



NASTAD™

NATIONAL ALLIANCE OF STATE
& TERRITORIAL AIDS DIRECTORS

NATIVE AMERICAN Report

NATIVE AMERICANS AND HIV/AIDS: KEY ISSUES AND RECOMMENDATIONS FOR HEALTH DEPARTMENTS

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INTRODUCTION

Native Americans had highly developed approaches to prevent illness and maintain health and wellness prior to contact with Europeans. There were well-established systems of traditional medicine, access to plants and animals for healing and to maintain adequate diets and social structure that, together with other factors, contributed to health and well-being. While still a strong part of Native American cultures, these systems have been systematically attacked and disrupted over hundreds of years.

Today, Native Americans¹ face profound health challenges, including HIV/AIDS. Yet despite significant attention to the health disparities faced by racial/ethnic minority populations, the unmet health and wellness needs of Native

Historical events with lasting repercussions mean there are complex issues health departments must understand in their work with Native American communities.

Americans are often overlooked. Although the overall numbers for Native Americans are small and often relegated to the "other" category for statistical purposes, Native Americans *are* impacted by HIV/AIDS, and in some states, they are the largest racial/ethnic minority population.

Historical events with lasting repercussions mean there are complex issues health departments must understand in their work with Native American communities. Health department staff often face numerous challenges in providing health and human services to Native Americans and may lack

¹ This Report generally uses the term "Native American" to refer to all tribal/aboriginal groups within the United States; in some places, the term "American Indian and Alaska Native" is used as well and is intended to refer to the same racial/ethnic minority group.



cultural competence and understanding of Native Americans in this country.

This report is intended to serve as a resource for health departments seeking to work with Native American communities to address existing health disparities, particularly those related to HIV/AIDS. To meet the needs of a national audience, this report is necessarily broad in scope. It leads with an overview of the historical underpinnings and key economic, social and health conditions and cultural amplifiers affecting

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Native Americans' HIV/AIDS risk, as well as examples of cultural values and strengths within Native American communities. An overview of how national and federal funds are distributed to address HIV/AIDS services for Native Americans is followed by profiles of several jurisdictions' work with Native American communities to provide HIV/AIDS services. Guidance from these health departments and recommendations from health departments and key Native American HIV/AIDS leadership are offered for health departments seeking to work more effectively with Native Americans. The report concludes with a series of recommendations and next steps for health departments

and NASTAD regarding providing HIV/AIDS services to Native American communities, followed by references/resources and other background information.

There are many excellent sources of information on the impact of HIV/AIDS on Native American communities. A review of these sources points to several factors to be considered when identifying priorities, determining funding allocations, crafting and funding HIV/AIDS care and prevention services, and working with Native American communities. The challenge is to avoid stereotyping, as each Native American tribe has a unique culture and characteristics, tribal governance, federal and state recognition status, etc. and no one tribe can speak for another. Therefore, the issues profiled in this report only scratch the surface of what to consider when working with Native American communities. Health departments must deliberately engage with each group in their state or jurisdiction to find out the unique issues that pertain to that tribe, nation or community.

NASTAD developed this report in response to its organizational priority to help health departments better address the HIV/AIDS epidemic among communities of color. NASTAD staff reviewed print literature and information available on-line and conducted key informant interviews with health department staff and representatives from national and local Native American agencies to help frame the issues. NASTAD selected the states to profile using convenience sampling.

Limitations: This is not an exhaustive inventory of work being done in Native American communities that may be sponsored or paid for through state and local health department HIV/AIDS programs. Nor does it adequately address all Native communities in the United States; Native Hawaiians are a significant omission that will be addressed in the future. Finally, to develop material



for a national audience detailing the issues and concerns around HIV/AIDS in Native American communities cannot possibly address the diversity of culture, custom, residence and tribal governance and sovereignty issues. This report, therefore, provides a general overview and some specific examples as means to spur thinking and action by health departments in addressing HIV/AIDS among Native American communities.

HISTORICAL UNDERPINNINGS

As with other communities of color, there are many “historical underpinnings” that influence HIV/AIDS risk among Native American communities. Understanding HIV/AIDS in Native American populations cannot be undertaken without understanding the cultural contexts in which Native Americans live, although summarizing 300 years of history will necessarily be incomplete. Historic relationships with the federal government and with U.S. health care systems have engendered a large degree of mistrust. Perhaps most illustrative as the reason for this mistrust is that, for a good portion of U.S. history, the U.S. policy towards Native Americans was summed up as “The Indian Problem.”

History and Tribal Governance

Early in the history of contact with Europeans, Native Americans were exposed to new diseases they had never before experienced, devastating many tribes and communities. In fact, there is evidence that through some early military campaigns and “trading” experiences with Native Americans, the relatively new U.S. government had an express policy of deliberate introduction of diseases like smallpox through infected trade blankets and/or provision of alcohol with the intention of creating dependency (Oropeza, 2002; Vernon, 2001).

Throughout the history of U.S.-Native American interactions, a complex

HIV/AIDS AMONG NATIVE AMERICANS

- Native Americans are impacted and at risk for HIV/AIDS in rural, reservation² and urban settings.

CDC surveillance data indicate that there were a total of 2,875 cumulative AIDS cases among American Indian/Alaska Natives (AI/AN) reported to the CDC through December 2002 (CDC 2003: table 3). Among states with confidential name-based HIV reporting, there were 962 HIV cases reported among AI/AN in 2001 (CDC, 2002b: table 8). Furthermore, the *rate* of AIDS among AI/AN is high: although not higher than rates for African Americans (76.4/100,000) and Latinos/as (26.0/100,000), the rate of AIDS among AI/AN (11.2/100,000) is higher than that for whites (7.0/100,000) and Asians and Pacific Islanders (4.9/100,000) (CDC 2003: table 5).

HIV/AIDS among AI/AN is both a rural and urban problem: an analysis of cases reported through December 1997 indicated that 68% of AI/AN persons with AIDS were in urban areas (metropolitan areas with more than 5000,000 people) at the time of diagnosis, although more AI/AN with AIDS lived in rural areas than others with AIDS (CDC, 1998).

When national data are presented by race/ethnicity, American Indian/Alaska Native cases look relatively insignificant compared to all others but Asian and Pacific Islanders because American Indian/Alaska Natives comprise a little more than 1% of the overall U.S. population (Ogunwole, 2002). However, when data are presented as rates for each population, i.e., HIV/AIDS cases per 100,000 American Indian/Alaska Native, etc., the impact of HIV/AIDS on Native Americans is much more evident (CDC, 2003: 14).

- Published data are not adequate for HIV/AIDS among Native Americans.

“While the actual numbers of HIV/AIDS among Native Americans are relatively low, in a small population they are alarming. Even worse, these numbers are conservative and do not reflect the true burden of the epidemic on the Native American community.” Michael Bird, Executive Director, NNAAPC (October 2003).

Because several states with large Native American populations (e.g., CA, NY, WA) have only recently begun HIV surveillance, there is a significant gap in information about the AI/AN most recently infected (Bertolli, et al., 2004). As Michael Bird, Executive Director of the National Native American AIDS Prevention Center (NNAAPC) said in testimony to the U.S. Commission on Civil Rights, these are only cases that are reported of those who come into the health care system. In his testimony, Bird also calls into question whether the Indian Health Service and tribal³ health

continued on page 4

² A reservation is technically defined as a tract of land reserved for a tribe “when it relinquished other land rights to the U.S. Government through treaties” (Oropeza, 2002). Tribes have a sovereign relationship with the U.S. government. “Reservation” is the most common term referring to the specific lands of federally-recognized tribes—other terms for the places where tribes live include rancherias, pueblos, reserves, etc. Many Native Americans do not live on reservations (or other designation for the land) and some non-natives live on reservations.

³ “Tribe” is used in this document to denote a specific group or community of Native Americans, usually defined by a combination of bounded territory, shared culture and language history.

systems are reporting HIV/AIDS, despite the fact that IHS is authorized to participate in state surveillance systems (Bertolli, et al., 2004). The “complex jurisdictional and capacity issues” that have resulted from policies towards AI/AN have led to “gray areas regarding authority and responsibility among tribal, state and federal public health agencies for surveillance and public health response on tribal lands” (Bertolli, et al. 2004:224).

- Misclassification is a problem in many areas that underestimates the impact of HIV/AIDS among Native Americans.

Underreporting and racial misclassification of American Indians and Alaska Natives is a problem across health related issues, with one study finding that Native Americans in general are undercounted by 38% nationwide (Burhansstipanov, 2000). The impact of this on a state-level may vary. For example, Alaska has not found this a problem (Cordes and Bell, 2003). However, although Bertolli, et al. said the contribution of misidentification of race/ethnicity to underestimation of HIV/AIDS is unclear (2004:234), they do cite a considerable body of research that has raised this as a significant concern, as have others (Nakai, 2003; Rowell and Bouey, 2002). Bird notes that “after generations of discrimination and acculturation, many Natives either self-identify as White or Hispanic or are misclassified as such by service providers” (2003:3).

- Aggregation obscures risk.

Lumping Native Americans into an “other” category with other racial/ethnic minorities (usually Asian/Pacific Islanders), or in some cases into one overall American Indian/Alaska Native category, can create problems in identifying communities most at risk for HIV/AIDS. In some cases, overriding concern about breaches in confidentiality with small sample sizes is the rationale and may be a limitation. However, this masks the impact of the epidemic on Native Americans, who, with over 500 distinct tribes, are very diverse. “This problem with small numbers of cases affects surveillance for AI/AN populations and creates a paradox for health administrators and tribal leaders as there is a clear need for data to monitor health status, including HIV/AIDS, at a local community level” (Bertolli, et al., 2004:225).

series of legal decisions and governmental policies towards Native Americans have changed the landscape of tribal governance. Throughout this history, two different interpretations of a key concept in Native American governance—sovereignty—have held sway in these policies and legal decisions. Sovereignty is the concept that Native American tribes are sovereign entities that can operate as independent, foreign nations. One interpretation is that tribes have inherent powers of sovereignty that predate the “discovery” of America. In

opposition is the interpretation that tribes have only limited sovereignty given by Congress (Olson-Raymer, n.d.). These interpretations were used by the United States government to set up and/or break treaties and trust relationships with various Native American tribes. In many cases, these policies were extremely paternalistic, if not outright genocidal, towards Native Americans.

Express U.S. policy towards American Indians in the contiguous United States was reviewed by Ken Dunning and others for the New York

Throughout the history of U.S.-Native American interactions, a complex series of legal decisions and governmental policies towards Native Americans have changed the landscape of tribal governance.

State HIV Prevention Planning Group during a plenary presentation in November, 2003. Dunning shared an excellent on-line history published by Humboldt University. The following is a brief synopsis of U.S. policies towards Native Americans. The terms used to describe these policies are extremely telling.

19th Century: Removal and Assimilation

In the 1800’s, the U.S. policies towards Native Americans were referred to as: Removal, Reservations, Allotment and Assimilation, and Elimination. During this era, many Native Americans were removed from their lands, most notably the Cherokee, who were forcibly moved from North Carolina to Oklahoma during the “Trail of Tears.”

Reservations were specific geographical tracts of land set aside to control and confine Native Americans. This was further refined into the allotment and assimilation policies to further “detritalize [Native Americans] by destroying the idea of communal land ownership on the reservations” (Olson-Raymer, n.d.). The often remote and isolated reservation lands have created challenges for economic stability and problems associated with high unemployment, welfare dependency and health issues. While dubbed “reservations” by the U.S. government (i.e., where land was “reserved” for a specific Indian tribe), use of the term reservation or some other term denoting place is not



always used by the Native American tribes that live there. Instead, many Native Americans call their tribe and the place where they live a “nation,” as in the Navajo Nation or Onondaga Nation rather than a reservation. In fact, some Native American communities do not recognize U.S. citizenship. The Iroquois, or Haudenosaunee, issue their own passports (NALCHA, 1995).

Assimilation was also a key strategy to control Native Americans and wrest resources and land from them. One of the key tools in this strategy—one that has had a devastating impact on Native Americans and still reverberates today—is the boarding schools. In the mid 1880’s, the Bureau of Indian Affairs (BIA) initiated boarding schools, many of them Christian oriented, that were intended to assimilate Native American children in the Western tradition and replace their Native languages with English.

In essence, this policy was meant to “acculturate” Native Americans by removing children from their families and culture and teaching them to reject their

Native cultures (NMAC, 1999; Oropeza, 2002; Vernon, 2001; New York State HIV PPG Presentations, November 2003). Indian children were disciplined for speaking their Native tongues or expressing any form of their Native cultures (Oropeza, 2002). Families were forced to send children to boarding schools far from their communities and the experience for these children was very traumatic. They lost connections to their native culture and communities, language and social organization, as well as basic familial skills such as parenting. (Ironically, BIA boarding schools that exist today are instead focused on preserving Native American culture.)

Elimination was simply war against Native American tribes. “The rationale for eliminating Indians grew out of a belief that Indian resistance was equivalent to a declaration of war against the U.S.” (Olson-Raymer, n.d.: 6). This was the era of the military campaigns in the West that culminated in the Battle of Little Bighorn with General Custer. By the end of the 1800s the Native American population had decreased

from between 6-10 million at the time of the nation’s birth to less than 250,000 and their land had been decreased in similar fashion from 138 million acres to 48 million acres (Olson-Raymer, n.d.).

20th Century: Reorganization and Termination

While the 20th Century saw some changes in U.S. policies towards Native Americans that were purportedly intended to right past wrongs, these policies were often extremely paternalistic and continued to break down Native American sovereignty and culture. The policies were known as Reorganization, Compensation and Termination, and Self Determination. Native Americans were not allowed to vote until 1924, when the U.S. Congress passed the Indian Citizenship Act to extend citizenship and voting rights to American Indians. Also, the Indian Civil Rights Act of 1968 provided constitutional protection to American Indians living under tribal self-governance (Olson-Raymer, n.d.).

Government reports published in the early 1900’s led to the reorganization of the U.S. Bureau of Indian Affairs (BIA). The 1934 Indian Reorganization Act (IRA) attempted to reorganize tribal government based on a Western, democratic model, which supplanted traditional governmental organization. In many cases, the BIA enacted tribal councils and appointed leaders wholly outside of local, tribal processes. In many places, this has resulted in competition and conflict among Native Americans within a tribe.

According to the Law Alliance, “While the IRA (Indian Reorganization Act) may have been proposed with the best of intentions, its results have been destructive for many Indian nations. It has led to conflicts of political and social government between the traditional and the Bureau of Indian Affairs (BIA) tribal councils. In today’s

HISTORICAL UNDERPINNINGS: KEY THEMES

- 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. However, not all Native American tribes recognize this trust responsibility and some actively reject it.
- 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.

context, any work done on Indian territories must be aware of this situation" (NACHLA, 1995:33).

Through Compensation and Termination, the U.S. government sought to compensate tribes for their losses through the Indian Claims Commission. This policy often created more internal strife within tribes. Termination sought to eliminate the federal government's historical trust responsibilities to several Indian nations. Known as Public Law 280, the U.S. "terminated" federal recognition of tribes in California, Oregon, Minnesota, Wisconsin and Nebraska. These tribes were then only subject to state jurisdiction (Olson-Raymer, n.d.). California was not part of the public health model for Native Americans through the IHS until they filed a class action suit known as the Rincon Decision (1974) (Pierce-Hedge, 2003). The suit charged that the IHS had not provided California Indians with health care comparable to that provided in other states. The U.S. district Court in San Francisco agreed. In 1975, California was the first state to supplement federal Indian Health money (Heizer, 1978: 126; *Sacramento Bee*, September 7, 1981).

Another key aspect of the "termination" policy was relocating Native Americans to urban locations. Intended to separate Native Americans from their cultural roots and communities, the Urban Relocation Program began in the 1950's and offered Native Americans the opportunity to leave their tribes and relocate to major cities with promises of better jobs and housing. These promises did not always meet expectations, and many Native Americans found themselves without any support system in these cities (Oropeza, et al., 2001; Oropeza, 2002). Since the 1950's, this migration to urban areas in search of better economic opportunities has impacted the community support that is traditionally a protective factor in Native

American communities (Day, 2003). In cities like New York, places like the American Indian Community House were formed to help provide services and community "home" for Native Americans who had migrated to the cities from tribes all over the U.S. (NALCHA, 1995).

From 1963 to 1989, a policy of Self Determination was intended to protect Native Americans' rights and increase their political and economic affairs self-sufficiency. While this did help in many respects, it did not help further clarify the competing concepts of sovereignty or settle how states and the federal government related to tribes.

The Present: Self Governance

Presently, the concept of Self-Governance has been advanced as a means to assert Native Americans' greater governance over their own affairs. In 1994, President Clinton said that the U.S. would operate in a government-to-government relationship with federally-recognized tribes. According to U.S. law, "states cannot interfere with self-government powers of federally-recognized tribes" (Olson-Raymer, n.d.: 25), although this is complex and open to legal challenges (e.g., in Alaska, villages are recognized as tribes, yet recent court rulings have denied claims of tribal sovereignty).

Yet, many issues remain unresolved, even internally within Native

While not necessarily reflective of the intent of current public health, these experiences and policies have impacted the way many Native Americans view government institutions, creating "justified mistrust of U.S. government programs and health institutions" (Rowell and Bouey, January 2002).

American tribes (e.g., control over resources, gaming, etc.). Federal recognition is also a complex issue. Over 300 tribes are not recognized by the federal government, either because they never signed a treaty, their recognition was "terminated" in the 1950's, or they have been unable to gain recognition (Olson-Raymer, n.d., p.23). Many tribes that do not meet the federal recognition criteria have relationships with individual states.

One overriding theme that emerges when reviewing the history of American Indians' experience with Western culture and the U.S. government is the concept of trauma as a pervasive factor in Native Americans' lives. This trauma is not the same as that experienced by other racial/ethnic minority populations in the United States and so, in this respect, they do not have a "shared experience" of the *same type* of oppression as other minority groups. However, as with other minorities in the U.S., the experience of oppression is ongoing and is perpetuated today in both overt and subtle ways. Native Americans experience antagonism to self governance and economic opportunity such as gaming from state and local governments and communities. Native American land claims continue to be denied and the federal agency responsible for the trust funds for many tribes [Department of Interior], continues to severely mismanage these funds. Alcoholism and other diseases continue to ravage many Native American communities. In many respects, many Native Americans view everything in their lives through the lens of this experience of trauma (Elm 2003; Pierce-Hedge, 2003).

While not necessarily reflective of the intent of current public health, these experiences and policies have impacted the way many Native Americans view government institutions, creating "justified mistrust of U.S. government programs and health institutions" (Rowell and Bouey, January 2002).



RELATED ECONOMIC, SOCIAL AND HEALTH CONDITIONS

“Hand in hand with poverty is a host of other factors, such as poor health, poor diet, and related diseases. Native peoples have historically contracted and continue to contract, almost every disease at higher rates than the general United States population.” (Vernon, 2001: 6)

The many causes of disparities in health for racial/ethnic minority communities have been well-documented. Economic and social determinants of health, both external to and within the primary and preventive health care systems, affect Native Americans as well as other populations. These other factors intersect with the ongoing effects of past events as well as current events and issues faced by Native American communities, such as those surrounding governance and sovereignty. Moreover, cultural norms and traditions must be considered in efforts to reduce the risk of HIV/AIDS among Native Americans and to engage and retain them in care and services.

Following are many of the issues impacting Native American communities which should be considered when addressing HIV/AIDS in these communities. Overall, Satter outlines four areas of importance when designing programs: local religious and cultural morals regarding sexual activity, homosexuality, drug use and contraception; the cultural and spiritual concepts of illness and health and their significance; the language used in the home and that which will be used to discuss HIV/AIDS among the family; and who in the community and family is turned to for advice (Satter, 1999). NASTAD used information from NNAAPC and other written sources, as well as personal inter-

views with Native American leaders, as sources for this section.

Multiple Health Concerns

“As current research in the area of HIV/STD risk in Native communities would suggest, a significant factor in risk has been the change and loss of cultural lifeways due to rapid environmental and economic development. Although Native people are also significantly at risk for HIV/AIDS, many communities have a relatively low perception of their risk. Lack of awareness and mobilization to address HIV/AIDS, along with cultural barriers in presenting HIV information at tribal/intertribal health norms has resulted in relatively low prioritization in health planning agendas.” (Nakai, 2003)

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 concern/consequence. “There is often great denial about HIV as a problem in AI/AN communities” (Rowell and Bouey, January 2002).

STDs

Sexually transmitted diseases (STDs) also significantly affect Native Americans (Rowell and Bouey, January 2002; Maldonado, 1999; Vernon 2001). Several CDC reports (CDC, 1998;

CDC 2002a), indicate that American Indians and Alaska Natives are highly impacted by STDs, including that Native Americans comprise the second highest rates of reported gonorrhea, chlamydia, and primary and secondary syphilis of any racial/ethnic group (CDC, 2002a). “High chlamydia, gonorrhea and syphilis rates among AI/AN suggest that the sexual behaviors that facilitate the spread of HIV are relatively common among AI/AN” (Bertolli, et al., 2004: 233).

Alcohol

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 Supplement 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 (Bertolli, et al., 2004, p.226). Chronic liver disease was the fifth leading cause of death among Native American men in 1996 and the sixth leading cause of death for Native women in 1993 (Maldonado, 1999).

In her comprehensive review of HIV/AIDS and Native Americans, Vernon states, “The relationship between alcohol, Natives, and AIDS cannot be ignored in the fight against the spread of HIV/AIDS.” She further elaborates, “The total effect of alcoholism on Natives is staggering. Alcohol-related accident death rates are approximately three times higher among Natives than among the rest of the U.S. population, and deaths from alcohol-related diseases run four times the national average. Chronic disability, unemployment, family disruption, child

abuse, and the destruction of tribal unity together demonstrate the devastating impact of alcohol in Indian country” (Vernon, 2001: 5).

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 among Native Americans (Walters, 2002, Simoni, 2004).

Injection drug use is a major risk factor for Native American women; Native women are “more likely to inject drugs than any other ethnic group among women,” and to have IDU sex partners (Rowell and Bouey, 2002; also in Vernon, 2001). 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 (CDC, 1998:155), highlighting the synergy between injection drug use and the challenges gay/bisexual/transgender/Two-Spirit Native Americans face (see *Sexuality* on p.14).

Furthermore, Native American youth are particularly vulnerable to substance use, particularly marijuana (CSAP, 2002).

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. Data reported in a HRSA fact sheet indicate that 25.9% of American Indians/Alaska Natives lived in poverty between 1998 and 2000. This percentage is higher than in any other racial group and has been even higher in the past (Rowell and Bouey, 2002). In addition, 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...” (Vernon, 2001: 47). She further notes that unemployment rates for Native women are higher than for women overall. Other diseases associated with poverty prevalent among Native American women, such as diabetes, can weaken immune systems, and lack of resources impact their access to and timeliness of care.

Violence/Domestic Abuse

One of the most striking issues described by Vernon is the impact of domestic violence on Native women’s HIV/AIDS risk. Also linked to poverty, which can lead to powerlessness, domestic violence is high among Native women overall. Vernon cites Department of Justice statistics that show that Native Americans represent 0.6 percent of the U.S. population but 1.4 percent of victims of violence, and that “the violent crime rate against Native females was. . . the highest among all female ethnic categories” (Vernon, 2001: 51). 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.

Education

Others factors influencing healthy behaviors in Native American communities are

education level and dropout rates. Sharon Day says that dropout rates can now be as high as 85% locally (Day, 2003) and published reports indicate that dropout rates for Native Americans have been twice the national average—higher than any racial/ethnic group (Reyhner, 2004).

Suicide

There is a high rate of suicide among Native Americans. This high rate of suicide is tied to issues surrounding poverty, alcoholism and other issues, as well as the stigma that surrounds being HIV positive and/or being gay/bisexual/transgendered. Native American gay youth are particularly vulnerable (Oropeza 2002). Vernon says that, “Many gay/bisexual youth begin to believe they are destined to die of AIDS, hence they do not engage in long-term relationships; they suffer from low self-esteem and depression; they engage in reckless behavior, and they attempt suicide” (2001: 69). Overall, Vernon reported that Native American suicide rates were 44 per 100,000 for young people aged 15-24, although this is highly variable among tribes.

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. It is difficult for local agencies to support programs when they don’t have the capacity to manage funding and report on it (Day, 2003). “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” (Nakai, 2003).



CULTURAL AMPLIFIERS IMPACTING HIV/AIDS RISK

Following are some important concepts health departments should explore when talking with Native American communities about HIV/AIDS programs. These should be considered along with the social/health issues and the impacts that historical underpinnings have had on Native American communities. Again, it is important to note that there is great diversity among Native American and Alaska Native cultures and these are 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.

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 (Oropeza, 2002).

Language/Communication

Generalizing about Native American language, culture and communication styles is not useful in working with specific individuals and/or Native American communities. NNAAPC has offered considerations for approaching Native American communities (Oropeza, et al., 2001). 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. These factors underscore the importance of involving local, indigenous community members in HIV/AIDS prevention and care services.

Sexuality

One of the consequences of overgeneralization about various “communities” is the idea that Native Americans are accepting of homosexuality or gay and alternate gender roles. NNAAPC reports that “While some Native Americans may know of alternative gender roles and sexualities within their tribes, they may not embrace these roles as acceptable. Native American individuals and communities are just as likely to exhibit the same type of homophobia prevalent in mainstream society” (Oropeza, 2002: 6). This may be due to many factors, including how “Westernized” they are.

At the same time, a recent introduction of the concept of “Two-Spirit” was an attempt by Native American gay, lesbian, bisexual, transgender activists to reclaim what in many Native American cultures was acceptance of more than two gender roles. Historically, the concept of “Two Spirit” (sometimes called *Berdache*, although that is not a Native American term), or a third gender among Native American tribes related to boys or girls who persistently preferred the activities of women or men, respectively, which manifested before puberty, making sexual behavior a “less important defining trait” (in *Two Spirit News*, Summer 2002).

However, Nic Metcalf says that in terms of understanding Native communities, there must be a distinction made between the concept of Two Spirit among urban and rural Natives. Two Spirit is an urban intellectual concept, whereas the rural Natives consider men who have sex with men (MSM) as gay, and Two Spirit is considered by some Native Americans to refer to having dual mental states, or an “evil” side. What is important is to try

and meet men where they are in that spectrum (Metcalf, 2003).

In addition to the array of ways to approach the concept/categorization of Native American gay and bisexual men and MSM, the stigma associated with this behavior must also be considered (Rowell and Bouey, 2002). “Lack of understanding and discriminatory treatment of two-spirit men creates an environment where HIV/AIDS can spread unimpeded. Discrimination against two spirit men discourages them from seeking medical services, especially where there are concerns about personal treatment and confidentiality on the part of the IHS” (Vernon, 2001: 24).

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. And Native American gay/bisexual men (often called “Two Spirit”—see above), who are the group of Native Americans at most risk for HIV, are often doubly-stigmatized for their HIV and their sexuality.

Trauma

As representatives of the New York State HIV Prevention Planning Group (PPG) told that group in November 2003, the overall effect of these historical relationships is one of trauma and you “can’t effectively deal with HIV without addressing trauma—what we need to do in prevention needs to look different” (Dunning, 2003).

Internalized Racism

Stereotypes and the effects of assimilation policies and practices may also result in internalized racism within Native American communities since these ideas can influence how Native

American people think as well as non-Natives (Hill, 2003). Internalizing negative attitudes of the dominant culture can erode a positive Native American identity and lead individuals to abandon the cultural heritage and traditions that can help mitigate the effects of trauma and other stressors that may put individuals at risk for HIV infection (Walters and Simoni, 2002).

STRENGTHS AND RESILIENCY IN NATIVE AMERICAN COMMUNITIES

While there are many challenges facing Native American communities, there are also great strength and resiliency. Many Native American communities are turning to their traditions and cultural values to help them address the health and social issues they are facing. 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 (Walters, et al., 2002).

Holism/Circle of Life

Unlike Western or Euro-American cultures, Native American cultures are not dualistic.⁴ Like other non-Western, non-dualistic 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.

NNAAPC has used the “circle of life” concept as a centerpiece in its self-help curriculum for Native Americans living with HIV/AIDS (Lidot, 2003).

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.

Importantly, this concept does not simply refer to the individual, but the community as a whole. Using a “holistic” approach is helpful for both practical reasons (e.g., like the fact that there are so many competing priorities as outlined above) and spiritual ones (e.g., traditional beliefs, the connectedness to the earth, etc.) (NACHLA, 1995; Nakai, 2003).

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 with 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 (Oropeza, 2002). In addition, it is important to reach out to these healers and not alienate them when working in these communities (Nakai, 2003; Satter, 1999; Vernon, 2001)

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. In New York State, egalitarian gender relationships have meant that women are relatively empowered there (Elm, 2003) and are often the gatekeepers of the community.

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 (Dunning, 2003).

Group Emphasis and Collective Ownership

Many Native American communities stress identity with clan/tribe/extended family over individual or nuclear families, although the family is also a central value in Native American cultures. Also, one of the key differences between Western and most Native American cultures, traditionally, is the idea of collective rather than individual ownership. Native American cultures generally stress collective responsibility for maintaining the land (Dunning, 2003). Therefore, the Western individualistic approach to personal responsibility for health may not resonate well in Native American communities without attention to its connection to these values on family and tribe.

Additional sources for the preceding section include documents distributed at the November 2003 New York State HIV Prevention Planning Group presentations and those produced by NNAAPC.

⁴ Dualism refers to the concept that Western or European cultures tend to frame human interaction in terms of opposing principles such as good vs. evil, black and white, as opposed to other ways of thinking that incorporate a spectrum of influences on human interaction.



NATIONAL/FEDERAL FUNDING OF NATIVE AMERICAN HIV/AIDS SERVICES

“There are at least two rationales for ongoing federal commitments to allocate resources to (American Indian/Alaska Native) programs and services. The first is a fundamental desire by the U.S. to address the compelling and often Third World conditions found in many native communities... In many parts of Native America, economic and social conditions resemble the emergency states associated with natural disasters which require federal interventions. The second rationale...is the unique legal and political relationship between the U.S. and Indian tribes nationwide.”

—*Senator Ben Nighthorse Campbell, chair, and Senator Daniel K. Inouye, vice chair, Senate Committee on Indian Affairs, in a letter to the Senate Committee on the Budget, Feb.29,2000, as reported in Concurrent Resolution on the Budget, FY 2001, Report of the Committee on the Budget, United States Senate, Mar 31, 2000, p.188 (As reported in A Quiet Crisis—U.S. Commission on Civil Rights, 2003, p.1).*

Minority communities have been supported to develop programs and services to help eliminate health disparities. Yet many Native American communities still lack necessary resources to develop culturally relevant and effective programs. Moreover, for some Native communities, sovereignty considerations preclude acceptance of federal funds. Despite these limitations, local prevention efforts are in place in some communities and some state and local health departments provide direct services or contract with Native American community-based organizations (CBOs), tribal

governments or other agencies that serve Native American communities.

Health care and prevention services for Native Americans are supposed to be provided through several mechanisms. The United States established responsibility for providing social and other services to Native Americans through the Bureau of Indian Affairs, housed originally in the Department of the Interior. The Snyder Act, passed in 1921 authorized regular appropriation of funds for Indian healthcare for what became the Indian Health Service (IHS), now housed in the Department of Health and Human Services (HHS, 2004; U.S. Commission on Civil Rights, 2003: 34).

Congress established the IHS in 1955 to provide comprehensive health services for American Indian/Alaska Natives. These services are located in tribally contracted or operated health programs, most of which are in the Western U.S. As of 2002, the IHS had 36 hospitals, 63 health centers, 44 health stations, and 5 residential treatment centers. IHS also funds 34 urban Indian health projects to provide a variety of health and referral services. In addition, there are 13 hospitals, 158 health centers, 28 residential treatment centers, 76 health stations, and 170 Alaska village clinics that are solely administered by American Indian tribes and Alaska Native corporations (IHS, 2004). The Indian Self-Determination and Education Assistance Act (1975) allowed Indian tribes that accept federal resources to choose whether or not to administer health services themselves or let them remain administered through the government's health care system (U.S. Commission on Civil Rights, 2003).

Native Americans who are members of federally-recognized tribes are eligible for services through the IHS. As of 2002, IHS served an estimated 1.6 million (or 60%) of the 2.5 million Native Americans in the United States (U.S. Commission on Civil Rights, 2003).

However, most of the IHS funding goes toward services located on or near a Native American reservation. Therefore, these services may not be accessible for many Native Americans who are members of federally-recognized tribes but who do not live near these services. In addition, there are many Native American tribes that are not federally-recognized, and some Native American nations do not participate in *any* federal programs.

A recent report from the U.S. Commission on Civil Rights cited data indicating that only 28% of Native Americans had private health insurance and 55% use IHS for all their health care needs (U.S. Commission on Civil Rights, 2003). A National Minority AIDS Council (NMAC) Fact Sheet reported that in 1996, 39% of Native Americans were enrolled in Medicaid, but that, under law, “states are required to provide Medicaid coverage for Native Americans if they are eligible whether or not they live on or near a reservation or in an urban area and whether or not they are eligible for IHS services” (Maldonado, 1999). By 2000, the U.S. Census reported that up to 26.8% of Native Americans lacked health insurance (HRSA, July 2002).

Specifically for HIV/AIDS, in addition to the IHS and tribally operated medical care facilities, some Native American community-based organizations may receive or accept funding directly from agencies in the Department of Health and Human Services (HHS), particularly the Centers for Disease Control and Prevention (CDC) and the Health Resources and Services Administration (HRSA), for various HIV and STD prevention and care and treatment services. The Substance Abuse and Mental Health Services Administration (SAMHSA) and other HHS agencies may also provide small grants to various Native American communities that accept federal funds for HIV/AIDS-related issues as well.

Within the CDC, the National Center for HIV, STD, and TB Prevention (NCHSTP) supports cooperative agreements and interagency agreements to promote the health of AI/AN populations. Funding for HIV prevention in the total amount of approximately \$730,000 was provided to four AI/AN community-based organizations, representing 1.3 percent of the total amount of \$57 million awarded directly to fund community-based organizations in fiscal year 2003. The prevention funding provides for culturally sensitive prevention education programs, as well as HIV counseling and testing services, support for behavior change, and case management.

Approximately \$990,000 was provided for capacity building assistance to one tribal and one AI/AN national organization, representing 2.6 percent of the \$37 million awarded for capacity-building assistance in fiscal year 2003. Beginning in fiscal year 2003, NCHSTP also supported regional capacity-building for HIV/STD prevention in AI/AN communities in two 4-state Indian Health Service (IHS) administrative regions under memoranda of agreement with local tribal entities and IHS area offices. Contractual arrangements have been established to place capacity-building coordinators in these two regions. The purpose of these arrangements is to leverage available resources for STD/HIV prevention and control activities through better coordination and outreach (linking agencies that have resources with populations in need of services).

HRSA has funded Native American communities for HIV/AIDS care and treatment services directly through its Special Projects of National Significance (SPNS) program since 1991. In 2004, there are seven SPNS projects in American Indian/Alaska Native communities—two in Alaska, and one each in California, New Mexico, North Dakota and Washington State. HRSA has also funded a Technical Assistance Center at the University of Oklahoma to provide technical support

to site grantees on the development and refinement of local program objectives (HRSA, 2004).

In addition, the IHS and HRSA have jointly funded the Phoenix Indian Medical Center's HIV Center of Excellence (HIVCOE) to establish a "clinically based center for HIV prevention, care, medical treatment and research, as well as a model of care for American Indian/Alaska Natives. There is a collaborative effort between the HIVCOE and the Pacific AIDS Education and Training Center (AETC) to provide training and skills building for health care providers working with American Indian/Alaska Native communities in Arizona, California and Montana, as well as Nevada and Hawaii.

Another national program for Native American health care and prevention has been the Turning Point Program by the National Association of City and County Health Officials (NACCHO), supported through funding from the W.K. Kellogg and the Robert Wood Johnson Foundations. This broad public health initiative centered its efforts on building public health infrastructure from the ground up by working with local communities to develop community partnerships focused on public health. While not specifically focused on HIV/AIDS or Native Americans per se, project director Vince Lafronza said the tribes they worked with reacted enthusiastically to this program. The projects focused in Native American communities led to an Indian Health Forum which resulted in some helpful "policy principles" for working with Indian communities (see recommendations) and even led to a change in NACCHO's membership criteria to allow tribes to become members, as well as the election of a Native American representative to their board (NACCHO, 2001). (A documentary released in January 2004 on public health and social justice issues in rural America profiles the Fort Peck tribes in Montana.)

While there are no national data on the number of CBOs funded by health departments that specifically target Native American communities, several initiatives are profiled below. In 1999, NMAC estimated that about .8 percent of the total HIV/AIDS prevention dollars (then about \$353 million) in the United States were targeted directly to Native Americans.

This patchwork of service delivery systems, coupled with the complexity within Native American communities and areas of residence, results in a complex and highly variable approach to HIV/AIDS prevention, care and treatment services that may be available to Native Americans in tribal, rural and urban settings. The fact that direct funding from CDC and HRSA comes in the form of competitive, often short-term (3 to 5 years) awards may contribute to instability and sustainability issues. Furthermore, many Native Americans don't believe that the IHS views HIV as a priority (Pierce-Hedge, 2003; Nakai, 2003; Vernon, 2001). The confusing and incomplete array of care and prevention service options for Native American communities means that

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many Native Americans do not receive needed services. Structural barriers to effectively reaching Native Americans with HIV/AIDS prevention and care and treatment services impede effective service-delivery.

HEALTH DEPARTMENT PROGRAMS WITH NATIVE AMERICAN COMMUNITIES

Many health departments have successfully worked with Native American communities to address HIV/AIDS. At NASTAD's request, the following states offered profiles of the work they are doing. These examples do not represent a comprehensive overview of the work being done with Native American communities; they are simply examples of strategies currently underway. They have not been analyzed for, nor are they being represented as "best practices." Rather, they are approaches some health departments have undertaken. They are offered here to help spur thinking and critical discussion among AIDS directors and health department leadership, and between health departments and Native American communities and representatives, about how best to meet the HIV/AIDS prevention, care and treatment needs of Native American communities.

ALASKA

Penny Cordes, Alaska Department of Health and Social Services, HIV/STD Program, provided assistance with this profile.

Alaska is often defined by its ruralness because of its huge land mass and relatively small population. In reality, most Alaskans live in an urban area rather than in a rural community. The majority (78%) of the state's approximately 640,000 residents live in one of three cities - Anchorage, Fairbanks, or Juneau - or on the road system connected to Anchorage. Over 40% of the state's popu-

lation resides in the Municipality of Anchorage alone. Although the majority of the Alaska Native population resides in rural communities, Anchorage has more Alaska Native residents than any other community in the state. Census 2000 figures show a statewide total of 119, 241 persons (19% who identify as American Indian/Alaska Native (98,043 one race only; 21,198 AI/AN and one or more other races). Of these, 26,995 (23%) reside in Anchorage. Another 11% of the statewide total of Alaska Natives resides in the boroughs of Fairbanks and Juneau. (www.akepi.org/hivstd/hppg/hivprev-plan04.pdf) (www.alaska.ihs.gov/dpehs/).

The collective term *Alaska Native* refers to the descendants of the culturally distinct Aleut (Unangan), Alutiiq, Athabascan, Eyak, Haida, Inupiaq, Tlingit, Tsimshian, and Yupik peoples of Alaska. While there are some residents of Alaska who are of "Lower '48" Native American heritage, this profile uses the term Alaska Native to reflect the majority category of indigenous people in the state. There are 229 federally recognized tribes in Alaska, most of which are associated with widely dispersed villages with populations ranging from less than 100 to 2000 persons. Many of these villages are only accessible by airplane or seasonally by boat. The population of rural villages is predominantly Alaska Native. However, these small rural communities make up only 13% of the total population of the state. Another 9% of the population of the state resides in one of 13 communities with populations between 2,000 and 9,000. These towns serve as rural hubs of transportation, commerce, school administration, and health and social services for the villages in their respective region. Alaska Natives make up from 10% to 75% of the populations of the regional hubs.

Alaska is a low HIV prevalence state. Through December 2003, the cumulative total of HIV/AIDS cases was 925. Of these, 203 (22%) were among American Indians or Alaska Natives. Thus AI/AN are over-represented

among HIV/AIDS cases compared to their proportion of the state's population. As with the distribution of the population of Alaska, the majority of HIV/AIDS cases, even those among Alaska Natives, are among persons residing in one of the urban centers at the time of diagnosis. However, the proportion of cases among rural residents has increased over the past five years. Females, especially among more recent cases, were less likely than males to live in one of the three urban centers at the time of first HIV diagnosis. (See Epidemiology Bulletins on HIV at www.akepi.org/bulletins.)

The distribution of the population, cases of HIV/AIDS, and health and social service infrastructure in the three geographic categories—urban center, rural hub, and village—presents unique challenges for the planning and delivery of HIV prevention and care services for Alaska Natives.

The urban centers of Anchorage, Fairbanks and Juneau have the most developed health and social services infrastructure and each city has one (Fairbanks and Juneau) or more (Anchorage) organizations receiving Ryan White CARE funding and State HIV prevention funds. These organizations employ HIV prevention specialists and offer a range of interventions that target priority populations based on behavioral risk categories and employ intervention models with evidence of effectiveness. These interventions reach Alaska Natives roughly in proportion to their representation in the community or the environment in which the interventions are delivered (Alaska Natives are over-represented in correctional facilities and substance abuse treatment programs). Because of resource limitations, the interventions are designed to reach the behavioral risk groups regardless of race/ethnicity, and are not targeted or tailored specifically for Alaska Natives. Nor can the agencies consistently employ Alaska Native staff or volunteers

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to deliver the interventions. Hence these interventions are not culturally specific.

To increase the cultural appropriateness of interventions for Alaska Natives, the State funds the Alaska Native Health Board to conduct HIV prevention interventions in rural settings, and most recently, in urban centers. The Alaska Native Health Board (ANHB) is a non-profit organization whose membership is made up of representatives of each of twelve Alaska Native regional non-profit health organizations plus an additional ten villages or consortia of tribes. ANHB's mission is health promotion, disease prevention and health systems development for Alaska Natives (www.anhb.org/documents/statewide_health_plan.pdf). Although based in Anchorage, their mandate is statewide and, for HIV prevention, their focus has been predominantly rural community mobilization and capacity building for regional health corporations over the past fifteen years for which they have received HIV prevention funding from the state. Since 2002, they have received state funding to provide interventions to reach Alaska Natives in Anchorage. One intervention is a multi-session HE/RR group for women in substance abuse treatment programs and in the only correctional facility exclusively for women. This is a collaborative effort, pairing the HIV prevention expertise of the Anchorage Neighborhood Health Center and the

cultural knowledge and substance abuse recovery expertise of an ANHB staff member. The other state funded intervention is an adaptation of the Popular Opinion Leader (POL) intervention for men who have sex with men (MSM). The ANHB POL worker extends the intervention outside of the bar environment of the original POL model and into the largely hidden social network of Alaska Native MSM in Anchorage and in rural hubs. This involves creative use of internet chat rooms to recruit and support POL volunteers and extensive air travel to conduct training for volunteers in rural hubs. POL volunteers reach some MSM in villages through their social networks.

As in other states, the Indian Health Service funds health care for beneficiaries in Alaska. Unlike Native Americans in the contiguous U.S., Alaska Natives are not disenfranchised from federally funded health care when they relocate to the cities. There are IHS funded, clinics and hospitals in the three urban centers and most rural hubs. Most of the federally funded health services are delivered through contracts with Alaska Native regional health corporations under provisions of the Indian Self-Determination and Education Assistance Act (PL93-638) of 1975 and subsequent federal legislation. There are twelve regional health corporations, each corresponding to one of the Alaska Native Regional (for profit) Corporations established under the Alaska Native Claims Settlement Act of 1971. Currently, there are seven tribally operated hospitals and 21 tribally operated health centers staffed by physicians and/or mid-level practitioners. In Anchorage, the Alaska Native Tribal Health Consortium (ANTHC) operates the Alaska Native Medical Center that serves as the tertiary level referral hospital for the regional hospitals and the tribally operated primary care facility in Anchorage. Starting in 2003, HIV care for Alaska Natives has been enhanced by a HRSA Title III grant to

ANTHC which funds case managers at five tribal health facilities (Juneau, Fairbanks, Anchorage and two rural hubs) and maintains a clinical team in Anchorage that provides direct patient medical care and mental health counseling, as well as clinical consultation, collaborative case management and provider educational services for tribal health program personnel. Case managers provide prevention counseling for HIV positive persons. In the three urban centers there are also state and federally funded substance abuse treatment programs that are tribally operated and state correctional facilities and community residential centers (half-way houses). State funded HIV prevention CBOs conduct group sessions in these facilities.

Rural hub communities have the tribally operated hospitals or clinics mentioned above, some have correctional facilities in which HIV testing and STD services are available, and all have substance abuse treatment programs. Each of the rural hubs is also served by a State Public Health Nursing Center that provides HIV counseling and testing, STD services and, in some sites, HIV prevention education in community settings. There are no community-based organizations with an HIV prevention focus based in any of the regional hubs. Periodically there have been time-limited projects under HRSA Special Projects of National Significance grants to do community mobilization and HIV counseling and testing in a subset of villages in selected regions. The ANHB has been funded directly by CDC, starting in 2001, to do community presentations and public information PSAs in several rural hubs and villages to raise awareness about HIV, reduce stigma and discrimination, and encourage HIV testing. They have found that in rural areas there is still a great need to raise awareness and educate people about HIV transmission and prevention.



At the village level, there are 161 village-operated clinics staffed by Community Health Aides/Practitioners (CHA/P) who are employees of their respective regional health corporation. CHA/Ps provide primary care under standing orders and phone communication with physicians and mid-level practitioners located in the rural hubs. Regional health corporation providers and State public health nurses make village visits from monthly to quarterly depending on the size of the region. Village clinics provide a venue for the display of educational materials and condom distribution. While CHA/Ps have a role in STD treatment and STD partner follow-up, none of the health corporations have decided to involve CHA/Ps in HIV CT. Because almost all CHA/Ps are Alaska Natives from within the region, there is great hesitancy to elicit risk information and do risk reduction counseling with fellow residents. Village residents wishing to have an HIV test can request it of a visiting physician or public health nurse or they can seek out HIV CT when they travel to a regional hub or an urban center. Concerns about confidentiality are still a barrier to testing in the villages and rural hubs. Most villages do not have any substance abuse treatment programs, so village residents must travel to a program in a rural hub or urban center. Here they may access HIV CT and be exposed to HIV prevention presentations or one-on-one prevention counseling from a trained substance abuse counselor.

Although HIV testing is not widely accessed in the villages, there are two other contexts in which HIV testing is available for rural residents—prenatal care and military service. Alaska Native women residing in villages and rural hubs receive prenatal care at their regional hospital where prenatal HIV testing is routinely offered. Air transportation from village to rural hub is paid for by the regional health corporation for prenatal care. The Alaska National Guard is an important source

of employment for rural residents and Alaska Natives have a long and proud tradition of serving in the military. HIV testing is mandatory for recruits and active duty military including the rural men and women in the National Guard.

Given the widely dispersed communities of rural Alaska, the State HIV/STD Program strategy for HIV prevention in rural Alaska includes the following components:

- Fund Alaska Native organizations to conduct targeted outreach to persons at high risk (c.f. outreach to MSM in rural hubs and villages);
- Support the integration of HIV prevention education and risk reduction counseling into existing services available in rural hubs such as substance abuse treatment programs, correctional facilities, halfway houses and women's shelters. The HIV/STD Program provides training in prevention counseling for providers in these settings.
- Reduce the burden of sexually transmitted diseases (of which Alaska Natives have the highest incidence) through aggressive partner follow-up of cases of reportable STDs, enlisting the help of public health nurses and CHA/Ps;
- Conduct partner services for 100% of newly reported cases of HIV or AIDS across the state. Confidential, voluntary partner notification services conducted by specially trained public health personnel bring risk reduction counseling and HIV testing to the sex and/or needle sharing partners of persons known to have HIV. Regardless of location, in person partner services are either carried out directly by personnel from the HIV/STD Program or coordinated with a public health nurse in the region. In 2003, 153 named partners were notified and agreed to HIV testing. Eleven (7.2%) were newly found to have HIV infection. For rural areas, where perception of risk is not high and where persons

with risk factors may not seek out HIV testing, this strategy, although resource intensive, reaches those at highest risk.

The HIV/STD Program will continue to work with the ANTHC Title III program in their efforts to enhance HIV care services and prevention for HIV positive persons through educational opportunities for Alaska Native regional health corporation providers. Beginning in 2004, the HIV/STD Program intends to augment the social marketing work begun by ANHB to increase HIV awareness and risk perception in other regions of the state.

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One of the key lessons the health department has learned in working with ANHB over the years is a greater appreciation and understanding of the challenges they faced in working with leadership in rural areas where there was a reluctance to deal with sexuality and same-sex issues and where HIV was not perceived to be a problem. In fact, as in other Native American communities, HIV is still low on the list of priorities among Alaska Natives contending with so many other issues.

leadership in rural areas where there was a reluctance to deal with sexuality and same-sex issues and where HIV was not perceived to be a problem. In fact, as in other Native American communities, HIV is still low on the list of priorities among Alaska Natives contending with so many other issues.

One challenge to working on American Indian/Alaska Native HIV prevention is that, as with prevention in general, the progress is made in a slow, ongoing way that doesn't always show immediate results. In addition, when focusing on behavioral risk groups at highest risk for HIV, it is hard to do so openly in rural areas. For that reason, Cordes agrees that it is important to respect the local processes for bringing these issues to the fore and to work with Alaska Native organizations and local entities to raise awareness and open the door to public discussion about HIV in the communities. Meanwhile, the public health personnel work quietly behind the scene to confidentially inform named partners of HIV positive person of their possible exposure and to offer testing and referrals.

CALIFORNIA

By Dana Pierce-Hedge, Chief of the HIV Care Branch, Office of AIDS, California Department of Health Services

The American Indian population in California is comprised of members of indigenous California tribes as well as members of tribes from throughout the United States. There are more than 107 indigenous California tribes, representing about 20 percent of the nation's approximately 500 tribal groups.

California Department of Health Services (DHS) Indian Health Program (IHP)

IHP's Mission Statement: The mission of the Indian Health Program (IHP) is to improve the health status of American Indians/Alaska Natives

(AI/AN) living in urban, rural, and reservation/rancheria communities throughout California. According to the U.S. Census, there were 627,562 American Indians in California in 2000. This includes 333,346 declaring American Indian as their sole race. An additional 294,216 people stated they were American Indian and one or more other races.

IHP administers HIV testing and counseling funds through a Memorandum of Agreement with the State Office of AIDS (OA). Funds are distributed annually to Indian health clinics through a competitive process and all counseling staff are trained by OA. Nine current HIV grantees provide confidential testing and counseling services to Indians in urban and rural California. Clinics may offer the standard blood test, the new oral test, or same day results with the new OraQuick finger stick blood test.

California HIV Planning Group (CHPG)

As advocates for persons living with, affected by, or at risk for HIV, the California HIV Planning Group (CHPG) provides community perspectives, advice, and recommendations to the California Office of AIDS (OA) in the planning, development, and allocation of resources for a comprehensive, client-centered continuum of prevention. This includes prevention policies that are integrated into care services. Its 38 members include persons living with HIV/providers, advocates, and policy makers, representing diverse communities throughout the state.

Last year the CHPG was combined in include both care and prevention. Prior to that time the planning group was dedicated to prevention issues. The membership was expanded and the recruitment process solicited care participants to join the planning body. The membership currently has 38 individuals that represent all aspects of California's diversity. There are Native

There are Native Americans on the CHPG from rural areas as well as urban locations. Discussion at a recent meeting voiced the perspective that Native representation in the State, although small in comparison to the general population, still needs to be considered at every level of planning services for California.

Americans on the CHPG from rural areas as well as urban locations. Discussion at a recent meeting voiced the perspective that Native representation in the State, although small in comparison to the general population, still needs to be considered at every level of planning services for California. Various community-based clinics throughout the state provide a variety of AIDS/HIV services. The challenge is to get all of the various federally funded programs coordinated. The state is trying to accomplish this task through CHPG by coordinating state funded programs both in prevention as well as care.

IDAHO

Lisa Kramer, Idaho State Department of Health and Welfare, and Joyce McFarland, Nez Perce Tribe, provided assistance with this profile.

Idaho recently initiated a project among the Nez Perce Tribe. One of six major Native American tribes in Idaho (along with the Coeur d'Alene, Kootenai, Northwestern Band of Shoshone, Shoshone-Bannock, and Shoshone-Paiute), the Nez Perce applied through the statewide RFP process for HIV prevention services by community



based organizations. Currently in the midst of a four year project, the Students for Success Program provides individual and group level interventions, health communications, mentoring and prevention case management to reduce risky sexual behaviors and alcohol, tobacco and other drugs (ATOD) use.

This is the first time that one of the Native American nations in Idaho applied through Idaho's general RFP process. According to Lisa Kramer, HIV Prevention Specialist in the Idaho Department of Health and Welfare, the participation of members of the Nez Perce on the state community planning group facilitated their success in the RFP process because the community planning group members helped share information within the tribe about Idaho's HIV prevention priorities.

Idaho has one statewide community planning group: the Idaho HIV Care and Prevention Council (IHCP). Since January 2003, the ICPC has functioned as a planning group for both HIV prevention and care services. This collaboration has proven to be valuable in the development of prevention services for persons living with HIV/AIDS. Historically the ICPC has identified MSM, IDU, and Women at Risk as the priority populations. This year they modified the priority population as Persons Living with HIV/AIDS, MSM, High Risk Heterosexuals, IDU, and Youth (identified as a person 13-24 years of age who engages in sex and/or uses needles). The ICPC currently has 32 members, two of which are Native American. (As of the 2000 U.S. Census, Whites, non-Hispanic, constituted 89% of Idaho's population and American Indian/Alaska Native constituted 1% of Idaho's population.) The 2002 Epidemiological Profile for HIV/AIDS in Idaho indicates that of the 673 individuals reported in Idaho with HIV infection at the time of the report, nine (9) were American Indian/Alaska Native.

Students for Success is a primary prevention and early intervention program

servicing the tribal community on the Nez Perce reservation in north central Idaho. It incorporates the HIV prevention program into its existing youth ATOD prevention program. This project is delivered through the Nez Perce Education Department and is targeted to both male and female youth under 19 years of age.

This is a multi-faceted program of information exchange, peer mentoring, skills-building, and prevention case management. The program is considering possible curricula, including the "Get Real About AIDS" curriculum. Culturally specific information is a part of the overall Students for Success program.

Through Nez Perce Youth Leadership, peer educators between 12-18 years of age provide HIV/AIDS and ATOD education to youth and adults. High-risk youth are identified and referred into individual-level prevention case management (PCM). The peer educators work with adult mentors to receive ongoing training on current prevention information and presentation skills. They are responsible to take part in quarterly trainings and an annual Nez Perce Youth Summit.

According to Joyce McFarland, Director/Prevention Specialist of the Students for Success Program in the Nez Perce Tribe, the program is a continuation of efforts started under the Center for Substance Abuse Prevention (CSAP) Minority Substance Abuse and AIDS Initiative. After this funding cycle ended in September 2002, Students for Success discontinued the core intervention services of case management. With the resources from the state of Idaho STD/HIV prevention program, they were able to reinitiate this component while expanding to also offer mentoring for at-risk youth. Due to a gap in service, the program experienced the demands of a start-up phase and training of new staff.

Native American youth between 9-18 years of age living on the Nez Perce reservation are accepted into case management or mentoring if they meet the eligibility requirements of: 1) exhibiting

high-risk sexual behaviors, 2) being a child of a substance abusing parent or guardian, and 3) being at-risk for dropping out of school or being an actual school dropout. The latter two criteria are related to increased risk for substance abuse, which can be a co-factor to risky behaviors that can lead to HIV infection. The case managers provide the standard functions of case management, including outreach, assessment, linking, monitoring, advocacy, and assistance with daily living, as relates to the primary goal of HIV prevention.

The Students for Success Program works to meet the state of Idaho evaluation requirements, while maintaining its own independent evaluation plan.

The Students for Success Program works to meet the state of Idaho evaluation requirements, while maintaining its own independent evaluation plan. This includes administering the CSAP Minority Substance Abuse and AIDS Initiative survey, which collects data on risk factors related to HIV transmission and ATOD use. Students for Success also piloted a survey instrument called the "Survey of Nez Perce Culture," with the assistance of the program evaluator, Dr. Elizabeth Harris. This survey combines questions on culture and ATOD use to see which level of acculturation is conducive to prevention of substance abuse.

Lisa Kramer reports that while Idaho would love to expand current programs targeting the Indian community, there is limited funding and limited response within the Indian community to provide these services. The Students for Success Program was the first proposal Idaho received directly from a tribe. Idaho does fund other CBOs and

local health districts to provide counseling and testing, health communication, outreach and public information on reservations. Kramer reports communication and timelines around prevention activities are ongoing challenges, as is building and maintaining trust between tribes and state government.

NEW MEXICO

Don Torres, Section Head, Infectious Disease Bureau, HIV/AIDS Hepatitis Programs, and Vivian Amelunxen, HIV Prevention Program Manager, provided assistance for this profile.

Until recently, New Mexico has centered its health department HIV/AIDS prevention and care/treatment efforts focused on Native Americans in urban areas, since 55% of their American Indian population is urban, living in cities like Albuquerque and Santa Fe. Yet although New Mexico has reported low rates of HIV among Native Americans on reservations and pueblos, there have been some recent shifts. Co-morbidity with STD is of particular concern, as they have been addressing an outbreak of syphilis on the Navajo Nation that shows a disproportionate impact on the Indian community.

In addition to a large urban Indian population, New Mexico is home to roughly 21 tribes—including 19 pueblos, two Apache reservations and three Navajo communities—within which there is a wide range from traditional to Western ways of life. American Indians comprise 8.9% of the state's total population. This diversity among Native Americans in New Mexico has meant that there is no single thread to pull together in developing HIV/AIDS services in the state. In addition, each of the nations or pueblos is sovereign, and pueblos elect new governments every year, leading to turnover that makes continuity and trust building difficult.

As in other states, Native Americans in New Mexico access services in a variety of ways. Native Americans regularly go

New Mexico has tried to facilitate the coordination across states by sponsoring things such as case conferencing calls among field staff to discuss the recent syphilis outbreak, funding a staff person on the Navajo Nation, and supporting a social marketing program on syphilis.

between various IHS, private and public health providers because of concerns about confidentiality and stigma, as well as access and geography/location. In addition to federal resources for prevention and care, the New Mexico legislature has a long tradition of appropriating HIV/AIDS resources in its general fund. Roughly \$300,000 in FY 02 was appropriated by the State for HIV/AIDS care and \$1 million overall for HIV prevention as well as \$740,000 for syringe exchange and some tobacco settlement funding.

In New Mexico, HIV/AIDS care services are organized through a series of Health Management Alliances (HMAs). While all of these geographically-oriented HMAs serve Native Americans, New Mexico is currently funding the First Nations Health Source for infrastructure development over a 3-4 year period. These HMAs have encountered familiar challenges with providing care services in terms of issues with capitation and cost reimbursement regulations that must match a client to services. For Native Americans who utilize multiple agencies for their care and who may avoid public clinics for confidentiality and other concerns, this has led to problems in linking resources for their care.

The recent syphilis outbreak on the Navajo Nation highlighted the need for effective primary prevention on New Mexico's reservations and pueblos. Coordinating the provision of primary prevention and care and treatment for HIV and other STDs among Native Americans in New Mexico is no simple matter. The Navajo Nation straddles four states, and, in addition to coordination across those jurisdictional boundaries, health departments must also work with the Indian Health Service and the public health system of the Navajo Nation itself.

New Mexico has tried to facilitate the coordination across states by sponsoring things such as case conferencing calls among field staff to discuss the recent syphilis outbreak, funding a staff person on the Navajo Nation, and supporting a social marketing program on syphilis.

New Mexico funds four regional health districts to provide HIV prevention services, responsive to the priorities identified by their prevention planning group. Counseling and testing, partner counseling and referral services, health education/risk reduction and integration with other services are provided through these districts. In addition, like other health departments, New Mexico has found that it works much better to fund contractors who have established trust, ties and relationships with Indian communities and leaders to provide many prevention services. Currently, four of the fourteen contractors New Mexico funds serve Native American communities, comprising 13% of New Mexico's overall funding for HIV/AIDS prevention in 2002. (Native Americans made up 6% of HIV cases that year.) They have also recently funded a contract to address the syphilis outbreak on the Navajo Nation.

The stability of these contractors has gone a long way towards building and maintaining trust and continuity of services. Two of the contractors New



Mexico funds work directly with specific nations or pueblos, and two are inter-tribal. These include the Albuquerque Area Indian Health Board, the Navajo AIDS Network, Dine College and the Health Management Alliance for Native Americans, based in Albuquerque, which has statewide responsibility for primary prevention in Indian communities. New Mexico also has a provider agreement with the Navajo Nation's CTR program for the provision of counseling and testing services and has placed a disease intervention specialist (DIS) there to help with the syphilis outbreak.

A social marketing campaign using radio spots and, potentially, posters, is an exciting new initiative under development. New Mexico is working with a Navajo-language radio station that serves rural listeners in the Four Corners area to develop the campaign.

The focus on Native Americans in New Mexico has been aided by their strong representation on New Mexico's planning bodies. Their participation has helped the prevention planning group look at issues impacting poor, rural Native Americans and regional challenges, and a transgender member has been instrumental in helping the state address the issues among transgender and gay Native Americans. (For prevention, New Mexico has regional action groups and one non-geographic American Indian group give input into a statewide group.)

New Mexico AIDS Director Don Torres reports that, "A key factor facilitating attention to Native American HIV issues in New Mexico comes from the new administration of Governor Richardson, who has made it a policy priority to look at health disparities in his state."

New Mexico Governor Bill Richardson appointed a Native American to head the public health division and this

has served to refocus the health department's work and led to more trust and entrée with leaders in the Native American community.

Torres and Amelunxen report that some of the next steps for further work in Native American communities include using the new rapid testing technology to establish a stronger testing program on the Navajo Nation and working with younger Native Americans to address their unique needs.

NEW YORK STATE

Collaboration Between the AIDS Institute and the Native American Community to Advance HIV Prevention

By Susan J. Klein, New York State Department of Health AIDS Institute

According to the U.S. Census Bureau there were over 76,755 self-identified Native Americans/Alaska Natives residing in New York State (NYS) as of July 1, 1999. Of these, 33,896 (44%) are estimated to reside in New York City (NYC). More than half live outside of NYC. Native American peoples that have traditionally resided in NYS are the 6 nations of the Iroquois Confederacy (Onondagas, Mohawks, Senecas, Cayugas, Oneidas, Tuscaroras) and the 13 Algonquin tribes of Long Island. Native

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This relationship is multifaceted
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Americans from other tribes and communities of the U.S., Canada, Mexico, the Caribbean and Central and South America also reside in NYS. As of December 2001, NYS Department of Health (NYSDOH) data indicated that 88 Native Americans had been diagnosed with AIDS, of whom 55 were still living, and 37 Native Americans were living with HIV.

The New York State Department of Health (NYSDOH) AIDS Institute, Division of HIV Prevention has an active, collaborative working relationship with the Native American community. This relationship is multifaceted and it continues to evolve.

HIV Prevention Services

Since the early 1990s the AIDS Institute (AI) has worked closely with and provided funding to two primary agencies serving Native Americans in NYS, both of which were founded prior to the HIV/AIDS epidemic—the *American Indian Community House (AICH)* (profiled in the following story) and *Native American Community Services of Erie and Niagara Counties (NACS)*.

An intergenerational approach to HIV prevention for Native American communities in Central and Northern NYS, the Generations Program trains Native American Elders as HIV educators, uses these Elders in providing behavior-based primary HIV prevention education to Native American youth ages 10-15 and facilitates Native American youth production of HIV prevention public information to influence Native American community norms in support of safer behaviors. The Generations Program provides services at the Mohawk Nation at Akwesasne and in Syracuse, to both the urban Native American community in Syracuse and the nearby Onondaga Nation.

Native American Community Services of Erie and Niagara Counties (NACS) was formed in 1975 to address unemployment in the Native American community in Buffalo, NY. In the mid-1990's, NACS was one of the first

agencies to begin addressing the impact of HIV/AIDS in the local Native American community. Today, NACS offers a variety of programs, including prevention services.

NACS' services are designed to provide accurate and current information, enhance self-esteem and cultural understanding, encourage good decision making skills, and teach positive living skills. Services available include alcohol and substance abuse prevention, youth suicide prevention workshops, adolescent pregnancy prevention, HIV risk reduction and prevention, resiliency skills and assets building, and information and referral. HIV Risk Reduction and Prevention provides HIV/AIDS information through a specially designed HIV curriculum for Native American youth. Community education is provided in these and other topics through prevention workshops, NACS Newsletter articles, outreach, surveys, special health and wellness events and presentations to community groups.

In 1997 the AI developed, produced and distributed the "Protect Our Nations" poster and brochure. These were created in cooperation with NACS and with substantial input from the Native American community. Native artists designed the poster and brochure cover as well as other artwork for the brochure.

In 1994, NACS was funded by the AI to develop a Native American cultural competency training curriculum for existing HIV educators. Community input meetings and questionnaires gathered information for the Native American Training Initiative (NATI) from members of Native American communities. Based on community input, the NATI curriculum was expanded to meet the needs of potential Native American HIV educators. The curriculum *Empowering Native American HIV Educators, Protect Our Nations* was published by the AI. Five one-day NATI training sessions held across the state offered basic information on HIV/AIDS

for potential Native educators and a cultural competency workshop for non-Native educators. More than 75 Native American peer educators were trained to educate their communities about HIV/AIDS.

Policy Development

The Native American Leadership Commission on Health and AIDS (NALCHA), funded by the AI, brings together leaders from different Native American communities to discuss HIV/AIDS and Native Americans (see related story below). NACLCA also conducts HIV/AIDS-related needs assessments, which are shared with the AI. Together, the AI and Native communities seek to meet priority needs.

The AI facilitated inclusion of the NYS Native community in "Eliminating Health Disparities, Conversations with American Indians and Alaska Natives" published by ETR Associates, Inc. Pamela J. Everingham (Onondaga Nation, Snipe Clan) was featured in the monograph.

Internal AI Staff/Staff Development

The Division of HIV Prevention has employed Native American staff, one as a contract manager and one test counselor. To strengthen the understanding of Native American culture, traditions and history among staff from all backgrounds and cultures, display tables are used to showcase materials from AICH, NACS and the National Native American AIDS Prevention Center (NNAAPC). Reading materials are circulated and staff attend meetings at which Native American issues are featured.

HIV Prevention Community Planning

Since its inception in 1994 the NYS HIV Prevention Planning Group (PPG) has included eight (8) Native American PPG members. Many have held leadership positions within the PPG as Committee Co-chairs. Both major AIDS Institute-funded agencies serving

Native Americans, AICH and NACS, have had ongoing participation in the PPG. The Native American community has also participated actively in the PPG's needs assessment activities. AICH Outreach Education Coordinators and representatives of NACS have participated in the Statewide Regional Gaps Analysis (RGA) and AICH hosted a Native American Discussion Group in NYC as to inform the RGA.

PPG agendas have featured and will continue to highlight Native American history, culture, traditions and discussion of HIV prevention issues as well as epidemiologic information about HIV/AIDS and Native Americans. For example, the November 2003 full PPG Meeting featured a plenary presentation offered by Chief Lyons (Onondaga) and an epidemiologic overview of HIV/AIDS among Native Americans, a Native American materials packet, an evening Storytelling program, a breakfast panel discussion on gay and lesbian Native Americans as well as Supplemental Day sessions on Native Americans and Substance Use and Native Americans and Trauma.

WORKING TOGETHER TO ADDRESS A PRIORITY UNMET NEED FOR NATIVE AMERICAN TEST COUNSELORS IN NEW YORK STATE

By Ken Dunning and Cissy Elm, American Indian Community House and Mara San Antonio-Gaddy and Susan J. Klein, NYS-DOH AIDS Institute

The American Indian Community House (AICH) was founded in 1969 by Native American volunteers as a community-based organization, with a community-elected Board of Directors, mandated to work to improve the status of Native Americans and to foster intercultural understanding. AICH has expanded



since then to include programs in job training and placement, health services, HIV services, and alcoholism and substance abuse counseling, education and referral. In addition to meeting direct social needs, AICH sponsors programs in cultural enrichment through a performing arts group and a permanent gallery/museum. Together, with the people, these programs form the American Indian Community House. The HIV/AIDS Project (New York City) was created in 1990 to provide prevention education, deliver HIV related services, and provide culturally relevant referral/case management services.

Funded as well by the NYSDOH AI, the Outreach Education Coordinator (OEC) Network started in 1995. It is designed to empower and assist Native American communities to openly address the issues of HIV/AIDS and to develop culturally relevant outreach, education and prevention case management services.

The NYSDOH AIDS Institute (AI) funded a Community Development Initiative, the Native American Leadership Commission on Health and AIDS (NALCHA), which brought together Native American leaders from across NYS to discuss issues relating to HIV/AIDS. The goal of the first year was to produce a document entitled, "A Native American Leadership Response to HIV and AIDS." Out of this document was the birth of the Outreach Education Coordinator (OEC) Network. Funded as well by the NYSDOH AI, the OEC Network started in

1995. It is designed to empower and assist Native American communities to openly address the issues of HIV/AIDS and to develop culturally relevant outreach, education and prevention case management services. Currently there are five regions: Syracuse—Onondaga Nation, Buffalo, Akwesasne-Mohawk Nation, Riverhead, and NYC, each with an OEC who is responsible for the following:

- Carrying out a risk reduction program to improve the health status of their community;
- Promoting healthy behavior among Native Americans who are at "risk" within their communities;
- Providing HIV prevention case management and referral services to Native Americans who seek their assistance; and
- Working on the development and maintenance of the Native American OEC Network within her/his community.

NALCHA maintains an ongoing needs assessment process to gather input from the Native American community. Community views and perspectives are elicited not through a "scientific" process, but rather, in ways that are consistent with Native American community values and culture. Needs assessment strategies are community based (e.g., on nation territories and in urban communities and at community health fairs, schools, health clinics, street outreach locations, pow wows and other community gatherings), open and inclusive.

Through the needs assessment process, community members identify and prioritize key HIV-related needs and services for their respective communities. During 2001-2002, top priorities across several regions reflected the need for more Native American people to be tested for HIV and for access to Native American test counselors.

In November 2002, staff from the AICH and the AI met by telephone conference call to discuss ways in which AICH and AI could work together to fill this priority unmet need. Drawing upon the respective strengths of AICH and AI, NYS was able to implement a plan to meet the need for Native American test counselors by preparing AICH's regional Outreach Education Coordinators (OECs) to offer HIV counseling and testing. This plan addressed several components:

Training

Each OEC completed courses, available at no charge through the AI's Statewide Calendar of HIV/AIDS Training, prior to initiating testing. Four courses comprised the basic core to prepare the OECs to offer testing. These courses were: HIV/AIDS Confidentiality Law, HIV Testing Procedures, Implementing HIV Reporting and Partner Notification and Practicing the NYS Domestic Violence Screening Protocol. Arrangements were made for OECs who were unable to attend the scheduled training courses to receive comparable training one-on-one from AI staff.

In addition, the AI has experienced Anonymous Counseling and Testing (ACT) Program staff in each NYS region. ACT staff worked with the OECs to help them prepare for implementation of HIV counseling and testing. For example, ACT staff met with the OECs to review policies and procedures, forms, and other aspects of establishing HIV counseling and testing as a new service. OECs also observed experienced ACT staff conduct HIV counseling and testing sessions.

Counseling Message

The OECs are best suited to determine if and how to tailor the counseling message to Native Americans and this aspect is ongoing. Together, NYS will learn as much as possible about how the counseling session should be tailored to meet the needs of Native Americans.

Responsible Physician

NYS law requires laboratory tests, including HIV tests, to be ordered by a physician. An ordering, or “responsible,” physician was identified in each region to work with the OEC.

Supplies and Materials

The AI provides each OEC with a supply of OraSure test kits, gloves and any other materials that the OECs needed. AICH and AI worked together on promotional fliers.

Referral Resources

The OECs have extensive linkages with health and human service agencies in their regions, including HIV/AIDS service providers. The AI’s Statewide Resource Directory is another source of information for referrals, including for those who test positive.

Evaluation

AICH and AI agreed that the OECs would use the Counseling and Testing Scannable (CTS) forms. Together, specific questions were identified focusing on test seeking behaviors and feedback on the services received. Completed CTS forms are provided to the AI monthly. AI staff enter, clean and compile the data which are shared back with AICH. Together, AICH and AI review the information that is collected to assess the success of the testing initiative and to inform future planning.

AICH initiated HIV C&T in Syracuse and Buffalo on October 29, 2003. Start-up in other regions has been delayed by turnover among OECs. AICH and AI are committed to continue working together so that HIV counseling and testing can begin in other AICH regions in the future.

NORTH CAROLINA

Evelyn Foust, Branch Head, HIV/STD Prevention and Care Branch, and Pete Moore, Senior Public Health Advisor, provided assistance with this profile.

Although there are over 80,000 Native Americans living in North

Carolina, there is only one federally recognized tribe, the Eastern Band of Cherokee, in the western part of the state. The Lumbee tribe is currently seeking federal recognition. In addition, along with the Eastern Band of Cherokee and the Lumbee, the state recognizes the Coharie, Waccamaw-Siouan, Haliwa-Saponi, Indians of Person County and Meherrry tribes (<http://www.doa.state.nc.us/doa/cia/flyer.htm>). (Historically, the Tuscorora were also part of North Carolina, but officially moved to New York in the 1700’s — http://www.ncsu.edu/stud_orgs/native_american/nctribes_orgs/ncnahistory.html.) Because of this diversity, the North Carolina HIV/STD Prevention and Care Branch believes that the Indian communities have their own cultural beliefs and values that should be reflected in the programs they fund to serve them.

To better understand Native American communities and incorporate culturally appropriate information into their programs and address the HIV/AIDS needs of Native Americans in North Carolina, the Division of Health HIV/STD Prevention and Control Branch recently contracted with a Native American community-based organization, the Native American Interfaith Ministry, Inc. (Healing Lodge), to conduct a needs assessment [a knowledge, attitudes, behaviors and beliefs (KABB)] survey among Native American communities. The state health department and planning group were concerned about the high rates of HIV and syphilis among the Native American communities in North Carolina, particularly those in the Eastern section of the State. The STD/HIV Prevention and Care Branch wanted more information on the Native American community overall because, although they had done needs assessments or surveys among other populations before, they had no specific information on Native American communities.

The Healing Lodge was a natural group for the health department to contract with for this work because the health department had previously worked on a HRSA SPNS project with them that

focused on culturally competent access to care. The Healing Lodge was formed in 2001 and is a coalition of tribal chiefs, government associations, and ministers. The impetus for this association came from the tribal ministers, who are very influential in the Native American communities in North Carolina. These tribal leaders started the Healing Lodge, which is an initiative to provide health information and training to the Native American community around Pembroke, North Carolina. The Healing Lodge supports health summits and workshops through a three-year American Indian Health Initiative. The ministers spearheaded the partnerships that became the Burnt Swamp Association. The acting head of the Healing Lodge, Dwayne Lowry, is the Chair of North Carolina’s AIDS Task Force.

To complete the needs assessment, the Healing Lodge subcontracted with the North Carolina Commission of Indian Affairs. This Commission, formed in 1971, currently has broad focus around advocacy for American Indian tribes and organizations. The Commission works on state legislation for American Indians, the use of funds for Native American communities and the local relationships between tribe and state government. According to its mission, the Commission must: deal fairly and effectively with Indian affairs; study, consider, accumulate, compile, assemble and disseminate information on any aspect of Indian affairs; investigate relief needs of North Carolina’s Indians and provide technical assistance in the preparation of plans for the alleviation of such needs; and confer with appropriate officials of local, state and federal governments and agencies and congressional committees about the implementation of resources.

In addition to the needs assessment, the Commission currently has an ongoing collaborative partnership with the North Carolina Department of Health and Human Services. One of the key things that the Commission has done is help legitimize the health department’s work.



North Carolina has collected over 1,000 surveys for the needs assessment. The HIV/STD Prevention and Care Branch hopes to use the results of the needs assessment to improve the cultural appropriateness of their ongoing social marketing campaigns through radio, TV, billboard and bus advertisements. The Branch has also funded outreach workers and provided technical assistance on counseling, testing and referral services and active outreach in Native American communities in eastern North Carolina.

According to Pete Moore in the North Carolina HIV/STD Prevention and Care Branch and Missy Brayboy, of

“...the tribes (in North Carolina) need clinics in each community where American Indians can go and receive clinical services and counseling in a culturally appropriate setting.”

Pete Moore, North Carolina HIV/STD Prevention and Care Branch

the Commission of Indian Affairs, one of the greatest needs among the Native American communities of North Carolina is having clinical facilities in these communities that have counselors and clinicians who are culturally competent. One of the key concerns in Native American communities is privacy and confidentiality. Moore says that “the tribes need clinics in each community where American Indians can go and receive clinical services and counseling in a culturally appropriate setting.” Brayboy says, “you ...have to deal with the spiritual side; have to go back and reconnect to the basic value system to make significant change and impact; you have to help individuals reconnect with their basic values to make behavior change.”

One of the key next steps North Carolina sees to accomplishing this is to target prevention messages to Native American communities in areas where they get their information. Moore suggests several recommendations for health departments wishing to do more to address the epidemic in Native American communities: be aware of the political landscape; pay respect to the tribal governments; ask questions rather than offer answers, but describe what you have to offer; be sensitive to the history of existing trauma in a community; and empower communities to do this work themselves.

NORTH DAKOTA

Karin Mongeon, HIV/AIDS Program Manager for the North Dakota Department of Health, provided assistance with this profile.

North Dakota is home to four Native American reservations: Standing Rock Sioux, Turtle Mountain Chippewa, Spirit Lake Nation and the Three Affiliated Tribes (Mandan, Hidatsa and Arikara). Although North Dakota has documented a disproportionate impact of HIV/AIDS on Native Americans in the state, they have not previously been able to provide a lot of HIV prevention in these communities. North Dakota has IHS facilities although, as in other rural, tight-knit Indian communities, confidentiality is a significant concern. The health department provides HIV counseling and testing to Native Americans through its public testing sites.

At the request of the community planning group, a needs assessment was conducted in 2001 to determine the reasons Native Americans in North Dakota weren't accessing services and found that there was a perceived lack of risk among these communities. The needs assessment was conducted by Leander McDonald, PhD, an assistant professor at the Center for Rural Health, located in the University of North Dakota

School of Medicine and Health Sciences. Dr. McDonald is the associate director of research for the National Resource Center on Native American Aging and has assisted 88 sites representing 132 tribes in conducting needs assessments. The resulting baseline data has assisted the tribes in the development of long-term care infrastructure and in strengthening grant proposals to address identified needs.

At the CPG's recommendation, North Dakota moved forward with a media campaign even prior to the completion of the needs assessment, based on other less formal data that indicated a lack of perceived risk.

The findings from the needs assessment solidified the need for North Dakota to develop a public information campaign to dispel myths about HIV/AIDS and its risk among Indian communities in North Dakota. The Department of Health contracted with KAT Productions, a local multimedia agency which has spent years working with and building trust in North Dakota Indian country to develop the public information campaign. The campaign, entitled “Call Upon Your Spirit of Courage,” includes radio spots, a poster, an educational video, brochures, and periodic newspaper spots or advertisements. There are five “calls to action” revolving around the campaign:

- Accept responsibility
- Make healthy choices
- Reach out
- Teach others
- Lead

Although they had considered developing separate campaigns for each of the Indian communities in North Dakota, tribal leaders consulted during the development phase of the campaign told KAT Productions that if there were input from all communities, an overall, statewide campaign would be acceptable. To develop the campaign, the media agency conducted market

research among tribal leaders, tribal health care professionals, college-aged Native Americans, and community educators. A key result of the market research was identification of the theme's campaign, "Call Upon Your Spirit of Courage," which the tribal leaders said spoke to Native American cultural values and would be effective in their communities. The campaign began by targeting the general population, but North Dakota expanded the campaign to include a campaign brochure targeting Native youth.

As testament to the impact of this program, in 2002, "Call Upon Your Spirit of Courage" was recognized nationally by the Public Health Information Coalition's Bronze Award for Excellence.

As testament to the impact of this program, in 2002, "Call Upon Your Spirit of Courage" was recognized nationally by the Public Health Information Coalition's Bronze Award for Excellence.

With positive initial feedback on the campaign, in 2004, North Dakota will be conducting an evaluation of the campaign's effectiveness and communities reached. They have some sense that the reach of the campaign could be expanded because, although they sent materials to those they thought were the public health gatekeepers in Indian communities, they have heard that not all the information was actually disseminated and used beyond those recipients.

One important reason for the success of the program may be the contractor selected for the campaign. Because they had previously done work in Indian Country, KAT Productions knew and had established ties with tribal leaders in

each reservation. They had the capacity to meet the needs of the RFP the health department issued for the campaign. (The health department did send the RFP to tribal universities, but they lacked the capacity to meet the requirements in the RFP.)

In addition to evaluating the campaign, Karin Mongeon, HIV/AIDS Program Manager for the North Dakota Department of Health, says that they are currently considering options for how to better serve Native Americans in North Dakota. One problem is lack of resources and experience. Funding is a major barrier in a state that receives only \$750,000 in support from CDC for HIV prevention annually. The prevention planning group has been a major impetus for increased attention in this community, and their efforts have resulted in increased representation by Native Americans on the planning group; a quarter of the representatives on the 2003 planning group there are Native American.

OKLAHOMA

John Cocke, Program Coordinator and Aisha Shah, Contract Monitor at the Oklahoma State Department of Health, provided assistance with this profile.

In Oklahoma, which is home to the largest number of Native Americans of any state, the state health department has funded the Indian Health Care Resources Center of Tulsa to provide HIV/AIDS prevention for Native men who have sex with men (MSM) and their sexual partners, including HIV positive MSM in the Tulsa and South Eastern region of Oklahoma. Indian Health Care first received funding in 1995, and in 2002 received about \$78,000 for the urban program. The rural component of the program was funded for two years at around \$51,000. They have also received a small amount of funding (\$4000) from the United Way.

The services provided by Indian Health Care include HIV prevention

outreach for MSM in community settings like pow-wows, health fairs, and other events, as well as a group level intervention with four successive skills-building sessions focused on safer sex behaviors. It also includes a counseling and testing component for MSM who want a confidential or anonymous HIV test. The program has two HIV prevention coordinators: John Cocke (Osage, Peoria and Cherokee) and Glen Arnold (Mexican Native). Based in Tulsa, they both also travel to most parts of South Eastern Oklahoma to conduct HIV prevention trainings that target behavior change. They utilize a pre- and post-test knowledge, attitude, behavior and belief (KABB) survey for all group level interventions. According to John Cocke, the focus of Indian Health Care's prevention programs is on providing culturally correct HIV prevention services and modeling safe Two Spirit roles for Two Spirit MSM, as well as instilling a sense of community among Two Spirit MSM and their sexual partners.

Aisha Shah, Contract Monitor for the project at the Oklahoma State Department of Health, reports that over 100 Native MSM have received outreach, 35 received a four-session group level intervention, and 40 received an HIV counseling and testing session over a twelve-month period in the urban program. The rural program targeted 140 Native MSM for outreach.

Cocke reports that "it has taken some time to win the trust of the MSM native population in Oklahoma. The Native community in Oklahoma looks at the consistency of a person working in their community. If you just breeze in and only see them once in a while they will not open up. It took us since 1995 to win the trust of the people. We worked with them every month until they trusted us; they knew we would be there for them."

"Since then we have won the trust of the targeted population, MSM are now very open to our programs, and trainings on HIV/AIDS prevention,"



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Cocke says. Furthermore, Shah reports that the program has been successful in providing a supportive format for men who cannot openly express their feelings within a larger community. This group format gives them a chance to learn relationship skills, negotiate safer sex practices, and this in turn reduces their risk of acquiring HIV.

However, there are some key issues that impact the ability of Indian Health Care’s ability to work with and provide services to Native Americans in Oklahoma, including tribal government issues, urban-rural differences and trust. Cocke reports that, “Most of our tribes are not open to the Two Spirit’s role in our community, but we have found that the traditional people of the thirty-seven federally-recognized tribes in Oklahoma who do know about Two Spirit people’s traditional roles are very open to helping reach our targeted population.”

Cocke further elaborates, “When I have talked to tribal leaders, they say that they have many problems [to address within] the tribes and [that] HIV and the Two Spirit people are not a

priority. This is from some leaders in the Five Civilized Tribes, who have adopted more of the non-native way of life and the Christian way of life. The other tribes in Oklahoma, who were the last to civilize, have more of a compassion for our Two Spirit people, but it is not talked about. The tribes know that there are still Two Spirit people, but we do not have the roles as in the past. I feel as we continue to be consistent with our message of the Two Spirit people, we will finally bring our roles back to the tribe. At my last conference, there was an elder from the Lakota tribe who said that the last part of our sacred Hoop that needs to be healed is our Two Spirit people. When that is done, he said, our people and tribes will be whole again.”

Both Cocke and Shah say that reaching rural Native MSM is very difficult. One reason Cocke cites is that many of them are “closeted, married, live in small towns, [and do] not want people to know their behavior,” and are also significantly impacted by drug and alcohol addiction. Shah told NASTAD that incorporating the MSM program into the rural setting was difficult because the stigma, isolation, and cultural values of Oklahoma did not allow the men to identify as gay or bisexual, and they were afraid to congregate for a four-session group level intervention. In addition, the lack of incentives to offer people to come back for multiple-session interventions was a barrier. Staffing concerns were also a concern, both in terms of facilitation skills and cultural appropriateness.

Shah feels that a one-on-one approach would be more feasible for activities in the rural areas. Evidence-based programs that have demonstrated behavior change will be funded in the future. There are plans to conduct a statewide needs assessment to measure the needs in the rural areas. This will give Oklahoma an idea about the needs, and expectations of providing culturally appropriate HIV care for the Native and Two-Spirited community in Oklahoma. The HIV/STD prevention services at

the Oklahoma State Health Department will utilize the community-planning group’s priority population and the Oklahoma epidemiological profile to fund additional programs.

Because of the evaluation process during 2002, Oklahoma now has documentation showing that this program is working for Native Two Spirit men. There were 16 one-on-one interviews, and the men, in their own words, expressed how the program has changed their lives and their behavior. (Copies are on file at Indian Health Care.) Funding has become a problem since the rural program was eliminated. But because Oklahoma has built rapport with rural Two Spirit men, they still check on them. Cocke says that “Because they are so isolated, they feel no one cares about them, and I strongly feel that we need to incorporate our rural outreach again.”

According to Shah “Future funding in Oklahoma is concentrated around HIV-positive people and their mental as well as social and behavioral needs. The Centers for Disease Control and Prevention has placed additional emphasis on professionally delivered prevention case management services for HIV-positive individuals and the Oklahoma State Health Department is in tune with the CDC’s new initiative.”

In addition to this program funded by the health department, the Indian Health Care Resources Center also organizes an annual retreat, which is both a cultural as well an educational gathering. Native Americans from all over Oklahoma as well as the United States gather to form community partnerships, and target HIV prevention in the Native Two Spirited/Gay community. They have ceremonial dances, prayers, and a cultural meal to end the whole event. They discuss and share success stories from all over the United States and a common goal towards preventing HIV.

RECOMMENDATIONS

While the challenges health departments may face 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.

Building trust and establishing rapport with the tribal leaders and elders who are the gatekeepers for health issues in their communities are critical.

An analysis of the programs supported by the health departments profiled in this Report point to 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;
- Re-assessing current situations to respond to a changing epidemic (e.g., NM syphilis outbreak);
- 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. State and local health departments should endeavor, whenever possible to safely do so, to refrain from grouping Native Americans/Alaska Natives with other

racial/ethnic minority groups in an “other” category, and, in places with large Native American communities, attempt to disaggregate the AI/AN category.

These themes are echoed in the literature and by Native Americans NASTAD spoke with for this Report. Sharon Day and Nic Metcalf from Minnesota offered the following recommendations:

- Designate seats from rural communities for the planning groups and make planning more respectful.
- Recognize the distinctive cultural needs from different tribes and adjust programs accordingly.
- Acknowledge the complexity of doing this work.
- Convene meetings with IHS programs and tribal officials on how to work more closely.
- Address staffing issues in health departments.
- Change the way agencies are funded—resources are inadequate and existing resources are too categorical/not holistic.
- Develop infrastructure in local/tribal agencies through capacity building that is culturally appropriate (e.g., not a workshop format) and encompasses a spiritual framework.
- Follow through!

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. The full version of these “tips” can be used as a guide for health department staff; here are just a few of these important “tips” (see Appendix II for full version):

- ✓ 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.
- ✓ Promote awareness and understanding of Native American issues among your community planning group and include Native Americans as members.
- ✓ Use a variety of methods to promote awareness and understanding of Native American issues among Health Department staff.

CONCLUSION AND NEXT STEPS

Working with Native American communities to address HIV/AIDS is important and must be done sensitively and collaboratively with Native American communities. But there clearly are challenges. As with other communities of color, the fact that HIV/AIDS significantly impacts Native Americans, coupled with their small population sizes, makes it imperative that they not be left out of HIV/AIDS prevention and care and treatment efforts.

To follow up on this Report, NASTAD intends to collect more examples of how state and local health departments have successfully worked with Native American communities and will continue to support information sharing and technical assistance between health departments wishing to improve their work with Native American communities. NASTAD also plans to help facilitate a national dialogue between representatives from health departments and Native American agencies and communities about ways to build trust and capacity in Native American communities, further address the structural barriers to providing services in Native American communities, address confidentiality issues, further identify culturally competent models for health departments, and facilitate outreach to the Indian Health Service.

Thirteen Policy Principles for Advancing Collaborative Activity Among and Between Tribal Communities and Surrounding Jurisdictions. Generated at the NACCHO Turning Point Spring Forum 2001 in Washington, D.C. (Used with permission and 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.*

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APPENDIX I.

Overview of National Data

Demographics

There is a rich diversity within and across Native American communities. There are over 550 federally-recognized Native American tribes¹ in the United States. Individual states recognize many others and still others are not recognized by the federal government. There are up to 300 distinct languages (HRSA 2002; Oropeza 2002; Maldonado, 1999). About half of Native Americans live on or near reservations,² with the other half residing in other rural and urban locations. Native Americans' political structure (i.e., band, tribe, chiefdom, confederacy), cultural traditions, and economic, class and gender relationships are equally diverse. In addition, there are differences in how families and relations are constructed. A Western, nuclear family may not be the primary frame of reference for Native communities that rely on extended families and clans for familial support and governance (Oropeza, 2002; Dunning, 2003; Indian Health Service, 2004).

According to decennial census data collected in 2000, just over 4.1 million people (1.5% of the U.S. population) identified themselves as American Indian or Alaska Native.³ Of these 4.1 million, nearly 2.5 million identified themselves exclusively as American Indian or Alaska Native (a 26% increase from 1990 data) and 1.6 million identified themselves as American Indian or Alaska Native in combination with another of the five census categories for race. Also, Native Americans overall are a young population relative to whites: a third of the Native American population is under the age of 18 (33.6%), 60% are between the ages of 18 and 64 and 6.3% are over the age of 65 (Ogunwole, 2002).

Geographically, about half of all Native Americans live west of the Mississippi River. Four in ten Native Americans live in western states. The West not only has the largest Native American population, but the West also boasts the highest proportion of Native Americans in its total population. The ten states with the largest number of Native Americans, in order, are: California, Oklahoma, Arizona, Texas, New Mexico, New York, Washington, North Carolina, Michigan and Alaska. Together, these states are home to more than half of the entire population of Native Americans in the U.S. (Ogunwole, 2002). Nineteen states have a Native American population in excess of the national proportion of 1.5%. The states with the highest proportion of Native Americans or Alaska Natives are Alaska (19%), Oklahoma (11%) and New Mexico (10%). The remaining sixteen states are Arizona, California, Colorado, Idaho, Montana, Nevada, Hawaii,

Oregon, Utah, Washington, Wyoming, Kansas, Minnesota, North Dakota, South Dakota and North Carolina.

HIV/AIDS Among Native Americans

As with other communities of color, HIV/AIDS cases among Native Americans have increased since the mid-1980s. AIDS diagnoses by year increased from 157 in 1998 to 206 in 2002 among American Indian/Alaska Natives (CDC, 2003, table 3). There were cumulatively 2,875 diagnoses of AIDS among American Indian/Alaska Natives through 2002, or 0.32% of all AIDS cases (2,875/886,575) reported (CDC, 2003, table 3). When it comes to HIV data, as of 2002, there were an estimated 1,565 American Indian/Alaska Natives living with HIV and AIDS; based on data collected from the 30 states with confidential name-based HIV infection reporting since 1998 (CDC, 2003, table 8).⁴

Misclassification and Aggregating Data

HIV/AIDS among Native Americans may be greater than current statistics indicate. "Underreporting and the lack of detailed HIV surveillance of AI/AN may result in significant undercounting of HIV infections" (Rowell and Bouey, January 2002).

In some instances, Native Americans may be misclassified into other racial/ethnic categories (Belongia, et al., 1995). Many Native Americans are of mixed heritage and are often classified as African American, Asian/Pacific Islander, Latino or Caucasian (Oropeza et al., 2001). Underreporting and racial misclassification of American Indians and Alaska Natives is a problem across health, with one study finding that Native Americans in general are undercounted by 38% nationwide (Burhansstiipanov, 2000). This concern was identified early in the epidemic and championed by the National Native American AIDS Prevention Center (NNAAPC) (Rowell and Bouey, 1997). In an *MMWR* focused on HIV/AIDS among American Indians and Alaska Natives in 1998, the problem of misclassification of Native Americans into other racial/ethnic populations was also noted, "One limitation of these data was the possible under-representation of the impact of the HIV/AIDS epidemic among AI/ANs because of misclassification of AI/ANs to other racial/ethnic populations (i.e., previous reports have indicated high rates of misclassification of AI/ANs to non-Hispanic white or Hispanic categories" (CDC, 1998:160).



However, as with other aspects of HIV/AIDS among Native Americans, misclassification is not a universal problem in the U.S. Alaska has studied the issue and found little problem with the accuracy of race/ethnicity data of cases of HIV/AIDS in Alaska Natives. “In Alaska, where Alaska Natives are the largest minority group and where there is an extensive health care system serving Alaska Natives almost exclusively, less misattribution of race/ethnicity occurs than in the contiguous U.S.” (Cordes and Bell, 2003).

Besides racial misclassification, lumping all Native Americans in an “other” category with other racial/ethnic minorities (usually Asian/Pacific Islanders), or in some cases into one overall American Indian/Alaska Native category, can create problems in identifying communities most at risk for HIV/AIDS. In some cases, overriding concerns about breaches in confidentiality when using small sample sizes are the rationale for these lumped categorizations, and this may need to be a limitation in presentation of some data. However, not only does this mask the impact of the epidemic on different communities of color, but it may also serve to perpetuate the “pan-Indian myth” and fail to make programs culturally appropriate. “While there are similarities in indigenous peoples, there are many cultural, behavioral and social differences that must be taken into account...By aggregating AI/AN into one category we compromise the effective[ness] and impact of public health activities” (Satter, 1999: 3).

As HIV data for all states become available, CDC needs to ensure that good HIV reporting data exist for Native Americans. State and local health departments should endeavor, whenever possible to safely do so, to refrain from grouping Native Americans/Alaska Natives with other racial/ethnic minority groups in an “other” category, and, in places with large Native American communities, attempt to break down the AI/AN population.

¹ “Tribe” is used in this document to denote a specific group or community of Native Americans, usually defined by a combination of bounded territory, shared culture and language history.

² A reservation is technically defined as a tract of land reserved for a tribe “when it relinquished other land rights to the U.S. Government through treaties” (Oropeza, 2002). Tribes have a sovereign relationship with the U.S. government. “Reservation” is the most common term referring to the specific lands of federally-recognized tribes—other terms for the places where tribes live include rancherias, pueblos, reserves, etc. Many Native Americans do not live on reservations (or other designation for the land) and some non-natives live on reservations.

³ Not all Native Americans participate in the United States census process.

⁴ Importantly, HIV data does *not* include many of the states with the highest proportion of Native Americans, because until recently some states have not reported HIV cases, also CDC does not accept HIV data from non-name-based HIV reporting states. States that are not accounted for include: Alaska, California, Connecticut, Delaware, District of Columbia, Georgia, Hawaii, Illinois, Kansas, Kentucky, Maine, Maryland, Massachusetts, Montana, New Hampshire, New York, Oregon, Pennsylvania, Rhode Island, Texas, Vermont and Washington.

APPENDIX II.

Lessons Learned in HIV Prevention: “Tips” for Health Departments Working with Native American Communities

*by Susan J. Klein, M.S., Director, Division of HIV Prevention, AIDS Institute,
New York State Department of Health, Albany New York*

- ✓ Study, learn and become knowledgeable about Native American history, including sovereignty and governance issues, in both the United States and within your jurisdiction.
- ✓ 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. Remain sensitive to the fact that public health activities such as HIV name reporting and partner notification may be “lightning rods” in the context of sovereignty and other issues.
- ✓ Be sensitive to Native American protocol. Native American governments and leadership have pre-established means for government-to-government relations and interaction.
- ✓ 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. Many times, Native American issues and/or concerns are overlooked in policy-making.
- ✓ Recognize and acknowledge that the federal government has not fulfilled treaties and promises and that your state government, of which you are a representative, may also not have fully honored obligations to Native American communities that are sovereign nations in your jurisdiction.
- ✓ Keep your word. Avoid making commitments that you cannot fulfill.
- ✓ Become familiar with the history, culture, traditions and values of Native American communities in your jurisdiction.
- ✓ Become familiar with the appropriate terminology used by a particular Native American nation/community. Each nation/community is different. Be cognizant of how Native Americans refer to themselves and their people. This includes:
 - Preference of the terms—Native American, Indian, American Indian, or a term in a Native language; nation or tribe; Nation territory, reservation, or reserve; etc.
 - Some Native Americans refer to their nation using a term in their native language, not the English term used commonly by outsiders (Haudenosaunee, not Iroquois; Lakota, not Sioux; etc.).
 - Some Native Americans also identify themselves according to their clan, or extended family.
- ✓ When historical facts and experiences of Native communities are shared, especially by individual Native Americans whom you know and care about, sometimes it can be difficult, even when there is no finger pointing or blame. 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. Try to understand the various perspectives on these issues.
- ✓ Respect and honor history, culture, traditions and values in your work and interactions with Native communities. Strive to meet Native people in person, do not rely on letters, email or telephone contact. Avoid stereotyping Native Americans, their nations and tribes.
- ✓ Recognize that “Native American” includes a broad range of perspectives and that there are different views concerning who is Native American, who represents traditional Native communities, what values Native people have, and other issues. Prevention efforts should incorporate a variety of Native perspectives.
- ✓ 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.
- ✓ Support culturally appropriate HIV prevention interventions developed and delivered by Native Americans. Select art work and any images for Health Department materials in consultation with members of Native communities.
- ✓ Recognize and acknowledge traditional concepts of Native American health and healthy lifestyles. This includes a holistic view of health, comprised of the physical, mental, emotional, and spiritual components of the individual and/or community.



- ✓ Seek assistance from a Native agency/agencies in meeting needs of individuals from Native communities, with their consent to do so.
 - Some Native medicine healers will not work with a non-Native caseworker. When an HIV-infected client with a non-Native caseworker wishes to access Native traditional medicines, a Native agency may be able to assist in the traditional process of finding a medicine healer on Nation territory and help other needs, such as transportation to the reservation.
 - At the same time, recognize that some Native people, especially those who may be at high risk for HIV/AIDS (i.e., MSM) may not be comfortable working with Native providers.
- ✓ Examine epidemiologic and other data concerning the health status of Native Americans in your jurisdiction and in the United States. Become familiar with the multiple epidemics and inter-generational trauma impacting Native American nations/communities. Some of the most common include substance use, diabetes, suicide, physical and sexual abuse, and boarding school experiences. The most effective HIV prevention may occur when Native American nations/communities have the means to address these related issues.
- ✓ Promote awareness and understanding of Native American issues among your community planning group and include Native Americans as members. Native Americans who are from and actively engaged in their Native nations/communities are the most knowledgeable about them. Support and encourage their participation. Be reasonable in your expectations. Remember that individuals speak from their own experiences and cannot speak for all members of their community or all Native communities.
- ✓ Raise awareness of Native American needs and issues among other planning/advisory bodies as opportunities arise.
- ✓ Respect and use needs assessments that are conducted by Native Americans within their communities in your needs assessments and planning processes. Involve Native Americans in your HIV prevention needs assessments and look for ways to meet identified needs.
- ✓ Use a variety of methods to promote awareness and understanding of Native American issues among Health Department staff.

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APPENDIX III.

Resources and Agencies

American Indian Community House (AICH)

Based in New York City, AICH represents over 70 different Native American tribes. AICH sponsors a breadth of social service programs, including those on public health. In addition to an HIV/AIDS project that provides services in NYC and throughout New York State, AICH publishes newsletters and reports, including *A Native American Leadership Response to HIV and AIDS*. For more information, visit: www.aich.org.

National Association of County/City Health Officials (NACCHO)

With support from the W.K. Kellogg and Robert Wood Johnson Foundations, NACCHO developed the Turning Point program, a broad public health initiative on building public health infrastructure. This program worked with several Native American communities. Information on Turning Point is accessible at: www.naccho.org.

U.S. Commission on Civil Rights

The U.S. Commission on Civil Rights has recently published two important documents related to Native Americans: *A Quiet Crisis: Federal funding and unmet need in Indian country (July 2003)*; and *Broken Promises: Evaluating the Native American Health Care System (July 2004)* <http://www.usccr.gov>

Capacity Building Assistance Providers

The Centers for Disease Control and Prevention has funded three capacity building assistance (CBA) providers through 2009 to provide capacity building assistance in their four focus areas. These agencies have put together a [CBA Fact Sheet](#) outlining the CBA services they provide and are briefly profiled below.

The National Native American AIDS Prevention Center (NNAAPC)

NNAAPC provides technical assistance to American Indian, Alaska Native and Native Hawaiian communities, including a number of resource guides and newsletters, including *Seasons* and *In the Wind*. NNAAPC is funded by CDC to provide CBA around strengthening organizational infrastructure for HIV prevention (CDC priority area 1) and strengthening interventions for HIV prevention (CDC priority area 2). They have a [Resource Guide](#) for Native American involvement in community planning, developed from a leadership training entitled, Native Leadership Empowerment Advocacy Participation (NLEAP). For more information, visit: www.nnaapc.org

The InterTribal Council of Arizona, Inc (ITCA)

Based in Phoenix, AZ, ITCA provides community planning TA/CBA (priority area 4). For more information, visit: www.itcaonline.com/program_hiv.html.

The Tri-Ethnic Center for Prevention Research (TEC)

TEC, based in Colorado State University provides CBA around strengthening community access and utilization of prevention services. For more information, visit: www.triethniccenter.colostate.edu.



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