIHB) represents Tribal Governments operating their own health care delivery systems through contracting and compacting, as well as those receiving health care directly from the Indian Health Service (IHS).

The NIHB, a non-profit organization, conducts research, policy analysis, program assessment and development, national and regional meeting planning, training and technical assistance programs, and project management. These services are provided to tribes, Area Health Boards, tribal organizations, federal agencies, and private foundations.

The NIHB presents the tribal perspective while monitoring federal legislation and opens opportunities to network with other national health care organizations to engage their support on Indian health care issues.

The Area Health Boards serve as the communication link between the NIHB and the tribes. Area Health Boards advise in the development of positions on health policy, planning, and program design. They gather information and review public opinion and proposals. In areas without an Area Health Board, the NIHB representative communicates policy information and concerns to the tribes in that area.

The ten Area Health Boards include: Aberdeen Area, Alaska Area, Albuquerque Area, Billings Area, California Area, Nashville Area, Navajo Area, Oklahoma Area, Phoenix Area, and Portland Area.

The two areas served by tribal appointments are: Bemidji Area and Tucson Area.

~Please see Appendix C for contact information for each of the 10 area tribal health boards.

URBAN INDIAN ISSUES¹¹

History of Urban Indian Health Programs

Prior to the 1950s, most American Indian/Alaska Natives (A.I./A.N.) resided on reservations, in nearby rural towns, or in tribal jurisdictional areas such as Oklahoma. In the era of the 1950s and 1960s, the federal government passed legislation to terminate its legal obligations to Indian tribes, resulting in policies/programs to assimilate Indian people into the mainstream of American society. This philosophy produced the Bureau of Indian Affairs (B.I.A.) Relocation/Employment Assistance Programs which enticed Indian families living on impoverished Indian Reservations to "relocate" to various cities across the country, i.e., San Francisco, Los Angeles, Chicago, Salt Lake, Phoenix, etc. B.I.A. Relocation offered job training and placement, and was viewed by Indians

as a way to escape poverty on the reservation. Health care was usually provided for six months through the private sector, unless the family was relocated to a city near a reservation with an Indian Health Service (I.H.S.) facility service area, such as Rapid City, Phoenix, and Albuquerque. Eligibility for I.H.S. was not forfeited due to Federal Government relocation.

The American Indian and Policy Review Commission found that in the 1950s and 1960s, the B.I.A. relocated over 160,000 AI/ANs to selected urban centers across the country. Today, 62.3% of all AI/ANs identified in the 1990 census reside off-reservation. This percentage represents 1.39 million of the 2.24 million AI/ANs identified in the 1990 census updated by IHS. The updated 1994 census identifies 1.3 million (58%) AI/ANs residing in urban areas. For comparison purposes, the I.H.S. total service population is 1.4 million with active users at 1.2 million. This figure includes 427,100 eligible urban Indian active users who reside in geographic locations with access to an I.H.S. or tribal facility.

In the late 1960s, urban Indian community leaders began advocating at the local, state, and federal levels for culturally-appropriate health programs addressing the unique social, cultural, and health needs of AI/ANs residing in urban settings. These community-based grassroots efforts resulted in programs targeting health and outreach services to the Indian community. Programs that were developed at that time were in many cases staffed by volunteers, offering outreach and referral-type services, limited primary care, and maintaining programs in storefront settings with limited budgets.

In response to the efforts of the urban Indian community leaders in the 1960s, Congress appropriated funds in 1966 through the I.H.S. for a pilot urban Indian clinic in Rapid City. In 1973, Congress appropriated funds to study unmet urban Indian health needs in Minneapolis. The findings of this study documented cultural, economic, and access barriers to health care and led to congressional appropriations under the Snyder Act to support emerging Urban Indian clinics in several B.I.A. relocation cities, i.e. Seattle, San Francisco, Tulsa, and Dallas.

The Urban Indian Health Programs (UIHP) consist of 34 non-profit 501(3) (c) programs nationwide. The programs are funded through grants and contracts from the I.H.S., under Title V of the Indian Health Care Improvement Act, PL 94-437, as amended. Approximately 45% of the UIHPs receive Medicaid reimbursement as Federally Qualified Health Centers (FQHC) and others receive fees for service under Medicaid for allowable services, i.e. behavioral services, transportation, etc. Over 28.8 million dollars are generated in other revenue sources. In the Omnibus Reconciliation Act (OBRA) of 1993, Title V, and tribal 638 programs were added to the list of specific programs automatically eligible for FQHC designation. The range of contract and grant-funded programs listed below are provided in facilities owned or leased by the Urban organization. The I.H.S. is required by law to conduct an annual program review using various program standards of I.H.S. and to provide technical assistance.

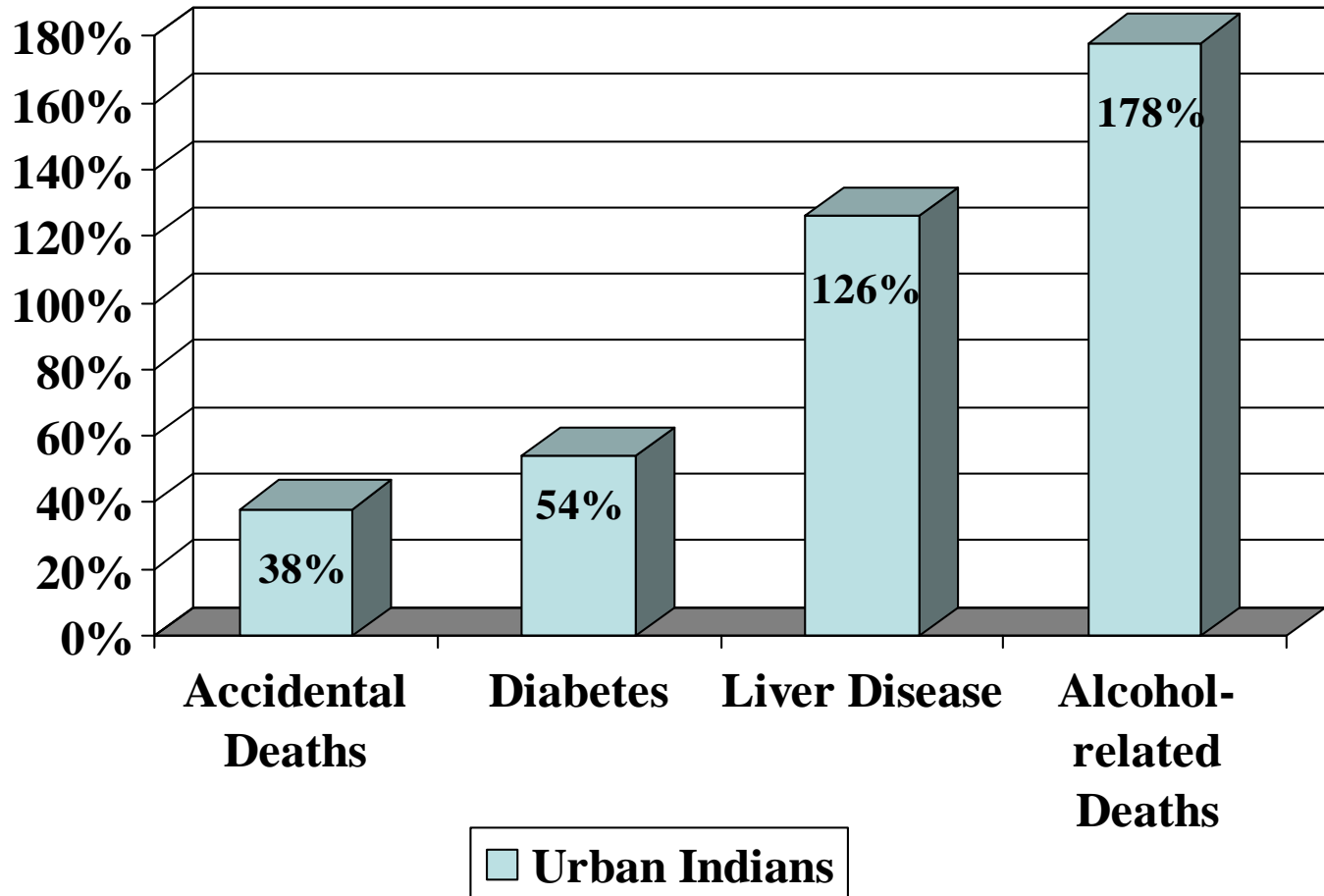
The range of I.H.S./Urban grant and contract programs include: information, outreach and referral, dental services, comprehensive primary care services, limited primary care services, community health, substance abuse (outpatient and inpatient services), behavioral health services, immunizations, HIV activities, health promotion and disease prevention, and other health programs funded through other state, federal, and local resources, i.e. WIC, Social Services, Medicaid, Maternal Child Health.

Urban Indian Populations

The following information was taken from a presentation that Scott Tulloch, CDC Assignee with the IHS National STD Program presented to the Region VIII Infertility Prevention Project Regional Advisory Committee, November 2008.

The information shows the the very significant health disparities that Urban Indians face compared to the general population for things like accidental deaths, diabetes, alcohol-related deaths. Lastly, there is a map which shows Urban Indian Health Organizations across the US.

Compared to the general population, urban Indians have:



Urban Indian Health Organizations



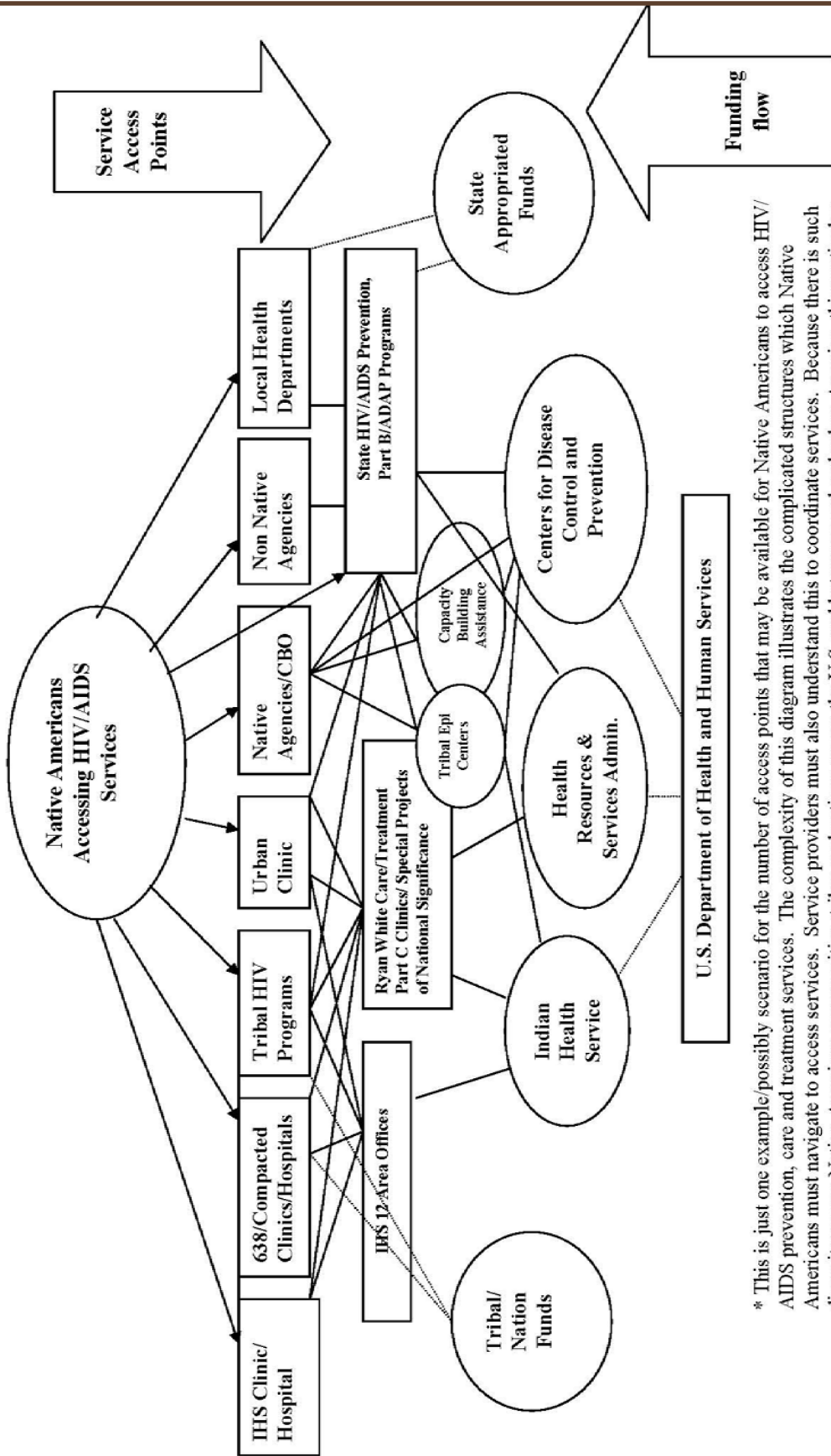
SERVICES AND FUNDING ISSUES¹⁰

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.

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.

SEXUALLY TRANSMITTED INFECTIONS AND HIV/AIDS AMONG NATIVE COMMUNITIES¹²

In the U.S., Native Americans face profound health issues that are exacerbated by poverty and social breakdown. Diabetes and alcoholism are perhaps the most talked about issues, but while overall numbers for American Indians are comparatively small, they are also significantly affected by HIV. As with other communities of color, HIV cases among American Indians have increased since the mid-1980s, ranking third in rates of AIDS diagnoses, after African Americans and Hispanics. Yet despite increasing attention paid to health disparities in other racial/ethnic minority populations, Native American are often overlooked. Few published reports describe the prevalence and patterns of risk behavior for HIV/AIDS among American Indian/Alaska Native (AI/AN) people. Data from national surveillance systems were examined to describe the spread of HIV/AIDS. These data indicate that HIV/AIDS is a growing problem among AI/AN people and that AI/AN youth and women are particularly vulnerable to the continued spread of HIV infection.

Even though AI/ANs have a relatively low rate of HIV, there are a few key issues that make AI/ANs an important group with which to collaborate, including the following:

- AI/ANs comprise less than 1% (0.9%) of the total U.S. population
- AI/ANs are disproportionately affected by STDs

2006 Surveillance Data showed:

- 2nd highest rates of Chlamydia (797.3 per 100,000)
- 2nd highest rates of gonorrhea (138.3 per 100,000)
- 3rd highest rates of P&S syphilis (3.3 per 100,000)

Compared to White, non-Hispanics, AI/ANs have:

- 1.7 times higher rates of Primary and Secondary syphilis (P&S)
- 3.8 times higher rates of gonorrhea
- 5.2 times higher rates of Chlamydia

The same sexual behaviors that cause STDs also cause HIV. Recent studies have demonstrated that being infected with an STD may make it 2 to 23 times easier to transmit HIV, depending on the specific STD.

CO-FACTORS IN HEALTH-RELATED BEHAVIORS FOR HIV RISK

American Indians/Alaska Natives are likely to face challenges associated with risk for HIV infection. The cultural, economic, health and social environments in which Native people live can contribute to HIV risk behaviors. The following are some of the issues impacting Native communities which should be considered when addressing HIV/AIDS in these communities:

- **Sexuality**

As Native culture has assimilated with Western philosophies, some of the traditional beliefs and practices which protected Native people have eroded. For example, previously-held attitudes regarding two-spirited people have been replaced by conceptualizations of men who have sex with men (MSM) as “deviant” and “immoral.”¹⁶ This has led to closeted sexual behavior; many men desiring sexual contact with men travel off-reservation to urban settings to avoid discrimination, homophobia, or violence, and return to potentially spread infections to males and females.

- **Alcohol Use**

Rates of alcohol use vary among Native American communities. There are complex historical events and cultural issues that have contributed to alcohol-related problems among Native Americans in North America (Frank et al., 2000). In some Native American communities, alcoholism is a severe problem. CDC’s Supplements to HIV/AIDS Statistics data show that the potential alcohol dependence was “twice as high as the percentage of non-AI/AN interviewees, and they were more highly associated with key alcohol dependence criteria than for any other racial/ethnic group.

- **Substance Use/Injection Drug Use**

In addition to alcohol, substance use is a major factor impacting Native Americans’ risk for HIV/AIDS. Links between substance use and sexual behaviors that increase the risk of HIV/AIDS in Native American populations have recently begun to be examined.¹³ Injection drug use is a major risk factor for Native American women; they are “more likely to inject drugs than any other ethnic group among women,” and to have IDU sex partners.¹⁴ And CDC has reported that a larger percentage of AIDS cases among American Indians/Alaska Native men who have sex with men were associated with injection drug use than in other populations.

- **Violence/Domestic Abuse**

One of the most striking issues is the impact of domestic violence on Native women’s HIV/AIDS risk. Also linked to poverty, which can lead to powerlessness, rates of domestic violence are high among Native women overall. Not only does the violence itself create risk, but it also impacts women’s ability to negotiate safer sex and can lead to post-traumatic stress disorder. For Native women, this risk factor is perhaps most striking as it is juxtaposed with the

traditionally strong and powerful role Native women have been afforded in many Native American communities.¹⁵

- **Stigma and Denial**

The stigma against HIV/AIDS in some Native American communities coincides with that found in the dominant society, and for some, there is denial that HIV/AIDS is a significant problem. For Native Americans with HIV/AIDS, this stigma is so great that they are often not able to be “out” with their families and neighbors about their HIV/AIDS status.

- **Confidentiality**

Native Americans as a whole have serious concerns about breaches of confidentiality within their communities. In general, many do not trust the Indian Health Service to protect their confidentiality. In addition, because communities can be very “small,” many people have relatives, friends or acquaintances working in a clinic, leading to the fear that those people will have access to confidential information and breach that confidentiality.²

- **Geographic Isolation**

This isolation characterizes many Native communities. Native Americans living on tribal lands do not have access to services and programs available to other Americans.¹⁷ This may contribute to reduced access to facilities for HIV/STD testing and treatment, and inadequate transportation can also be a limiting factor.¹⁸ As well, HIV-related stigma on rural reservations may be an additional barrier to seeking resources.¹⁸

- **Poverty and Unemployment**

Poverty and unemployment disproportionately impact Native American communities compared to other racial/ethnic groups and may place them at increased risk for HIV/AIDS. This is important because poverty is associated with poor access to primary and preventive care and services. Poverty means that Native Americans may remain in abusive situations and it can impede access to and use of condoms. In a special focus on Native American women, Vernon says that HIV and STD “tend to be diseases of poverty because they are intensified by conditions of economic hardship, whereby women do not have the money or time to get tested, hence their STD or HIV infection remains untreated,” which means that “the low economic status for Native women thus places them in a potential high-risk category.”¹⁵

- **Multiple Health Concerns**

Perhaps one of the key things impacting Native Americans’ risk for HIV/AIDS is that it is only one of many problems with which Native American communities are contending. Sovereignty issues may overshadow health-related concerns, and many of the issues related to alcoholism, diabetes, poverty, and unemployment are often more pressing and visible, rendering HIV less important. Faced with a myriad of other needs and challenges, prioritizing HIV/AIDS is often difficult for

many Native Americans since many of the following issues take on more immediate concerns/consequences.

- **Cultural Diversity**

The AI/AN population makes up 562 federally recognized tribes plus at least 50 state-recognized tribes. Generalizing about Native American language, culture and communication styles is not useful in working with specific individuals and/or Native American communities. Some Native American cultures are reserved and deferential to authority, precluding direct eye contact and withholding personal information until a trusting relationship is developed. Sometimes this can be perceived as unfriendly or uncooperative. Furthermore, some Western concepts are not easily translated into Native American languages, and non-natives would not necessarily understand some cultural elements of Native American languages.

- **Capacity within Native Communities**

Competing priorities, lack of resources and other concerns all impact the capacity of local Native American tribal health councils and service agencies to respond to HIV/AIDS. “Given the relative lack of health resources in Native communities, capacity for HIV/STD prevention can come and go quickly. Changes in tribal administration and availability of grants reserved for Native populations can have dramatic impacts on the existence of prevention and education programs”.¹⁹

To summarize, the authors of the HIV/STD Prevention Guidelines for Native American Communities stated “that HIV/AIDS in the Native community is clearly situated within a complex web of historical, social, cultural, economic, and health co-factors. Poverty, unemployment, substance abuse, discrimination, and violence all impact the likelihood of HIV/STD transmission within the Native community. For prevention and treatment programs to be maximally successful, this multifaceted context must be carefully considered.”

KEY STRENGTHS OF NATIVE COMMUNITIES THAT CAN MAXIMIZE HIV/AIDS PREVENTION EFFORTS

While there are many challenges facing HIV prevention efforts among Native communities, there are also some key strengths in which prevention programs can build upon. Family and community factors, spirituality, traditional practice, and other cultural strengths can and do offer opportunities to maximize the health and well-being of Native Americans. This section outlines some important AI/AN cultural strengths. It is not an exhaustive list; rather it serves as a basic view of strengths to begin a program.

- **Holism/Circle of Life**

Unlike Western or Euro-American cultures, Native American cultures are not dualistic. Like other non-Western, nondualistic cultures/communities, Native Americans tend to approach problems and issues within the context of all the other aspects of their lives. This concept of connectedness is often referred to as “holism,” but in many Native American traditions, health and people’s connection to it is conceptualized as the “circle of life” or a four-part medicine wheel that focuses on the mental, physical, emotional, and familial/community aspects of life.

- **Traditional Healing**

In most Native American tribes, traditional healers have been very important and many people seek them out for help in addressing health problems, including HIV/AIDS. Accessing these healers can help an individual towards overall well being and because these traditional healers are usually more accessible on or near a reservation, migration may occur among urban Native Americans wishing to access their services.² In addition, it is important to reach out to these healers and not alienate them when working in these communities.^{18,19}

- **Respect**

Respect is valued in many Native American cultures. One primary impact of the value of respect within Native American cultures is the importance of elders within many Native American communities. For this reason, most programs addressing HIV/AIDS in Native American communities stress the need to work with the elders within the Native American communities. In addition, for some Native American cultures, respect is also manifest in gender relations.²⁰

- **Cooperation and Consensual Decision-Making**

Cooperation and decision-making by consensus are key values in many traditional Native American cultures. Along with respect, this manifests in avoidance of direct, confrontational discussion and a contemplative, listening approach to problem solving. These values are often in conflict with American bureaucracies, including public health.²¹

By engaging in a common effort toward mutual understanding, each community builds capacities toward making change.³

ASSESSMENT AND PLANNING PROCESS

JSI recognizes that working with American Indian communities can take more time than usually planned.^{24,25} There is a long history of valid distrust of outsiders, and usually this distrust must be addressed before the real work can begin. We know that relationship building is of the utmost importance.

While we recognize the importance of building technical services on strong theory and science, our efforts did not impose specific western models or beliefs on the Native communities with whom we worked. Unique circumstances, tribal histories, cultural beliefs and practices, and “what works in Indian Country,” as well as advances in Western knowledge, were all factored in. To guide our efforts in our work with the model urban Indian and Tribal clinics, we instituted an overall project advisory group. This group was comprised with representatives from the National Native American AIDS Prevention Center, Northern Plains Epidemiology Center, Montana Department of Public Health–Communicable Disease Control and Prevention Section, and a Native American service provider.

JSI used a three step strategy to adapt training and TA for I/T/U settings.

1. Formative Research

Formative research activities are crucial to ensuring our understanding of how the context of the local community affects successful local programming. In particular, our research focused on understanding tribal history; identifying local goals, needs and assets; understanding factors that influence outcomes; identifying and targeting specific knowledge, attitudes, and behaviors for change; identifying and emphasizing proven local mechanisms for inducing change; involving local participants in developing intervention efforts that are appropriate to each community; piloting to determine whether program activities are having intended impacts; and revising program efforts, when necessary, to achieve local goals.

JSI viewed this formative research as playing a critical role during the developmental stages of our integration efforts. It was one of our building blocks of trust with the Native communities with whom we worked. It also laid the groundwork for effective program evaluation. Our formative objectives were: 1) learning all we can about these communities including their history and worldview, 2) engaging key stakeholders; 3) co-creating a logic model with a local steering group that depicts the program and subsequent evaluation accurately; 3) gathering information from past research on best practices, especially within Northern Plains communities, 4) assessing local community and organizational structure and capacity; 5) co-identifying measurable and feasible objectives; and 6) co-developing a logistically sound plan that includes training and TA given the resources available.

JSI believes in collaborative work with program directors, community members, elders, traditional healers, clients, and other key stakeholders in order to achieve

a balance between community perspectives and scientifically tested best practices.

Identify local needs and assets. We facilitated the organization of a local steering group whose responsibility was to guide on a local basis project activities (e.g., assessments, planning, implementation, and evaluation). When identifying local needs and assets, it was important to garner information from past studies and information systems already in place. It was also important to do some primary data collection to ensure that these general findings were applicable in the target communities. Thus, we informed ourselves about the community, its history, worldview, and needs/resources, first, through literature searches and analysis of locally available information. This information was then augmented and confirmed through interviews with key informants and focus groups of targeted sites (I/T/U).

Understand factors that influence outcomes. A valid logic model assisted not only program intervention, but also its evaluation. We facilitated the local steering group in creating their own logic model using examples from other successful programs as guides.

Target specific variables for change. The logic model and needs assessment aided in identifying specific factors to target for change. Usually these factors were a combination of improving knowledge and changing attitudes and behaviors. Priority was given to the locally-identified priority factors that are relatively amenable to change.

Identify proven mechanisms to induce change. Our needs assessment inquired into what has worked in introducing change within the local community. This information acted as the starting point for innovation planning. Using what has worked locally and what we know works nationally (evidence-based) in program development (e.g., organizational change), we also built upon efforts such as those previously supported by CDC in affecting individual behavior and community response.

Intervene in a way appropriate to the local population. Our collaborative approach incorporated the experience of local program staff, clients, and community members, and helped refine an intervention effort, so that it was appropriate for the local population. This refinement was critical to translating general results into effective local utilization and its sustainability.

Test an intervention early. Initial efforts to deliver the interventions were assessed (piloted) quickly. Guided by the logic model, tests looked for evidence that those elements that should change first (short-term outcomes) are in fact changing. These assessments were done through surveys, intervention satisfaction ratings, and qualitative methods such as interviews and focus groups.

2. Identification of Needs

We know that the identification and assessment of HIV-related prevention program needs inform program planning, priority setting, resource allocation, evaluation activities, and training programs. The changing HIV epidemic in the U.S. and particularly in AI/AN populations warrant ongoing identification of prevention and services needs among our targeted communities to address the challenges at hand. This becomes particularly important in times of tribal and IHS budget constraints and program scale-up.

Assessing the extent of integrated HIV prevention and related services for those at greatest risk (prevention) is crucial to a program addressing needs along a continuum of care.

Our needs assessment (see above) for comprehensive planning was the process by which we established the necessary evidence of the local geographic area being serviced, the populations and specific sub-groups at risk of HIV, the prevention and intervention needs of these communities, and gaps between existing needs and available resources. Finally, assessing the evaluation capacity of I/T/Us contributes to documentation of HIV prevention outcomes. A needs assessment report was generated for each local site.

JSI applied these guiding principles to its varied needs assessment activities:

- **Involve all stakeholders in needs identification process from planning through interpretation of results.** Stakeholders include both groups who will use results for decision making and groups whose needs are being assessed. Often this means combining people with very different backgrounds and perspectives (e.g., academic methodologists, tribal college faculty members, community members, and consumers). Each group must be recognized for the contribution it brings to the process.

This required establishing a common group language, or at least ground rules, for discussion, as well as assigning roles and responsibilities in the needs assessment process. The local steering committee provided this stakeholder involvement.

- **Identify needs based on both quantitative and qualitative data.** JSI urged the sites to consider already available (secondary) data, such as surveillance, service utilization and previous knowledge, attitude or behavior (KAB) or needs assessment data, and to build primary data collection efforts such as written and interviewer-administered surveys. Qualitative data gleaned through focus groups, key informant interviews, public meetings and observations are important both to guide and interpret quantitative data collection efforts. Quantitative, qualitative or combined approaches were used in as rigorous scientific approach as possible to enhance usefulness of results to planning and implementation.

- **Utilize multiple sources for gathering information.** Similar to the community services assessment process established by the CDC for HIV prevention planning, JSI used multiple needs assessment methods. These components included an assessment of provider, community member, elder, traditional healer, and client perceptions, attitudes, and behaviors among the affected clientele; a resource inventory describing individuals and organizations including traditional healing methods available in the service area; and an epidemiological profile and trends for the area.
- **Reach those not in care and not traditionally reached.** Women, drug users, and adolescents are among the growing, underserved and hard-to-reach AI/AN populations becoming infected with HIV. Many of these populations cannot be reached through traditional needs assessment methods. Discussions with the stakeholders helped inform participant recruitment strategies.

3. Planning

Planning is a process of defining needs, establishing priorities, diagnosing causes of problems, assessing resources and barriers, and allocating resources to achieve objectives.²² It should include clear goals, objectives, and strategies for action, as well as mechanisms for assessing progress. Strategies are developed to address specific barriers and incorporate available resources depending on the nature of the problem or issue of concern. Our facilitated planning with the local steering group will answer these basic questions: 1) Where are the facilities now? How is the problem or issue defined in the community and organization? 2) Where do they need to go? What are their goals and shared vision? 3) How will they get there? What steps can they take to reach their goals and what strategies are needed? What resources do they have and what are needed? 4) How will they monitor their progress? How will they evaluate their progress in meeting the short-, intermediate-, and long-term goals? Answers to these questions will inform the locally derived logic model and will engage stakeholders in a process that results in a final written plan. This plan clarified and articulated local shared values, with action steps identifying TA and training needs.

Our planning approach was based on key principles that ensure that planning is participatory, client-centered, flexible, inclusive, accessible, transparent, community-based, collaborative and rooted in sound evidence-based models.

Use of the PRECEDE-PROCEED planning model

The JSI team used the PRECEDE-PROCEED health promotion planning model²² as a framework, in conjunction with the toolkit *Roadmap to HIV Integration: HIV Prevention is Reproductive Health* for its TA on prevention planning. Two fundamental propositions with this model are: 1) health and health risk have multiple determinants and 2) health risks are determined by multiple causes. The eight phases of PRECEDE- PROCEED were included in our local needs assessment mentioned above, and are:

1. **Social assessment and situational analysis.** This phase involved assessing the communities' HIV prevention hopes or issues.
2. **Epidemiological assessment.** This phase helps identify the HIV-related hard numbers of the goals or issues identified in Phase 1.
3. **Behavioral and environmental assessment.** This phase identifies specific health-related behavioral and environmental factors that could be linked to the HIV-related issues identified in Phase 2. This is a critical step that identifies the risk factors the interventions then addressed.
4. **Educational and ecological assessment.** These are factors that influence behavior and are grouped as predisposing, enabling, and reinforcing. During this phase, the priority focus factors were identified within each group.
5. **Administrative and policy assessment.** With the systematic data identified in the first four phases, this phase assesses the organizational and administrative capabilities and resources for the development and implementation of HIV integration.
6. **Implementation, monitoring, and evaluation.** Although listed as the last phase, evaluation was included from the beginning. For example, identifying measurable objectives as part of earlier phases is critical to measuring effectiveness.

It is important to understand that adopting a participatory approach does not in itself address cultural issues, and participatory methods can be as culturally biased as other mainstream planning and assessment models. See the section entitled, Recommendations and Examples for information on how to modify existing participatory methodologies in order to overcome cultural bias.

LESSONS LEARNED

The effect and impact of HIV/AIDS on tribal communities is a complex matter, in that health issues are tied not only to biology but to social and cultural elements as well.²³ For American Indians, some of the unique issues include the reservation-urban circular migration, limited health resources, a low priority for HIV issues among tribal governments, underreporting of HIV/AIDS within this population, limited confidentiality within the communities, and a need to consider cultural values within the context of prevention and intervention.

JSI's work is concentrated within the Northern Plains tribal culture (tribes residing in Iowa, Minnesota, South Dakota, Wisconsin, Montana, North Dakota, and Wyoming). So, our work and the lessons learned are based on the tribal communities and world views of this region. Plains Indians have been able to accommodate outside views without surrendering their cultural heritage. The Plains cultures endure through their arts, healing traditions, powwows, tribal fairs, Sun Dances, sweat ceremonies, giveaways, and naming ceremonies, to mention a few. Urban Indians maintain their cultural ties in many ways; here are just two examples: by either returning to their reservations to take part in the ceremonies and powwows or by participating in their tribal social activities at urban Indian centers. JSI's prior work within Northern Plains communities gave staff the understanding and experience needed to take on the task of working with these communities for this integration project.

We stress the importance of keeping in mind that this work and its lessons may work differently within other regions and within other tribal communities and cultures. Cultural differences among American Indian, Alaska Natives, and Native Hawaiians must be considered, particularly regarding the impacts of geography, assimilation, colonization, and cultural histories. Native people have rich and multifaceted ways which must be understood to lessen misunderstandings in providing better prevention and intervention services. Inaccurate research, inadequate education, slanted media coverage, and dehumanizing stereotypes can make the most "educated" professional grossly uninformed about Indian life and culture³, which leads to damaged credibility and program development that does not "work." Thus, we feel it is very important that non-Indian providers and/or technical consultants educate themselves and understand the core values, beliefs, and histories of their target population and the need to convey information in a respectful manner.

The following are JSI's lessons learned in providing technical assistance and capacity building for HIV integration within Northern Plains Indian communities. *This knowledge was gained to-date and is thought of as "knowledge in progress," as our work continues.* It is provided as "tips" for working in Indian Country in integration HIV/AIDS services.

1. Organize An Overall Project Advisory Group.

A project-wide advisory group composed of members familiar with HIV in Indian Country and those working in our specific target area has been immensely useful. In some cases, members provided entry into the reservation community clinics. They also aid the project team in brainstorming solutions to our challenges and reviewing tools and materials.

2. Find a Local HIV Integration Champion.

Having a local champion on board as a team member who believes strongly that HIV prevention and intervention is crucial to local Indian health is a must. This person lives and works within the community politics, social and political structure, and local norms and values. She/he guides the project through all the necessary first steps of getting all the appropriate approvals and buy-ins from the clinic administration and tribal governing bodies, as well as provides the context in which integration can be planned and implemented.

We have found that the initial champion does not need to be a medical staff person. In our urban site, our initial champion was a mental health provider who introduced the project and our assistance to the clinical staff. When she left the clinic, our champion was a nurse practitioner who recently came on board. When she left, the champion was, again, a mental health provider. Thus, one can expect the champion to be any provider or person associated with the clinic, and this champion may change.

3. Introduce, Help Organize, and Use a Local Steering Committee.

Planning, cooperation, and decision-making by consensus are key values in many Indian cultures. Using a participatory approach to all activities, we have found the local steering committee to be very important for buy-in, community and provider input, cultural review of tools and processes, implementation, and planned evaluation. One of the strengths of our project is the collaborative team process between the technical advisors, on-site staff, and on-site steering committees, which includes the champion.

4. Recognize the Unique Characteristics and Needs of Different Tribal Entities and Clinics.

In light of self-determination, stereotypes about American Indians and the exclusion of the unique viewpoints of different tribal cultures, these communities are particularly oriented toward an understanding that a *one-size-fits-all* approach is inappropriate. Tensions exist between traditions, clinical services provided, current issues within the clinical setting, culture, and rural-urban-reservation factors. Homogenizing a process for HIV integration in Indian Country may not be culturally or clinically appropriate (all clinical settings are different, even mainstream), given that recognition of differences is valued more than compromise. Thus, there are distinct differences in the processes of integration, tools, and training across the sites in which we have been working. For example, one site, after focus group

input, decided to implement a two-step risk assessment process, while another site felt a one-step process was more appropriate. Each site emphasized the uniqueness of its clinical services and its patient population. The project's integration activities acknowledged such individuality by being flexible and adaptive.

5. Listen, for the Sites are the Real Experts for Integrating New Services within their Clinic.

All site staff were bounded by a single goal—to improve services and ultimately the welfare of American Indian people. We were most successful when we not only listened but also, more importantly, engaged and facilitated the staff as co-integrators and allowed the planning process and subsequent integration progress to progress from their needs and perspectives. One must not operate with an “I know best” attitude when providing technical assistance to American Indian people and organizations. This attitude will lead to resistance.

6. Earn Technical Advisor Credibility.

Credibility requires that collaborative efforts with clinic staff, stakeholders, and technical advisors be consistent in behavior, respectful of communities and clinics, and follow through on tasks in predictable ways over time. Predictability assures trustworthiness of the project and the advisor. Credibility needs to be earned, over and over again.

7. Do Not Underestimate Time Needed.

Despite our taking exhaustive steps to secure agreements with the clinics at the beginning, the formal approval and trust building process took more time than was initially anticipated or allocated. American Indians are sensitive to initiatives developed without their participation or input, and thus, outside initiatives are typically viewed with skepticism.

Gaining formal approval at the reservation level is usually a multi-step process and can vary greatly by location. The approval process may include the clinic administration, the Indian Health Service, the medical director, a Tribal Council committee, and the Tribal Council itself. The original one-year timeline did not fully allow for gaining formal approval, staff turnover, or integration activities that arose, and still arise. This, in turn, has had a rippling affect on planned integration technical assistance activities. JSI uses the partnership philosophy when working with tribes and/or communities. Within this partnership, different philosophies regarding time and decision-making are respected.

Working in Indian Country requires the forming of relationships that includes a thoughtful approach, building rapport, assessing, and planning. We found it is also important to build trust and credibility where the communities see outcomes of any effort as benefitting their Indian patients locally. Once the

relationship is established, a strong partnership results. The primary goal of HIV integration is to develop and/or change a care system to make it more culturally-competent and culturally-responsive, integrate new services, provide training, build enduring collaborations within referral networks, and observe intended outcomes. To accomplish this feat within a one-year time frame was a formidable task and could not be accomplished. There are multiple paths leading to HIV integration. Different clinical settings move at various paces, and these paces change over time and staffing. This is a part of the natural process of change, especially within Indian Country.

8. Know That HIV/AIDS May Not Be “On Their Radar.”

HIV prevention and intervention may be a low priority among clinical sites which are struggling to provide the most basic health services. The urgency for inclusion of HIV prevention into existing health services may not be seen as important, as administrators and leaders struggle to manage other health challenges. Other more prominent issues (e.g., unemployment, housing, transportation, sovereignty, etc.) may overshadow health-related concerns. Low prevalence rates (often influenced by less-than-optimal surveillance) within the Indian community also may hinder priority.

9. Know That HIV-related Stigmas are Alive and Well.

The stigma against HIV/AIDS in Indian Country mirrors that found in the dominant society. HIV-related stigma, especially in rural sites, is a barrier to seeking local services, and is compounded by the fear of confidentiality being breached. Additionally, the stigma may also result in individuals not being able to be “out” with families, friends, or with the community about their HIV status.

10. Have Flexibility, Much Patience, and Bravery.

There is a need to be able to change gears in response to arising circumstances that are out of the technical advisors’ control. For example, our urban site had a complete staff turnover twice, necessitating reintroduction of the integration project two times. We recently lost our champion at one of the reservation sites where we were still in the process of gaining formal approval. Our process required flexibility in our approach and methods, and the ability to adapt to changing circumstances, including understanding approaches that did not work. Reciprocity, or giving back, was an important requirement. Thus, we introduced other opportunities for consultation (e.g., trainings on hepatitis and clinic efficiencies, assistance with electronic health record introduction, etc.). Bravery surfaced in a willingness on the part of staff to add another thing onto their already loaded plate, and for us to do things in a different way and acknowledge possible limitations.

11. Understand the wider Socio-political context.

There is an inherent distrust of the majority culture. It is a reminder of the historical mistreatment of Indian people by the majority culture. Thus, outsiders can evoke an immediate resistance and animosity.

Our work was successful when it fostered, rather than hindered, trust building and clinical capacity within a participatory approach. We recognized that we work within a context of history that has not necessarily served Indian communities well—outsiders had brought mainstream ideas and processes to the communities that did not work in the past. Again, credibility is earned. Our process required establishing trusting relationships and could not proceed until this occurred. Building these relationships required more than professional assistance but also time spent with staff just chatting informally. The hit-and-go approach does not work.

12. Prepare for Clinical Training Topics To Be Similar.

While training topics proved to be similar across sites, cultural appropriateness of training and materials still needs to be considered. To reiterate, we worked with Northern Plains communities; however, each community had their unique differences (e.g., assessing risk in a culturally appropriate manner, taboos of asking sexually-related questions). In addition, urban sites work with numerous tribal affiliations, and reservation sites with only one. Training needs to respect the differences in the cultural views of clients seen within the framework of the uniqueness of each clinical setting.

Individual acculturation can also impact practice. Many Indian people neither work nor live immersed in their traditional culture, while some do. Thus, different approaches to prevention and intervention may be necessary. It is also important to understand that many taboos surround the discussion of sex and drug-related behaviors within some Indian cultures, and trainings in Indian Country should incorporate dealing with these taboos in a sensitive manner.

13. Prepare for Hesitation since Perceived Geographic Isolation impacts Comprehensive Integration Services.

The rural nature of one site and its isolation emphasizes its limited access to referral treatment services and programs. The staff expressed concern that HIV testing would open a “Pandora’s Box” without the necessary means for follow-through. Inadequate transportation can also limit testing and follow-up or completion of referrals.

The circular migration from rural or reservation areas to urban places and back again is not only a risk factor for HIV/AIDS transmission, but also poses a challenge for reservation services, as they have limited resources and expertise to address the health outcomes that result from this mobility. Our urban site, located within a large metropolitan area, has a large yearly

powwow which brings in Indians from many tribal affiliations. At this time of year, the clinic sees an increase in clinical visits. In addition, Indians may receive health care through multiple medical providers, such as on the reservation and then in urban community health centers, which impacts consistency in care and effectiveness of diagnosis and treatment.

14. Prepare Services for Confidentiality Protection.

HIV testing and care services are affected by concerns about a lack of confidentiality. This issue came up repeatedly when working with our sites. Rural reservations consist of close-knit families, many of whose members work in the facilities that provide care. This leads many high-risk or HIV-infected individuals to travel great distances to seek testing and care in order to avoid potential negative societal perceptions of their sexual orientation. Accessing these outside services is affected by barriers such as poverty, lack of transportation, and an inability to identify with non-Indian organizations. Even at the urban site, confidentiality is an issue because of the small size and cohesiveness of the Indian community within the urban area. Ensuring the confidentiality of client information is both extremely important and extremely difficult within these small communities.

15. Integrate HIV Prevention and Integration Within Non-medical Services Within Clinic.

The intricate social climate inhabited by Indian persons can lead to a series of interrelated behaviors which increase HIV risk.¹⁹ This issue came up repeatedly with our site work. Individuals, particularly within the sexual minority, may misuse drugs and alcohol. Others may find themselves within the cycle of partner violence which is a major concern with Indian women. Thus, integrating education, testing, counseling, and services may need to include other services within the clinical setting. A multifaceted context should be carefully considered during planning.

16. Consider American Indian Community Strengths and Resiliency.

While there are many challenges facing these communities, there are also great strengths and resiliencies that can be considered in integration planning. Incorporation of community factors, spirituality, traditional practice, cultural values, and holism are opportunities for maximizing health in a more culturally relevant way. We will soon be in the process of adapting an HIV risk prevention wheel to a medicine wheel format for one specific clinic.

17. Capitalize on Activities Already Underway.

Our project met many challenges, the least of which was the continual staff turnover which impacted greatly the technical assistance plan (e.g., training of staff) and necessitated reintroduction of the project and starting from scratch. Meeting the challenge of reestablishing a connection with one clinic, we found success when the new Executive Director of the clinic sought assistance in responding to an IHS RFP for integrating Rapid HIV Testing. As another

example, in another clinic, we were able to raise HIV integration as a priority by acknowledging their need for assistance in their integration of a new electronic health record technology. Thus, noticing these opportunities and capitalizing on them enabled us to move HIV integration forward.

We found clear challenges in our work but understand the importance of addressing HIV/AIDS within this community. Working with Native communities and providers who serve them must be done sensitively and collaboratively.

TIPS AND RECOMMENDATIONS FOR WORKING IN INDIAN COUNTRY¹

While there are challenges in addressing the HIV/AIDS prevention, care and treatment needs of Native Americans may be complex and daunting, there are strategies that work, even in resource constrained situations. Building trust and establishing rapport with the tribal leaders and elders who are the gatekeepers for health issues in their communities are critical. Knowing the local history of the Native American community and its experiences with the U.S. and state governments is important. Local variations and unique relationships exist which are difficult to generalize.

- There are a few things that are important in working with Native American communities:
- Establishing trust with and support from tribal leaders;
- Conducting an assessment of needs;
- Meeting communities where they are;
- Funding and/or supporting agencies or community-based organizations with a proven track record in the community and ensuring that people from the community can provide services;
- Forming collaborations with agencies working on other health and social issues;
- Addressing confidentiality;
- Challenging assumptions about the cultural values of the community; and
- Addressing the concerns around misclassification of data.

Sue Klein, Director of the Division of HIV Prevention in the New York State AIDS Institute came up with a checklist of tips for health departments working with Native American communities; here are just a few of these important “tips”:

- Be cognizant of Native American sovereignty. Many Native American nations self-identify as sovereign entities and may not consider themselves to be within your jurisdiction.
- Due to sovereignty issues, many Native Americans do not vote. Since there is no Native American constituency whose support is sought during elections, elective processes rarely result in support for Native American issues, including funding.
- Keep your word. Avoid making commitments that you cannot fulfill.
- Become familiar with the appropriate terminology used by a particular Native American nation/community. Be cognizant of how Native Americans refer to themselves and their people.
- Learn from history, but do not take it personally. Bear in mind that sovereignty issues continue to impact Native Americans and that the issues at stake often engender intense reactions.
- Avoid stereotyping Native Americans, their nations and tribes.

- Remain aware of issues in the external environment that are of concern to Native communities. Recognize that these, together with historical events or “underpinnings,” form the larger framework within which HIV prevention can be pursued.

Thirteen Policy Principles for Advancing Collaborative Activity Among and Between Tribal Communities and Surrounding Jurisdictions. Generated at the NACCHO Turing Point Spring Forum 2001 in Washington, DC (accessible at: http://www.naccho.org/files/documents/policy_principles.pdf)

1. *Don't plan for us without us.*
2. *Tribal consultation shall be the overarching principle.*
3. *No policies will be made for Tribes without the direct involvement of the Tribes.*
4. *Tribal systems, traditional and governmental, shall be respected and followed by others working with Tribes.*
5. *Trust responsibilities between states and Tribes will be respected and honored, with emphasis on building a policy bridge, not a policy wall.*
6. *Policies shall not bypass Tribal government review and approval prior to implementation.*
7. *Tribally specific data shall not be used/published without prior consultation with the Tribe.*
8. *Policies shall respect Tribal belief in matrilineal and patrilineal ways of life, reverence for elders, and respect for children.*
9. *Policies shall respect humanitarian principles and values.*
10. *Policies shall be honored by actions.*
11. *Training policies shall include developing knowledge of American Indian and Alaska Native sovereignty.*
12. *Blanket policies shall be very broad, consider economic, social, regional and cultural differences, and advance integration of public health and environment health action.*
13. *Sovereignty includes an inherent right to be in search of life, liberty and happiness as human beings.*

RESOURCES

AI/AN-Related References and Resources

You may find the following resource helpful in providing additional tips when working with this population:

Native Americans and HIV/AIDS: Key Issues and Recommendations for Health Departments: Native American Report – November 2004. National Alliance of State & Territorial AIDS Directors (NASTAD), Washington, DC.

HIV/STD Prevention Guidelines for Native American Communities: American Indians, Alaska Natives, & Native Hawaiians: 2004. National Native American AIDS Prevention Center & Rural Center for AIDS/STD Prevention: Denver, CO.

HIV/STD Prevention Guidelines for Native American Communities: American Indians, Alaska Natives, & Native Hawaiians. Rural Center for AIDS/STD Prevention (www.indiana.edu/~aids) and National Native American AIDS Prevention Center (www.nnaapc.org); 2004

A Nationwide Population-Based Study Identifying Health Disparities Between American Indians/Alaska Natives and the General Populations Living in Select Urban Counties. Castor Mei L, et al.; AJPH; August 2006, Vol 96, No. 8

The Persistence of American Indian Health Disparities. Jones, David S.; AJPH; December 2006, Vol 96, No. 12

HIV Prevention, Early Intervention, and Health Promotion: A Self-Study Module for Health Care Personnel Serving Native Americans. Mountain Plains AIDS Education & Training Center (www.mpaetc.org); 2nd Edition, 2008

Native Americans and HIV/AIDS; (devbehavpeds.ouhsc.edu/assets/pdf/pmm/AIDS.pdf); The Center on Child Abuse and Neglect; prepared by The University of Oklahoma Health Sciences Center under grant number 97-VI-GX-0002 from the Office for Victims of Crime (OVC), U.S. Department of Justice; March 2000

Community Readiness: A Promising Model for Community Healing. (devbehavpeds.ouhsc.edu/assets/pdf/pmm/Comm-Readiness.pdf); The Center on Child Abuse and Neglect; U. of Oklahoma Health Sciences Center; March 2000

Slideset: Methamphetamine, Alcohol and HIV: Risk & Prevention in Native American Communities. Corwin, Marla; Mountain Plains AIDS Education & Training Center

Slideset: *HIV/AIDS and Victimization: A Critical Link for American Indians Alaska Natives*. Naswood, Elton; Red Circle Project, AIDS Project Los Angeles

Organization and Financing of Alcohol and Substance Abuse Programs for American Indians and Alaska Natives. McFarland BH, et al.; *AJPH*; August 2006, Vol 96, No. 8

Screening for Alcohol Abuse Among Urban Native Americans in a Primary Care Setting. Shore J, et al.; *Psychiatric Services* (<http://psychservices.psychiatryonline.org>); June 2002, Vol 53, No 6

Surveillance Systems Monitoring HIV/AIDS and HIV Risk Behaviors Among American Indians and Alaska Natives. Bertolli J, et al.; *AIDS Education and Prevention*, 16(3), 218-237, 2004

Social Epidemiology of Trauma Among 2 American Indian Reservation Populations. Manson SM, et al.; *AJPH*; May 2005, Vol 95, No 5

Legal and Historical Roots of Health Care for American Indians and Alaska Natives in the United States. Shelton, Brett Lee; The Henry J. Kauser Family Foundation; February 2004

Disparity and Dispossession, Hope and Healing: Health in American Indian Communities. Benjamin, Diane; Healthy Generations; U. of Minnesota, Maternal & Child Health Program, School of Public Health; February 2007, Vol 7, Issue 2

Health Service Access, Use, and Insurance Coverage Among American Indians/Alaska Natives and Whites: What Role Does the Indian Health Service Play? Zuckerman S, et al.; *AJPH*; January 2004, Vol 94, No 1

A Quiet Crisis: Federal Funding and Unmet Needs in Indian Country. U.S. Commission on Civil Rights (www.usccr.gov); July 2003

Native American Health Care Disparities Briefing – Executive Summary. U.S. Commission on Civil Rights (www.usccr.gov); February 2004

HIV/AIDS Prevention in “Indian Country”: Current Practice, Indigenist Etiology Models, and Postcolonial Approaches to Change. Duran B, Walters K; *AIDS Education and Prevention*, 16(3) 187-201, 2004

Clinician’s Guide: Working with Native Americans Living with HIV. National Native American AIDS Prevention Center (www.nnaapc.org)

Creating a Vision for Living with HIV in the Circle of Life. National Native American AIDS Prevention Center (www.nnaapc.org)

Addressing Two-Spirits in the American Indian, Alaskan Native and Native Hawaiian Communities – Instructors Manual. National Native American AIDS Prevention Center (www.nnaapc.org)

Sexually Transmitted Diseases: An Advocacy Kit for Tribal Leaders. Project Red Talon, Northwest Portland Area Indian Health Board (www.npaihb.org)

Within the Hidden Epidemic: Sexually Transmitted Diseases and HIV/AIDS Among American Indians and Alaska Natives. Kaufman CE, et al.; Sexually Transmitted Diseases; May 2007, Vol 34, No 5

STDs in American Indians & Alaska Natives – National & State Fact Sheets. National Coalition of STD Directors, Indian Health Service, and Centers for Disease Control and Prevention; September 2007

HIV/AIDS Among American Indians and Alaska Natives Fact Sheets. Centers for Disease Control and Prevention (<http://www.cdc.gov/hiv/resources/factsheets/aian.htm>); rev. August 2008

Web sites:

The Center for Child Abuse and Neglect	devbehavpeds.ouhsc.edu/ccan.asp
National Native American AIDS Prevention Center	www.nnaapc.org/
Rural Center for AIDS/STD Prevention	www.indiana.edu/~aids
Mountain Plains AIDS Education & Training Center	www.mpaetc.org/
U.S. Commission on Civil Rights	www.usccr.gov
Project Red Talon - Northwest Portland Area Indian Health Board	www.npaihb.org
American Indian/Alaska Native Initiative	www.ou.edu/hiv/index.htm
Native American Women's Health Education Resource Center	www.nativeshop.org
The Navajo AIDS Network, Inc.	www.navajoaidsnetwork.org
Centers for Disease Control and Prevention – HIV/AIDS Resources	www.cdc.gov/hiv/resources/
AIDS Info	www.hivatis.org
Advancing HIV/AIDS Prevention in Native Communities	www.happ.colostate.edu/
Indigenous Peoples Task Force	www.indigenouspeoplestf.org/
Indian Health Service	www.ihs.gov
Inter Tribal Council of Arizona, Inc.: Regional STD/HIV/AIDS Prevention Project	www.itcaonline.com/program_hiv.html

Native American AIDS Project	www.naap-ca.org/
Center for AIDS Prevention Studies - U. of California-San Francisco	www.caps.ucsf.edu/index.php
The Henry J. Kaiser Foundation	www.kff.org/
National Indian Health Board	www.nihb.org/

A key resource to Native communities as well as to organizations that which to work with AI/ANs are the National Tribal-based Epidemiology Centers (NTEC). Their key activities include surveillance for disease conditions, epidemiological analysis, interpretation, and dissemination of surveillance data, investigation of disease outbreaks, development and implementation of epidemiological studies, development and implementation of disease control and prevention programs, and coordination of activities with other public health authorities in the region.

The NTECs were authorized by Indian Health Care Improvement Act in order to monitor progress toward Healthy People objectives. NTECs are located within tribal health programs to support tribes. The following map shows where each of the eleven NTECs are located.

Tribal Epi Centers Websites

Alaska Native Epidemiology Center
anepicenter@anthc.org

Albuquerque Area Southwest Tribal Epidemiology Center
Albuquerque Area Indian Health Board
epidirector@aastec.org

California Tribal Epidemiology Center
virginia.myers@crihb.net

Great Lakes Epidemiology Center
Great Lakes Inter-Tribal Council
<http://www.glitc.org/epicenter/>

Navajo Tribal Epidemiology Center

Northern Plains Tribal Epi Center
Aberdeen Area Tribal Chairman Health Board
<http://www.aatchb.org/epi/>

Inter-Tribal Council of Arizona Epi Center
<http://www.itcaonline.com>

Northwest Tribal Epi Center
Northwest Portland Area Indian Health Board
epicenter@npaihb.org

Rocky Mountain Tribal Epi Center
<http://www.mtwytlc.com/rockymountaineypi.htm>

Southern Plains Inter-Tribal Epi Center
Oklahoma City Area Inter-Tribal Health Board
<http://www.ocaithb.org>

United South and Eastern Tribes
Tribal Epidemiology Center
<http://www.usetinc.org>

REFERENCES

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- ² Laura Oropeza, *Clinician's Guide: Working with Native American Living with HIV (2002)*. National Native American AIDS Prevention Center.
- ³ John Poupart et al, *To Build a Bridge: An Introduction to Working with American Indian Communities (2001)*. American Indian Policy Center.
- ⁴ U.S. v. Winans, 198 U.S. 371 (1905); Lac Court Oreilles v. Voigt, 700 f. 2d 341 (1983); Lac du Flambeau v. Stop Treaty Abuse, 991 F. 2d 1249 (1993).
- ⁵ U.S. Constitution, Art. 1, sec. 8, clause 3
- ⁶ Johnson v. McIntosh, 21 U.S. 543 (1823).
- ⁷ Cherokee Nation v. Georgia, 30 U.S. 1 (1831).
- ⁸ Worcester v. Georgia, 31 U.S. 515 (1832).
- ⁹ 18 U.S.C. Sec. 1162; 28 U.S.C. Sec. 1360.
- ¹⁰ ACTIVITIES TO ADDRESS HIV/AIDS IN NATIVE AMERICAN COMMUNITIES. National Alliance of State & Territorial AIDS Directors (NASTAD): Native American Report – November 2004: Washington, DC.
- ¹¹ www.ihs.gov website.
- ¹² Centers for Disease Control and Prevention, Sexually Transmitted Disease Surveillance, 2006 Atlanta, GA. Department of Health and Human Services.
- ¹³ Walters, K.L., and Simoni, J.M. (2002) Reconceptualizing Native Women's Health: An "Indigenist" Stress-Coping Model. *American Journal of Public Health*. 92(4): 520-524.
- ¹⁴ Rowell, Ronald and Paul Bouey. (1997, April) Update on HIV/AIDS Among American Indian/Alaska Natives. *The IHS Primary Care Provider*. 22(4): 49-53.
- ¹⁵ Vernon, Irene S. (2001) *Killing Us Quietly: Native Americans and HIV/AIDS*. Lincoln: University of Nebraska Press.
- ¹⁶ Rowell, R. *HIV prevention for gay/bisexual/two-spirit Native American men: A report of the national leadership development workgroup for gay/bisexual/two-spirit Native American men*. Oakland, CA: National Native American AIDS Prevention Center, 1996.
- ¹⁷ U.S. Commission on Civil Rights. A quiet crisis: Federal funding and unmet needs in Indian country. Washington, DC: GPO, 2003.
- ¹⁸ Vernon, I. S. "Violence, HIV/AIDS, and Native American women in the twenty-first century." *American Indian Culture and Research Journal* 26, no. 2 (2002): 115-133.
- ¹⁹ Nakai, Anno. (n.d.) Building capacity for HIV/STD prevention in Native American communities (American Indian/Alaska Native/Native Hawaiian).
- ²⁰ Elm, Cissy. (2003, November) Presentations and interview during New York State HIV Prevention Planning Group Meeting. Elm is with the American Indian Community House.
- ²¹ Dunning, Ken. (2003, November) Historical underpinnings. Presentation made at New York State HIV Prevention Planning Group Meeting. Dunning is with the American Indian Community House.
- ²² Green and Kreuter, *Health Promotion Planning, An Educational and Ecological Approach*, 1999
- ²³ Barney, DD; Duran, BES & Rosenthal, C. (2004). HIV/AIDS care programs for American Indians and Alaska Natives. In E. Nebelkopf & M. Phillips (eds.): Healing and Mental Health for Native Americans. Walnut Creek, CA: Altamira Press. Pp. 149-158.
- ²⁴ Burhansstipanov, L. Native American Community-based Cancer Projects: Theory Versus Reality. <http://www.moffitt.usf.edu/pubs/ccj/v6n6/dept7.htm>
- ²⁵ Norton, IM & Manson, SM (1996.) Research in American Indian and Alaska Native communities: Navigating the cultural universe of values and process. *J Consult Clin Psychol* 64(5): 856-60.

APPENDICES

Appendix A: List of Federally Recognized Tribes

Appendix B: State-Tribal Relations

Appendix C: Contact Information for the 10 Tribal Area Health Boards

Appendix D: Protocol for Working with Tribes

Federally Recognized Indian Tribes

Please see the American Indian Policy Center's website for a list of Federally recognized Indian tribal entities within the contiguous 48 states:

<http://www.airpi.org/pubs/fedrecog.html>

This is the Bureau of Indian Affairs list of Indian entities recognized and eligible to receive services from the United States Bureau of Indian Affairs. Updated November 13, 1996. For further information, contact Daisy West, Bureau of Indian Affairs, Division of Tribal Government Services, MS-4641-MIB, 1849 C Street NW, Washington, D.C., 20240.

State-tribal relations¹

The devolution of congressional authority to the states in the last two decades has impinged on the government to government relationship Indian tribes have with the federal government.

In the early '80s, Ronald Reagan's policy of New Federalism began the trickle-down of regulatory and taxation authority to the state level. Despite Democratic control of the White House, that trickle has become a torrent.

From the state government's frame of reference, it doesn't make sense that the state can't assume regulatory and taxation authority over Indian country, just like every other area.

Conflicts over resource management, taxation and regulation erupt because state governments fail to understand or recognize the sovereignty of tribes. The U.S. Supreme Court clearly defined the relationship between Indian tribes and state governments in 1832. In *Worcester v. Georgia*, Chief Justice Marshall wrote, "The Cherokee Nation, then, is a distinct community, occupying its own territory, with boundaries accurately described, in which the laws of Georgia can have no force, and which the citizens of Georgia have no right to enter, but with the assent of the Cherokees themselves, or in conformity with treaties, and with the acts of congress. The whole intercourse between the United States and this nation, is, by our constitution and laws, vested in the government of the United States."

The framework set forth in this case (and two others that comprise the Marshall trilogy) make it clear that states are specifically excluded from relationship between two sovereign nations. These cases echo the constitution which specifically prohibits any state from entering into a treaty with another nations, and, through the commerce clause, gives congress the sole authority to deal with Indian nations. That a state government would try to exert taxation or regulatory authority over an Indian nation makes no more sense than if that same state government tried to tax Canada.

It is clear that the governments closest to Indian tribes need the most education. State government jealousy and resentment over casino revenues often cloud a clear point of view.

In small group discussion to address tribal-state relations, gaming kept surfacing. According to moderator Roy Taylor, gaming "takes us back to the ignorance displayed by all the players. This ignorance is based on racism, bigotry, power, etc. Because gaming is revenue related, it is the reason for its continued surfacing."

¹ www.airpi.org website.

The missing element, according to Taylor, is governance in an appropriate manner.

It is up to us to inform the general public. Our Congress has to be educated and needs to become even more knowledgeable about Native Americans in order for us to get their help, said Lorraine Rosseau, former tribal chair from South Dakota. Rosseau encouraged the group to go back to their homelands and to do something.

There is still a "Hollywood" image of Native Americans left from the '50s and '60s. This ignorance and negative view needs to be counteracted, one woman said.

Native Americans must out organize and communicate to survive and prosper. With a strategic plan, Native Americans can become more proactive, another participant said. She added that Native Americans must invite all, like in native tradition. We must offer gifts and talk over dinner with the hope that this will enhance the relationship.

Area Health Boards

The Area Health Boards serve as the communication link between the NIHB and the tribes. Area Health Boards advise in the development of positions on health policy, planning, and program design. They gather information and review public opinion and proposals. In areas without an Area Health Board, the NIHB representative communicates policy information and concerns to the tribes in that area.

The ten Area Health Boards include: Aberdeen Area, Alaska Area, Albuquerque Area, Billings Area, California Area, Nashville Area, Navajo Area, Oklahoma Area, Phoenix Area, and Portland Area.

The two areas served by tribal appointments are: Bemidji Area and Tucson Area.

Aberdeen Area

Aberdeen Area Tribal Chairmen's Health Board
1770 Rand Road
Rapid City, SD 57702
Phone: (800) 745-3466 or (605) 721-1922
Fax: (605) 721-1932

Alaska Area

Alaska Native Health Board
Lorena Skonberg
3700 Woodland Drive, Suite 500
Anchorage, AK 99517
Phone: (907) 743-6106
Fax: (907) 563-2001

Albuquerque Area

Albuquerque Area Indian Health Board
Marianna Kennedy, Director
5015 Prospect Avenue N.E.
Albuquerque, NM 87110
(505) 764-0036
Fax: (505) 764-0446

Billings Area

Montana-Wyoming Area Indian Health Board
Gordon Belcourt, Executive Director
207 North Broadway, Suite BR-2
Billings, MT 59102
(406) 252-2550
(406) 254-6355

Bemidji Area

No Appointment

California Area

California Rural Indian Health Board
James Crouch, Executive Director
4400 Auburn Boulevard, Second Floor
Sacramento, CA 95841
Phone: (916) 929-9761
Fax: (916) 929-7246

Nashville Area

United South & Eastern Tribes
Michael Cook, Executive Director
711 Stewarts Ferry Pike
Nashville, TN 37214
Phone: (615) 872-7900
Fax: (615) 872-7417

Navajo Area

Navajo Nation Division of Health
Anslem Roanhorse, Jr., Director
P.O. Box 1390
Window Rock, AZ 86515
Phone: (520) 871-6350
Fax: (520) 871-6255

Oklahoma Area

Oklahoma City Area Inter-Tribal
Health Board
Allan Harder, Executive Director
P.O. Box 57377
Oklahoma City, OK 73157
Phone: (405) 951-3965
Fax: (405) 951-3902

Phoenix Area

Inter Tribal Council of Arizona, Inc.
John Lewis, Executive Director
2214 N. Central Avenue Suite 100
Phoenix, AZ 85004
Phone: (602) 258-4822
Fax: (602) 258-4825

Portland Area

Northwest Portland Area Indian
Health Board
Joe Finkbonner, Executive Director
527 SW Hall Street, Suite 300
Portland, OR 97201
Phone: (503) 228-4185
Fax: (503) 228-8182

Tucson Area

No Appointment

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

Cultural Competence: What Is Needed in Working With Native Americans With HIV/AIDS?

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American Indian and Alaskan Native (AI/AN) people have a unique culture that is misunderstood by many health care professionals. There are nearly 2.5 million AI/ANs living in the United States in 300 different tribal or language groups and governed by 569 different tribal governments (U.S. Census Bureau, 2002). The myriad of ethnicities within the population labeled AI/AN or Native American makes it difficult to identify the scope of the HIV/AIDS problem under today's system of classification. Throughout the evolution of the health care system, AI/AN populations have experienced, as have other minorities, less than adequate attention with regard to specific and culturally appropriate treatment and prevention programs (Dickey, Tafoya, & Wirth, 2003). Perhaps nowhere is this more evident than in the area of HIV/AIDS prevention and treatment.

In 2000, then-U.S. Surgeon General David Satcher issued a call for action on the HIV/AIDS crisis in AI/AN communities. He stated an urgent need among Native communities as well as federal and state organizations and community health care providers to work together in an effort to fight the HIV/AIDS epidemic and to bring awareness to community members (Satcher, 2000). According to the Centers for Disease Control and Prevention (CDC, 2002), as of December 2002, there were 2,875 AIDS cases among AI/ANs. However, although the actual number of reported HIV/AIDS cases among Native Americans is relatively low, in this small population, the number is alarming. The number of AIDS cases

has doubled among this population within the last 5 years (CDC). In the period from 1996 to 2002, AIDS incidence decreased markedly among Whites, Blacks, Hispanics, and Asian/Pacific Islanders but increased among AI/ANs (CDC). During that same time period, the number of deaths from AIDS also declined among all racial groups except AI/ANs (CDC).

Many health professionals estimate the number of AIDS cases among AI/ANs to be much higher than what statistics are currently reporting and that the number of HIV cases could be as much as 10-times greater (Satcher, 2002). For example, a study of drug treatment patients conducted from 1991 to 1994 in New York City showed that the number of Native Americans testing positive for HIV was comparable to that of African Americans (Walters, Simoni, & Harris, 2000). This may indicate higher rates of HIV among AI/ANs within certain geographical populations.

As with other minority populations, there is still a great stigma associated with HIV/AIDS within AI/AN communities. Among AI/ANs, concerns over confidentiality are evident because of the close-knit communities in which they live and the tremendous

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stigma of homosexuality. Many AI/ANs are not seeking testing for HIV because of this concern. As a result, underreporting of HIV among this community remains high. In addition, many Native Americans are misclassified by health care providers as Hispanic, Caucasian, African American, or Asian. During data reporting, this misclassification skews the statistics of the AI/AN population, resulting in underreporting of HIV/AIDS cases.

Risk Factors

Despite reporting inconsistencies, it is important to recognize that HIV/AIDS is a significant burden among the AI/AN population. In addressing this burden, it is important that health care providers understand the unique risk factors and barriers affecting this population and develop the ability to overcome any obstacles in the process.

The AI/AN population is disproportionately affected by many of the social and behavioral factors associated with increased risk of HIV infection. Weaver (1999) notes that high rates of sexually transmitted diseases among Native Americans may serve as an indirect measure of high-risk sexual activity. In 2001, rates of gonorrhea were 3.9 times higher in the AI/AN population than in Whites (CDC, 2002). In fact, in 2001, rates of gonorrhea among AI/ANs increased another 5.2; Hispanics were the only ethnicity who had a more significant increase. The percentage of women 15 to 30 years of age screened at clinics of the Indian Health Service testing positive for chlamydia ranged from 3.1% to 10% that same year.

According to statistics compiled by the National Campaign to Prevent Teen Pregnancy (2004), AI/AN high school students are more likely to have had sexual intercourse and have higher teen birth rates than the national average, and AI/AN female students were less likely to have used condoms during their last sexual encounter. Each of these factors makes this population more at risk for contracting HIV.

Domestic violence also raises concern within the AI/AN culture. Various health agencies working with AI/AN girls and women report rates from 46% of their clients having been physically abused to 60%

of their pregnant clients currently being with an abusive partner. One agency working with an Apache reservation reported that up to 75% of its clients had been abused (Hamby, 2000). Each of these circumstances places women in a situation in which they are powerless to demand protective contraception during intercourse, thus placing them at risk of exposure.

Another contributing risk factor for HIV infection is alcohol and substance abuse. LaBrie and Earleywine (2000) reported that an initial review of studies attempting to correlate alcohol use and risky sexual behavior were mixed. However, their study involving 346 college students (using a survey instrument that does not require participants to answer sensitive questions directly) reported that indeed alcohol consumption had a clear impact on risky sexual behavior. Additionally, Kalichman, Weinhardt, DiFonzo, and Austin (2002) further reported alcohol use outcome expectancies, and alcohol used in sexual contexts was closely associated with unprotected sexual intercourse. Alcohol and substance abuse have long been challenges for AI/AN populations. According to Hanson and Venturelli (1998), in a 1995 study of college students and drinking, Native American students had the highest frequency of drinking episodes, binge drinking, and memory loss related to alcohol. Shaughnessy (2003) noted in a study of AI/AN students who attended schools funded by the Bureau of Indian Affairs that 80.7% of the students reported lifetime alcohol use, 48.8% reported current use, and 38.4% reported episodic heavy drinking.

Socioeconomic factors also play a role in health status for this population. According to the Population Resource Center (2003), only 538,300 AI/ANs live on reservations or land trusts. Of all races, the lowest percentage of AI/ANs, approximately 66%, live in metropolitan areas. As such, many live in rural areas where access to health care services is often limited. The poverty rate for AI/ANs between 1998 and 2000 was 26% higher than all other racial or ethnic groups (Population Resource Center). This also corresponds to health care access in that transportation issues may make it difficult to access whatever health care resources are available. Poverty rates also affect nutritional status, not only in the potential availability of food products but also in the types selected. For example, fresh fruit, which is high in

nutritional value but also higher in price, may not be an option on a limited income.

Nationally, 83% of the population at large have received a high school diploma and 26% have attained a bachelor's degree. Among the AI/AN population, those numbers are 71% and 14%, respectively (Population Resource Center, 2003). Education levels affect job opportunities and earning potential. Because the AI/AN population has a much lower level of education, the cycle of poverty issues is perpetuated.

Barriers

Cultural barriers, both within the AI/AN population and the general public, prevent effective dissemination of information on the topic of HIV/AIDS and the risk factors associated with its transmission (Dickey et al., 2003). Historical context is important in understanding the reticence expressed by many AI/AN people in accessing any government health care system or program offering assistance or education. Just as the Tuskegee Experiment led to distrust of health care providers and government officials among members of the African American community, history depicts how U. S. government policy has affected the trust of Native American communities by explicitly and implicitly depriving AI/AN people of their rich culture, traditions, language, spirituality, and extended family and social systems (Vernon, 2001). The suppression of AI/AN religion by the government led to the loss of valuable traditional knowledge including medical and healing practices. It was once illegal for Native Americans to even practice their traditional religion, and those who did were fined or jailed. The ban on American Indian religion was not officially lifted until the American Indian Religious Freedom Act of 1978.

In 1886, a U.S. government commission mandated the formation of boarding schools for AI/AN children under the direction of the Bureau of Indian Affairs. Additionally, during this time many Christian boarding schools for Native American children were also developed. Many of these children were forcibly removed from their families and placed in schools in which they were often forbidden to speak their native language. The children lost their free-

dom, their families, and their culture. Tribal lands were confiscated, and many tribes were exploited for their various skills. As a result, a foundation of trust continues to be a tremendous obstacle for many in the AI/AN community (Vernon, 2001). Because of this history of neglect and deception, AI/ANs may be hesitant to seek health services from non-Native providers. In addition, the patient-provider relationship, effective communication, and treatment adherence may also be compromised, affecting the quality of care received by AI/AN patients. If the patient does not trust the provider based on the previous cultural history discussed, then the relationship between the two parties is compromised. Whatever treatment protocols or directives for adherence the provider is recommending may be looked at with skepticism and mistrust.

What Can Be Done?

Providing health care professionals with avenues to achieve culturally competent health care practices is especially vital amid the current effort to eliminate health disparities. Among the AI/AN population, these disparities are because of (a) the lack of culturally specific training of health care professionals and health administrators serving these populations, and (b) the lack of funding provided for program development, data determination, and research (Dickey et al., 2003).

Many people, including health professionals, believe that most AI/ANs live on reservations. As stated previously, health care providers need to be aware that today, approximately two-thirds of the 2.5 million AI/ANs live in urban areas and receive health care in urban clinics/hospitals and other urban health service organizations (U.S. Census Bureau, 2002). Although the degree to which all of those individuals maintain the practices of their Native American culture is unknown, it is safe to assume that most, if not all, would take note of a provider's cultural sensitivity with respect to care and treatment.

Approximately half of AI/ANs live in the eastern United States. Many have no choice but to receive care from non-Native health care providers because of the lack of Native Americans working in the health care field. With the immense confidentiality

issues present on reservations and in tribal clinics, many Native Americans choose to travel off the reservation for HIV testing and care.

All over the country, physicians, nurses, social workers, and community leaders are confronting situations in which cultural backgrounds are influencing health care, and often in a negative way, particularly with respect to HIV care. Cultural differences affect who participates in health care and the quality of that health care as well as adherence to medications and patient satisfaction. All of these factors indicate a need for effective risk reduction strategies, especially HIV prevention strategies (Dickey et al., 2003). Complicating such efforts with regard to AI/AN, many providers may not know that they are providing care to Native Americans simply because they do not ask the ethnicity or cultural background of their patients/clients. Knowing the racial or ethnic background of patients/clients is not only important for understanding cultural characteristics but is also imperative for providing the highest quality of care.

Program Design

For any AI/AN health care program to be successful, it should be designed not only from the basis of Native American teachings but also from the basis of specific community culture, being certain to involve those communities, groups, or organizations in the planning and design of the program. Because of the existing stigma of HIV/AIDS and issues of confidentiality within Native American communities, it can be useful to incorporate HIV/AIDS education with other training programs to increase the dissemination of this important material (e.g., collaborating with diabetes education, alcohol and substance abuse programs, prenatal classes).

It is important for health care professionals to adopt culturally competent approaches to care in an effort to increase the quality of care received by AI/AN patients. A range of skills is involved in effective cross-cultural care giving, including developing alliances with patients, gathering of cultural information, discussing culturally sensitive issues, and negotiating a culturally appropriate intervention/treatment care plan. When health care professionals lack these skills, service becomes less than adequate.

Clients in crisis from the stress of medical illness often fall back on culturally defined modes of coping with illness and cultural conflicts.

Although customs may vary by tribe, some suggestions for enhancing care and treatment services for Native Americans include:

- Increase awareness among health care providers regarding the importance and impact history has had on the Native American culture and how that negative influence has created barriers to health care and services.
- Encourage health care professionals to be respectful of traditional approaches to healing and to refrain from judgment about traditional ceremonies and medicines.
- Allow the client to determine how much to share about his or her traditional practices.
- Communicate support and acknowledge traditional approaches and teachings that the patient/client values (e.g., smudging ceremonies that seek to cleanse negativity from the physical and spiritual body) and discuss ways to integrate traditional approaches or teachings into treatment services and action plans.
- Become familiar with communication styles of AI/AN people (e.g., eye contact, direct vs. indirect questions, conversation vs. talking to patients) and how differences in communication styles, if not fully understood, may lead to misinterpretation.
- Identify an AI/AN community member who is willing to serve as a cultural consultant for your organization.
- Attend or request AI/AN cultural training for your staff. Depending on the area of the country, training may be available through local tribal communities; the American Red Cross, which has a specific HIV training program for working with Native Communities; or the National AI/AN Provider Training Initiative, which is a part of the Department of Health and Human Services.

Available Resources

Recognizing the need for further training and education regarding cultural practices when working with AI/AN clients is the first task. The next is to

seek expertise in the subject. Depending on the area of the country in which health care providers are located, the opportunity for locating trainers in the area may be limited.

A curriculum entitled, *Changing Directions: Strengthening the Shield of Knowledge* (Dickey et al., 2003), is designed to empower non-Native providers and educators with information and support that builds respect and appreciation for Native people, as well as a deeper understanding. In this way, non-Native professionals can enhance the delivery of culturally competent healthcare including HIV services. This curriculum explores Native American culture in such a way that non-Native HIV providers and educators will come to understand how the experience of being Native American influences and shapes Native people's ability, desire, and comfort level in accessing and using HIV services in particular.

The goal of the curriculum is to provide health care professionals with information and opportunities for skill development in an effort to increase the quality and effectiveness of HIV/AIDS prevention, care, services, and treatment received by Native American people. Additionally, the curriculum is designed to increase providers' understanding and knowledge of Native American people and culture and to explore attitudes, approaches, and skills that foster the development and delivery of culturally competent HIV/AIDS care in both Native American communities and urban centers around the country. By varying the approach, interventions, and/or programs to incorporate Native teachings, health care professionals can increase both the number of Native Americans they serve and the effectiveness of their effort.

The Next Step

Acknowledging the issues surrounding HIV/AIDS care and treatment for AI/AN is only the first step toward improving the care received by this population. Working to eliminate the health disparities of AI/AN people requires understanding, education, and training. Additionally, it requires caregivers and practitioners to look beyond the physical ailments of their patients. It requires knowing how a patient's culture or background impacts his or her adherence

and attitude. A holistic approach to health care is essential in providing the highest quality of health care to AI/ANs. It is beneficial for nurses, who are often the frontline practitioners, to understand the importance of developing a trusting relationship with AI/AN patients and to identify needed differences in their approach to this population. These aspects of care are often the foundation for improving health outcomes among this population. Health professionals from all disciplines should be making concerted efforts to address cultural differences that often impede the progress of improved health care among the AI/AN population.

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Working with High Risk Subpopulations in Native Communities

Gay/Bisexual/Two-Spirit Native American Men

Despite traditional teachings in many tribes that do not condemn homosexuality, contemporary Native American communities often show much the same range of attitudes found in the United States as a whole, from outright hostility and violence to indifference and acceptance. Yet, Native American men who have sex with other men remain the highest risk group for HIV infection. Overall, there is a lack of HIV prevention programs in Native American communities that target gay/bisexual men, especially in rural communities. Two prevailing attitudes explain this gap in services: “We don’t know of any people like that in our community,” and “I would not be comfortable working with gay men because of my religious beliefs.” Any HIV prevention program that targets the Native American community must include efforts to reach this population.

Not all Native American men with a same-sex sexual orientation are acculturated into the gay urban mainstream subculture. They may have grown up close to their own tribal traditions, usually those living in a reservation setting, and their identity is rooted there. They may, or may not be accepted or at least tolerated by their community, yet feel at home there, and are reluctant to leave. On the other hand, there are Native American men who have grown up in urban settings, or have chosen to leave their rural homes, whose sexual orientation is same-sex, and who have assumed an urban gay identity who may or may not have knowledge of their specific ethnic and tribal traditions. It is important to accept the complexity of various identities among Native American men who have sex with other men and include their input in developing strategies to prevent the spread of HIV in this target population.

How these men view themselves from the inside out is critical information for those working in HIV prevention with this population. It may also suggest possibilities for promoting better mental and physical health overall and provide clues to improve outreach and access to this target population. The following are comments from a group of gay/bisexual/Two-Spirit individuals who participated in a NNAAPC work group convened to develop relevant social marketing messages to target this population.

The Navajo people do not really recognize the gay people except from a traditional point of view. So that was where I was trying to appreciate the difference between the modern gay and a traditional type of gay person...There is such a think as two gay persons who have a relationship that have sex reverse roles with one another...[We were] saying that...we’re only recognized as a woman in our relationship, and the man plays on the man’s role, and we only play the woman’s role, and we never cross...My mother always talked to me, and of course, she was very supportive of me as a gay person...She always tells me, ‘If I ever come to your house, I don’t want to see that man cooking or cleaning the house. This is your responsibility as a woman. This is what you wanted and what you got yourself into, and now you need to practice that...and your man’s responsibility is outside the house, from the door outside.’

For myself, as far as being a Native American gay male, I get a lot of my support from my family, and I think that’s more important to me than anything else...My mom has

always taught me that you go on your own, don't listen to anybody else...what you make of yourself is what you're going to be. And you can't let people tell you what you have to be. And so that was one of the traditional teachings I've had and that I talked about.

A lot of us felt that the *berdache* term for *gay*...Native American Indians...[wasn't] a good [word] to use because of where it came from...The root of the word came from Persia and that area, meaning...a male prostitute or a male person kept for sexual purposes.

The question of the use of the *two-spirit* term and identity is, I think, an important one, because there's a great deal of confusion and, in some cases, resentment against the term. But the important thing to recognize about it is that it arose and began to gain currency for a couple of reasons – the first being that it came out of one of the early gatherings, the annual spiritual gatherings for gay/lesbian Native people, and this was either 1990 or in the early 1990s...We heard from a medicine person from the Eastern Doorway of the Anishnabe people, and it was explained that the *two-spirit* comes out of the Algonquin dialect...*niizh manitoag*...*manitoag* means spirits and *niizh manitoag* means *two-spirits*...There are a couple of different explanations, but perhaps the clearest came from one of the people from the spiritual community in the Winnipeg area...The explanation for that culture is that it refers to the fact that each human being is born as a result of the union between a male and a female, and so every living human being carries both of those qualities of masculinity and femininity. Except in some individuals, both of those characteristics are simultaneously manifested in terms of...qualities or ways of presentation or behavior or interests.

That word [*two-spirit*] should not be translated into Native languages because that presents a totally different viewpoint. As an example, if I translated that concept from English into Navajo, of having two spirits in one body, one has to be living and the other has to be dead. So, it doesn't quite work.

We are distinct people...What applies to the greater dominant society does not and never has and never will apply to us. And so the best we've got for the moment is *two-spirit*...This is something we have for the time being...a shorthand, just like using the word *Native*, for all the terms that have always been used in all of our original languages.

Homosexual men in Native America do not always identify as “gay” in the terms of the modern urban mainstream gay culture. Self-identification is complex, with the range including those who have entirely and comfortably adopted a modern urban gay identity at one pole to those who have been raised in traditional tribal roles assigned to homosexual men at the other pole. Thus, assuming that a standard “gay approach” is based in urban mainstream gay experience is inadequate for organizing HIV prevention in Native American gay/bisexual/two-spirit men is out of step with the realities of Native American cultural diversity. Input from this population is essential in designing effective HIV prevention interventions.

Injection Drug Users (IDU)

Results of the 2005 National Survey on Drug Use and Health revealed that the rate of current illicit drug use was higher for Native American and Alaska Natives (12.8%) than among persons of other races and ethnicities. In both male and female Native Americans and Alaska Natives, a larger percentage of HIV/AIDS cases were associated with only injection drug use. Also, the percentage was higher for NA/AN men who have sex with men (MSM) and inject drugs. Furthermore, IDU-associated HIV/AIDS accounts for a larger percentage of cases among adolescents and adult women than men.

Comprehensive Harm Reduction education on injection drug use, must include education on how to prevent transmission of HIV through drug-related behavior and sexual activity which poses significant risk not only to the users, but to their sexual partners as well.

- Effective substance abuse treatment that helps people stop using drugs not only eliminates the risk of infection from sharing contaminated equipment, but, for many, reduces the risks of engaging in risky behaviors that might result in sexual transmission.
- For an injection drug user who cannot or will not stop injecting drugs, using sterile needles and syringes only once along with clean works remains the safest, most effective approach for limiting HIV transmission.
- An injection drug user who has never shared syringes will not get HIV from sharing syringes, but may still be at risk from sharing works, or from sharing pipes, or straws when snorting drugs.
- Sharing syringes allows a direct exchange of blood from one person's body into the bloodstream of another and is an efficient way to spread HIV and other blood-borne pathogens, such as Hepatitis B and C.
 - Injection drug users should be encouraged to take advantage of syringe exchange programs: also called Harm or Risk Reduction Programs if they exist in the area.
 - The North American Syringe Exchange Network maintains a list of some of the syringe exchange sites and referrals and can be accessed at www.nasen.org.
 - In many parts of the United States, sterile syringes may be purchased at local pharmacies without a prescription.
- Many rural reservations do not have pharmacies, outside the IHS clinic. This makes it particularly difficult for users to find clean syringes. Often the main source is from diabetic relatives or friends. When this is the case, the user should be encouraged to bleach their syringes after each use. Bleaching is not risk free! However, it is an important element for reducing the risk of becoming infected and should be done immediately before and after each use. The following are recommended procedures.
 - After each use and before using bleach, flush the syringe with cool water to rinse fresh or dried blood that may remain in the barrel.
 - Fill the syringe all the way up with undiluted bleach and shake in the syringe for a full two minutes. (Bleach will kill HIV after 30 seconds, but it takes up to two minutes to kill Hepatitis B.)
 - Discard the bleach and repeat.
 - Rinse the syringe two more times, shaking with water when you are finished to remove all of the bleach which can damage the veins.

- Rinse out your cooker with cool water then bleach for 2 minutes and throw water away. Remember not to ever share cotton, as it can not be cleaned.
- Other strategies for reducing personal risk while sharing syringes, are to always use the clean syringe first and to repeat the bleach procedure in between use by other partners.

Incarcerated Populations

The United States incarcerates more of its population than any other country. The disproportionate number of inmates of color has been well documented. It is estimated that the number of prisoners infected with HIV is 5 times higher than the general population. Current documentation indicates a higher infection rate among inmates of color, primarily among the African American and Hispanic populations. The infection rate among Native American prisoners is not readily available, but it can be assumed that there are Native American prisoners who are infected with HIV, if only because New York and Texas, states with large Native populations, rank second and third in the number of HIV infected inmates.

There is no consistent HIV testing policy among prisons and jails. Some states have mandatory testing upon entry into the institution, some upon exit, and many require the inmate to request the test and state the risk behavior that put the inmate at risk. Not all policies are consistently enforced, and many of the policies are, by their nature, barriers to inmates seeking to know their status. Some prisons segregate HIV prisoners from the general population, and some are required to wear armbands that identify them as HIV positive.

While many prisoners enter the system already infected, there are a number of risk behaviors occurring within the system, that indicate a variety of opportunities for infection. These behaviors include:

- Unprotected sex – either consensual or nonconsensual
 - Men who have sex with other male inmates
 - Any sex with male prison staff
 - Any sex with female prison staff
 - Any sex with visitors or prison volunteers
- Injection drug use
- Tattooing

Former inmates may be reluctant to discuss risk behaviors that occurred while they were incarcerated, because of the stigma attached to them. Nevertheless, this population should not be overlooked. It is not necessary to extract every detail of the behaviors that have put the individual at risk. The HIV test can be offered as part of the overall clinical or agency services.