HIV/AIDS AMONG AMERICAN INDIANS
AND ALASKA NATIVES

American Indians and Alaska Natives (AI/ANs)* have been disproportionately affected by HIV since the epidemic began more than 30 years ago.1 Though the overall number of AI/ANs living with HIV is small, this population has proven to be vulnerable to the disease’s effects as well as to a host of other related health issues. According to the U.S. Centers for Disease Control and Prevention (CDC), the transmission category for 75 percent (120) of the estimated 161 HIV diagnoses among AI/AN men was male-to-male sexual contact, while heterosexual contact accounted for 63 percent (32) of the estimated 51 HIV diagnoses among AI/AN women.2 In addition, the surveillance data may not reflect the true number of AI/ANs infected with HIV disease, as more than half (57.4 percent) of AI/ANs report they have never been tested for HIV.3,4 Compounding these challenges, AI/ANs experience high rates of poverty and homelessness, and are more negatively affected by many socioeconomic determinants of health.

Successfully engaging and retaining AI/ANs requires an understanding of their unique cultures and of the barriers they face when accessing care. This issue of HRSA CAREAction examines the strategies that Ryan White HIV/AIDS Program providers can use to offer culturally competent and sensitive care to their AI/AN patients.

DID YOU KNOW?

- Among 94 newly reported cases of AIDS in American Indian/Alaska Native (AI/AN) men, 50 were among men who have sex with men (MSM) and another 15 had a history of MSM and intravenous drug use.5
- In 2010, HIV was the ninth leading cause of death among AI/AN men and women aged 25 to 34.6
- The average life expectancy for AI/ANs is 72.6 years compared with the national average of 78.7 years.7
- In 2011, the AIDS rate (per 100,000) for AI/ANs was 6.4, compared with 4.2 for Whites.8

*AI/AN is used throughout this newsletter except where a publication calls out either American Indians or Alaska Natives but not both. In those instances, we follow the term used in the publication cited.
According to Morbidity and Mortality Weekly Report, nearly half (57.4 percent) of American Indian/Alaska Natives (AI/ANs) report that they have never been tested for HIV. Finding at-risk and HIV-positive AI/ANs and bringing them into care is an important part of addressing the care continuum, meeting the goals of the National HIV/AIDS Strategy, and fulfilling the mission of the Ryan White HIV/AIDS Program.

AI/ANs, however, have a historic mistrust of the medical system, creating a significant barrier to reaching and engaging this population. When AI/AN patients do present for testing and treatment, many have advanced HIV disease and, when compared with other racial and ethnic minorities, lower survival rates. We can—and must—do better.

At HRSA we are working hard to address these issues through education, training, and AI/AN-focused curricula by our AIDS Education and Training Centers (AETCs), including AI/AN-specific local AETC performance sites, such as the Alaska Tribal Health Consortium, the South Puget Intertribal Planning Agency, and Salish Kootenai College. Because of our dedication to increasing awareness of AI/AN needs, providing strategies for assisting AI/AN patients, and continuing our commitment to the provision of truly culturally competent care, we are devoting this issue of HRSA CARE Action to examining the impact of HIV/AIDS in the AI/AN population.

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**BARRIERS TO CARE**

**Cultural Diversity and Surveillance Challenges**

Far from being a homogenous population, the approximately 5.2 million people in the United States who self-identified as AI/AN in the 2010 U.S. Census represent 566 federally and State-recognized Tribes and unrecognized tribal entities, each of which has its own culture, belief, and practices.9

More than half of those self-identifying as AI/AN—about 2.9 million people—are multiracial, having also self-identified as members of one or more other racial and ethnic groups.10 This has created unresolved confusion about who is and who is not AI/AN. Research has shown that health care workers misidentify AI/AN persons who test for HIV as members of other racial and ethnic groups about 70 percent of the time,11,12 which results in significant underreporting of HIV among AI/ANs.13,14 In addition, Tribes that collect their own health data often are reluctant to share it with outside entities, presenting another barrier to HIV surveillance in the AI/AN population.

This state of affairs has fueled “the perception among policymakers and American Indians and Alaska Natives alike that HIV is a not a priority,” says Hannabah Blue, a contractor with the National Native American AIDS Prevention Center (NNAAPC), in Denver, CO. Recognition of the growing prevalence of HIV disease among Native communities is necessary, however, to secure adequate funding for comprehensive, innovative HIV programs that target these populations and address their unique needs.15

**Health Inequities**

The disproportionate impact of HIV/AIDS among AI/ANs is part of a cluster of poor health outcomes common to these populations nationwide. AI/ANs also have higher rates of chlamydia, gonorrhea, and syphilis than Whites or Hispanics/Latinos.16 The behaviors that put AI/ANs at increased risk for sexually transmitted infections also place them at increased risk for HIV.

AI/AN people experience high rates of comorbidities and coinfections, including heart disease, substance use disorders, and viral hepatitis, as well as suicide and unintentional injury.17 These interrelated problems facilitate both exposure to and
progression of HIV disease and interfere with the ability to seek and stay in care.

This disparity in disease burden between AI/ANs and other racial and ethnic groups has only grown more stark over time. As detailed in the U.S. Commission on Civil Rights’ groundbreaking research report *Broken Promises: Evaluating the Native American Health Care System,* compared with other racial and ethnic groups, AI/AN people are

- 770 percent more likely to die from alcoholism,
- 650 percent more likely to die from tuberculosis,
- 420 percent more likely to die from diabetes,
- 280 percent more likely to die from accidents, and
- 52 percent more likely to die from pneumonia or influenza.”

**Poverty and Other Economic Determinants**
Many of these health disparities are directly or indirectly related to the high rates of poverty among AI/ANs. In 2011, approximately 27 percent of AI/AN households reported living below the Federal poverty level (FPL), well above the national average of approximately 14 percent. In several States, including Arizona, New Mexico, North Dakota, and South Dakota, AI/AN residents have poverty rates exceeding 30 percent. In 2010, approximately 39 percent of AI/AN children lived in poverty, compared with 22 percent of children nationally.

Although a significant portion of AI/ANs who live at or below FPL are employed full time, unemployment remains a major concern for this population, both on reservations and in urban areas. According to the U.S. Bureau of Labor Statistics, unemployment levels among AI/ANs reached 14.6 percent in 2011—second only to that of African-Americans/Blacks and significantly higher than the national average of 8.9 percent. Together, poverty and unemployment drive the high rates of food insecurity, shelter instability, and incarceration, as well as the low educational attainment and elevated high school dropout rates that undermine the health and well-being of many AI/AN communities.

**Engagement in Care**
“AI/AN people inadvertently drive surveillance gaps in their population by delaying engagement in care,” says Jutta Riediger, project coordinator for the Northwest AIDS Education and Training Center’s Tribal BEAR (Building Effective AIDS Response) Project, located in Washington State and Oregon, which operates through the South Puget Intertribal Planning Agency (SPIPA). Delayed engagement in care reflects the realities of many AI/ANs’ lives, which are focused on fulfilling pressing basic survival needs before addressing HIV and other health care concerns.

Compared with members of other racial and ethnic groups, AI/ANs not only test later for HIV but are more likely to be simultaneously diagnosed with both HIV and late-stage AIDS or to progress to AIDS within 3 years of diagnosis with HIV; AI/ANs are also less likely to survive at 12, 24, and 36 months after diagnosis. Riediger says that many AI/AN people living with HIV (PLWH) do not even know they have HIV “until they present for care at emergency rooms with numerous opportunistic infections.”

Dr. Kevin Foley, clinical director of the substance use clinic Na’Nizhoozhi Center, Inc. in Gallup, NM, has had similar experiences. “To this day, many Navajo and other Indian people do not get tested until they have full-blown AIDS,” he says. “They neither know what HIV is nor knew how to protect themselves from contracting it.”

**Trauma**
Health disparities and socioeconomic determinants in any underserved population are associated with numerous factors, but for Native Americans, they cannot be fully understood outside the context of a modern-day Trail of Tears. During the 1950s, Native Americans from various Tribes began migrating in significant numbers from reservations to major urban areas under the Bureau of Indian Affairs Relocation Program. Some of those who relocated adjusted successfully while others did not. Many could not find the jobs they were promised or the affordable housing they believed was waiting for them. Some experienced their moves from the reservation to culturally alien urban centers as another in the long history of oppressive and genocidal acts against Native Americans in the United States.

As a result of these experiences, an overwhelming mistrust of U.S. Government programs and health institutions, as well as a condition known as *historical...*
trauma or intergenerational post-traumatic stress disorder, exists in some Native American communities and clients due to cumulative emotional and psychological wounding over lifespans and generations and emanating from massive group trauma experiences.

Dr. Maria Yellow Horse Brave Heart, director of Native American and disparities research at the University of New Mexico’s Center for Rural and Community Behavioral Health, explains that the historical trauma response often includes depression, self-destructive behavior, suicidal thoughts and gestures, anxiety, low self-esteem, anger, and difficulty recognizing and expressing emotions. It may include substance abuse, often as an attempt to avoid painful feelings through self-medication.

Indeed, a significant number of AI/ANs, including those living with or at risk for HIV, have untreated mental health issues, such as depression, which often is the result of unaddressed trauma, whether historical or relating to problems such as racism, homophobia, and intimate partner violence. Unresolved depression and trauma can affect an individual’s ability to access medical care and seek social and mental health support.

**Location and Migration**

Although most AI/AN people reside in cities, few clinics dedicated to serving this population are available in urban areas. As a consequence, “HIV-infected Natives are commonly referred to non-Native providers outside the reservation for medical management. HIV-specific training that does occur in tribal communities often lacks proper cultural orientation.”

Contemporary migration from reservations to urban areas reflects the search and need for employment, education, and housing opportunities. Rather than residing in “urban Indian neighborhoods,” however, AI/AN are often dispersed throughout metropolitan areas. For this reason, urban AI/ANs may share less of a sense of community than do their counterparts living on reservations, and may struggle to stay connected to their culture. AI/ANs may frequently migrate between reservation communities and urban centers to visit family and friends and participate in tribal ceremonies and events.

By contrast, many Alaska Natives may travel very little because of a lack of road infrastructure and may therefore be quite isolated. Only 2 percent of the land in Alaska is served by roads, creating an entirely different kind of geographic barrier, in which getting urgent medical care often requires flying.

**Stigma**

Riediger, whose office helps AI/AN PLWH manage their disease and builds the capacity of providers serving this population, notes that disenfranchised AI/AN PLWH may avoid care because of real and perceived fears of unwanted disclosure, stigma, and cultural insensitivity. These vulnerable PLWH tend to internalize culturally driven stigmas related to HIV, the body, illness, and sexuality. Research has shown that, regardless of the patient’s access to care or socioeconomic status, these psychosocial conditions can amplify fears of rejection, depression, and isolation, and can ultimately accelerate the progression of HIV disease.

Some AI/AN communities share the concept that some individuals are born with both a male and female spirit. In some cultures, this status can be referred to as “Two-Spirit.” In mainstream culture, these people would commonly be referred to as gay, lesbian, bisexual, or transgender. Recently, however, AI/AN Two-Spirit individuals have become particularly vulnerable to stigma in reservation communities. As Robert Foley, president and chief executive officer of NNAAPC, explains, “Historically, homophobia did not exist in Native communities, but outside influences have made being gay and accessing health care on some reservations socially challenging. Homophobia is common and, I think, a product of colonization. It also has helped fuel beliefs that do not welcome discussions about sex… and disease, facilitating infection.”

According to a study by Health Resources and Services Administration (HRSA) Special Projects of National Significance (SPNS) grantee researchers, “Native peoples have some of the lowest documented condom use rates.” This resistance was found to stem from shame around public discussions of sexuality, creating a barrier to HIV prevention, particularly in the MSM community where seroprevalence is high.

**STRATEGIES FOR CARING FOR AI/ANS**

Ryan White HIV/AIDS Program providers have always strived to deliver culturally competent care. To support these efforts, some AIDS Education and Training Centers (AETCs) across the country have performance sites dedicated to serving AI/ANs and offering training on how best to care for this population. Working collaboratively with AI/AN-serving organizations and involving AI/AN patients
Understanding Culture

Ryan White HIV/AIDS Program clinics are likely to embrace or already be practicing many strategies for approaching AI/ANs in holistically appropriate ways (see sidebar on p. 5). It is important to ensure, however, that such strategies are implemented in a culturally sensitive fashion.

The involvement of family and consideration of family structure is important when treating AI/ANs.53 Most AI/AN people embrace the concept of balance in relationships, in which family is paramount. For example, in the Swinomish Tribal Community, among others, traditional tribal healing practices view illness as a family affair; thus, if one family member is ill, the entire family is ill.

AI/AN PLWH may, however, be isolated from their families because of geography, stigma, addiction, or other issues. Creating a strong social support network for AI/AN clients, in which they feel the clinic is, in a sense, a new or extended family, helps to promote coping mechanisms for stressors as well as engagement and retention in care.54 Providers may want to consider establishing a well-staged reception area that greets new and current clients with comfortable seating (instead of standard hard waiting room chairs), and is family friendly. Health care facilities may also wish to include local artwork reflective of the community.55

Finally, providers who augment their HIV capacity and cultural competence often can create stronger relationships with local community leaders, who in turn can offer insight into local HIV risk factors and ultimately help to inform strategies concerning HIV prevention, testing, treatment, and care. For example, SPIPA learned that tattoo practices placed patients at significant risk for HIV and hepatitis C, prompting the agency to reach out to local tattoo parlors and their clients to deliver information about the need to use clean needles and ink and dispose of needles properly.

These dialogues also can lead to culturally appropriate discussions about safe sex practices—particularly in areas where childbearing is considered paramount to “keeping the Tribe going” and homosexuality is taboo. In these instances, says Riediger, discussions of condom use are couched in culturally relevant contexts, such as protecting future generations from mother-to-child transmission of HIV.
Improving Patient-Provider Communication

When working with AI/ANs, it is important to minimize formality and use a friendly approach to offset power differentials and promote kinship. Embracing basic AI/AN norms such as respect, humility, and honesty will go far. Providers may want to avoid language that makes assumptions about the patient’s priorities and avoid messages such as

- Biomedicine is “right” and a science-based approach is the only appropriate one.
- Traditional beliefs should be changed rather than built upon.
- Patients understand the concept of “chronic illness.”
- Adherence failure is the patient’s problem.

Providers working with AI/AN patients are encouraged to determine patients’ preferred learning styles and reading and health literacy levels and, where applicable, to use cultural themes, metaphors, or folktales to deliver health messages. Providers should also assess their personal cultural competence and sensitivity as well as that of the agency in which they work, and develop actions or offer training to address any deficiencies. Working in partnership with AI/AN communities can go far in addressing knowledge gaps.

Many languages are spoken in AI/AN communities; approximately 20 Native languages are spoken in Alaska alone. Although most individuals speak English, some elders may prefer to receive information in their native language, requiring translators. According to Terri Bramel, physician assistant at the Alaska Native Tribal Health Consortium, Native languages do not always have words that precisely match the meaning of many medical terms. Working with translators and AI/AN organizations can help to overcome this obstacle and increase provider sensitivity to patients’ cultural preferences.

Given AI/ANs’ historic distrust of government and health care institutions, it is important that providers communicate with patients about how their health information will be used and kept safe.

Providing Support Services as a Lifeline

HRSA’s ongoing responsiveness to the changing needs of hard-to-reach populations living with and affected by HIV has helped the Indian Health Service (IHS) and AI/AN-serving clinics move closer to becoming medical homes—that is, health care agencies where all required services are colocated under one roof or in nearby locations. This circumstance is often more easily accomplished in urban settings, where public transportation and medical providers are readily accessible. In rural areas, however, AI/AN PLWH commonly must be referred to medical providers who may be located several hundred miles away. For these PLWH, support services such as childcare and transportation are lifelines to care.

For example, Niki Graham, director of the Center for Prevention and Wellness for the Tribal BEAR Project’s Women 4 Wellness program, which operates from Salish Kootenai College in Pablo, MT, says that nurses at the local IHS clinic engage in heroic efforts to ensure patients are retained in care, assisting them with the completion and submission of paperwork and driving patients to their off-reservation appointments. The nurses, many of whom have friends and family members living with HIV and other serious diseases, use these trips to build rapport with patients, encouraging them to ask...
questions and discuss their fears and concerns about HIV and treatment adherence. “They also discuss the patient’s personal life, spirituality, and other needs as they relate to their HIV status,” says Graham. Patients arrive at their appointments better prepared to meet with their provider and with a stronger understanding of the importance of engaging in ongoing HIV treatment and care.61

**Healing Practices**

Dr. Foley says the Na’Nizhoozhi Center has engaged in numerous innovative practices to help patients remain in care, including hiring a medical case manager to conduct home visits and encouraging treatment adherence through directly observed therapy. From 2003 to 2007 the Center participated in HRSA’s SPNS American Indian/Alaska Native Initiative, which supported the integration of services for HIV-positive or at-risk AI/ANs. Like fellow grantee SPIPA, the Na’Nizhoozhi Center emphasized intensive, hands-on support for clients.

The Center’s program, entitled Integrating HIV, Substance Abuse, and Mental Health Services at the Navajo Nation: A Project of the Four Corners American Indian Circle of Services Collaborative, trained health care providers in case management, screening, counseling, and HIV testing. These providers served as patient navigators who engaged patients in intensive and culturally appropriate motivational interviewing; the creation of an HIV risk reduction plan and follow up; and enrollment in intensive HIV case management. This work helped to address the unique psychosocial and economic barriers faced by the center’s patients, who included AI/AN PLWH with substance use disorders. In addition to using conventional Western medical approaches, the Center has also helped to connect patients with traditional AI/AN healers.

For many AI/AN PLWH, the importance of engaging in cultural healing practices cannot be overstated. Orientation to medical care for many AI/ANs is built around the belief that the body must be “in balance” and that healing must involve a spiritual and cultural component. To rebalance, AI/ANs may burn sage, use sweat lodges, or join in a prayer circle. It is important for an AI/AN-serving clinic to communicate that it is both a “healing space” and a space that embraces the central role of family and community.52

The Na’Nizhoozhi Center and Navajo AIDS Network, as well as the *Clinician’s Guide: Working with Native Americans Living with HIV,*63 report that traditional medicine in conjunction with conventional Western medical treatment are more effective together. For HIV-positive AI/AN patients this can translate into an expedited reduction in HIV viral load and an increase in T-cells. As Shana Cozad, a member of the Kiowa Tribe of Oklahoma, explains, “You need to engage in both types of healing as a Native person living with HIV/AIDS. You have to walk in two worlds, which means medicinally you have to walk in two worlds as well.”

**HRSA AND FUTURE CARE CONSIDERATIONS FOR AI/ANS LIVING WITH HIV/AIDS**

The innovative, culturally competent approaches spearheaded by Ryan White HIV/AIDS Program providers have helped countless AI/AN PLWH to overcome not only internalized stigma around AIDS and sexuality but also structural barriers, such as geographic isolation and lack of health literacy, and successfully engage in HIV treatment, care, and support services. Together, the IHS and HRSA, with additional support from the Minority AIDS Initiative, are building on this groundwork, bolstering the capacity of IHS health centers to deliver treatment and care for HIV, hepatitis C, and substance abuse disorders to AI/AN PLWH. Health care professionals at community health centers serving AI/ANs also have additional training options through the HRSA-funded AETCS.

These efforts ensure that Ryan White HIV/AIDS Program services targeting AI/AN PLWH and their families advance the goals of the National HIV/AIDS Strategy (NHAS), implemented in 2010, which seeks to reduce the number of people who become infected with HIV; increase access to care and optimize health outcomes for people living with HIV; and reduce HIV-related health disparities.64–66 Strengthened through concerted efforts to coordinate and streamline HIV/AIDS programming across the Federal, State, and local levels, the Program’s alignment with NHAS has helped prepare HRSA and HIV care providers for the full implementation of the Patient Protection and Affordable Care Act (Public Law 111–148) in 2014.67 The new White House Care Continuum Initiative further strengthens the focus on outcomes.

These efforts have helped to ensure that the Ryan White HIV/AIDS Program continues to serve as a dynamic safety net for all PLWH, including AI/AN men, women, adolescents, and children living with HIV/AIDS, and their families. Perhaps Cozad captures the importance of such comprehensive, culturally appropriate care when she says, “I may never see a cure for HIV/AIDS in my lifetime; but I have known healing. That is different than a cure—I can feel that wellness in my heart and spirit, even when I feel sick.”
A Way to Wellness: Locating and Understanding Native-Specific HIV Data:

BE SAFE: A Cultural Competency Model for American Indians, Alaska Natives, and Native Hawaiians Toward the Prevention and Treatment of HIV/AIDS:
careacttarget.org/sites/default/files/file-upload/resources/BESAFE_NativeAmr_2006.pdf.

Changing Directions: Strengthening the Shield of Knowledge: Building Understanding That Leads to Cross-Cultural Competence. Southeast AETC:

Clinician’s Guide: Working with Native Americans Living with HIV:

Community Consultation Meeting: Access to HIV/AIDS Care Issues for Native Americans:

HIV in Communities of Color—The Compendium of Culturally Competent Promising Practices: The Role of Traditional Healing in HIV Clinical Management:

Indian Health Service HIV/AIDS Program and Tribal HIV/STD Advocacy Kit:

Mental Health and Substance Use: Treatment Considerations for Native Americans Living with HIV/AIDS. Texas/Oklahoma AETC:
www.aidsetc.org/DLMentalHealthSubstance AbuseTreatmentConsiderationsforNativeAmericansLivingWithHIVAIDS.php.

Ryan White HIV/AIDS Program Population Fact Sheet: American Indians and Alaska Natives:

Nizhoni SISTA, a culturally competent adaptation of the CDC Diffusion of Effective Behavioral Interventions (DEBI), for Navajo and AI/AN-focused male-to-female transgender women:

REFERENCES


3 CDC, 2013a.


6 CDC, 2013b.


8 CDC, 2013b, p.7.


16 CDC, 2013a.


