

CLINICIAN'S GUIDE

WORKING WITH NATIVE AMERICANS
LIVING WITH HIV



NATIONAL NATIVE AMERICAN AIDS PREVENTION CENTER

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HEALTH RESOURCES AND SERVICES ADMINISTRATION



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The mission of the National Native American AIDS Prevention Center is to stop the spread of HIV and related diseases among American Indians, Alaska Natives and Native Hawaiians, and to improve the quality of life for members of our community infected and affected by HIV/AIDS.

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ABOUT THIS CLINICIAN'S GUIDE

This is a practical resource for medical providers who are confronted with basic cultural challenges presented by Native American patients living with or at risk for HIV infection.

This guide responds to three questions:

- 1. What history and cultural factors amplify the difficulties faced by Native Americans with HIV?**
- 2. How do these cultural amplifiers affect a patient's access to services?**
- 3. What can a medical provider do to address cultural barriers to help empower Native American patients living with HIV?**

In addressing these questions, a Clinician must understand some important aspects of Native American history, and how this history continues to affect the health and well-being of Native Americans today.

WHO IS NATIVE AMERICAN?

The term Native American came into use in the 1960s to denote American Indians and Alaska Natives served by the Bureau of Indian Affairs (BIA). There is no single federal or tribal criterion to identify a person as Native American. Government agencies and tribes have differing criteria to determine who is eligible to receive services. Some tribal-specific enrollment requirements dictate eligibility based on a minimum blood quantum, a maternal or paternal lineage, or birth on the tribe's reservation. A Native American may or may not be enrolled with his or her tribe. This occurs for any number of reasons, including family history, lineage, low blood quantum, adoption, or simply the choice not to be enrolled.

Importantly, the physical appearance of Native Americans varies from individual to individual. Through the years, many stereotypes of Native Americans, both negative and positive, have been portrayed through the media. Although many Native Americans may have a similar physical appearance, the reality is that many Native Americans are of mixed heritage, and may appear to be Asian Pacific Islander, African American, Latino, or Caucasian. Native Americans are often misclassified under these racial groups in state HIV/AIDS surveillance data. Obviously, this has been problematic in state and federal HIV/AIDS funding allocations for Native Americans.

NATIVE AMERICANS TODAY

Native Americans make up one percent of the United States population, with an estimated total of 2.3 million individuals. This population includes over 550 federally recognized tribes and maintains over 150 distinct languages. Some tribes have thousands of people who speak the language while others have only a few. About 40% of the Native American population live in rural settings or on or near reservations, rancherias or pueblos (reservations); the remaining 60% reside in urban areas. Reservation lands were reserved for a tribe when it relinquished other land rights to the U.S. Government through treaties. Tribes were often forced to reside on reservations that were geographically distant from the ancestral lands they had occupied for centuries. Reservations are usually located in isolated areas, resulting in high incidences of poverty, unemployment, welfare dependency, and related morbidities, including obesity, diabetes, alcoholism, chemical dependency, and family violence, among others.



RELATIONSHIP WITH U.S. GOVERNMENT

Federally recognized tribes are sovereign nations and possess formal government-to-government relationships with the United States. This legal status was established through treaties, Acts of Congress, executive orders, and other administrative actions. As a consequence of this status, decisions about federally recognized tribal lands and people generally involve the review and consent of the tribes.

Not all tribes meet the criteria for federal recognition, however; these exceptions do not possess the same sovereign status, but they may have formal recognition in their states. Still other tribes have neither federal nor state status, either as a consequence of not meeting criteria or of a choice not to seek such recognition. Native Americans from tribes that do not have federal or state recognition are nonetheless "Native American."

BOARDING SCHOOLS

In 1886, a U.S. government commission ordered the formation of a boarding school system under the auspices of the BIA. Many Christian boarding schools for Native Americans also developed around this time. These schools were organized to educate Native American children and, in the process, replace their dialects with the English language. In these schools, students were disciplined for speaking Native languages and were taught to reject their cultures, including their beliefs, languages, songs, dress, and way of life. This school policy significantly contributed to the endangered state of Native American languages and culture today.

Sadly, as a consequence of boarding school experiences, many of these children suffered lifelong emotional problems which have affected the health and well-being of subsequent generations. Many boarding school children suffered the trauma of

forceful removal from their homes, shame for being Native American, and poor treatment while in the schools. Consequently, these children were not exposed to Native-parental role models during their formative years, and as adults, they lacked parenting skills. Needless to say, the aftermath of boarding schools continues to affect Native Americans today. Some BIA boarding schools still exist, but now focus on preserving Native American culture rather than destroying it.

URBAN RELOCATION PROGRAM

The urban relocation program was yet another federal program that was in effect from the 1950s through the 1970s. Many present-day urban Native Americans are, or are the children of, Native Americans who were relocated to major cities in the United States. This policy persuaded Native Americans to leave their reservations with the promise of housing and job opportunities in these major cities. Many Native people eventually found themselves without financial means to sustain themselves or to return home. Those that remained were faced not only with the problems they experienced on the reservation but also with the added factor of discrimination. Despite hardships, many of these Native Americans established themselves to some degree and are now part of urban Native American communities.

HEALTH HISTORY AND CURRENT TRENDS

The Native American population is younger than that of the general U.S. population and simultaneously has lower life expectancies. This latter trend is the result of higher morbidity and mortality rates associated with a wide variety of diseases and other causes. Perhaps most significant among these causes are the near-absence of those linked to the more chronic health problems.

Data from the mid-1990s indicate that Native populations residing in the vicinity of Indian Health Service (IHS) service



facilities had notably higher rates of death than those in other U.S. population groups. These differences were quite pronounced for causes associated with injuries and poisoning, accidents, suicides, homicide, firearms, alcoholism, chronic liver disease and cirrhosis, tuberculosis, and diabetes mellitus. Conversely, Native populations exhibit significantly lower death rates associated with malignant neoplasm and HIV. Native American mortality rates associated with gastrointestinal, heart, and cerebrovascular causes are comparable to general U.S. populations.

Recent data demonstrate a shift in causes of death among Native Americans toward the more chronic diseases typical of the general population. This shift demonstrates what should be interpreted as a positive change, although considerable care must be exercised before accepting such conclusions. The service population described by these data include American Indians and Alaska Natives who reside "on and near" reservations. The data do not include urban Native American populations, nor do they account for whether or not those individuals actually use IHS services. In light of these limitations, one must also acknowledge how this summary presentation of information can mask local variation. Consequently, while the general trend shows improvement in health status, local manifestations of these changes may not describe parallel shifts. In fact, many communities continue to suffer the high morbidity and mortality rates of earlier periods. Providers must be aware of underlying morbidity and mortality trends in the community, how these affect perceptions and expectations, and how they might impact a service delivery system.

This Guide cannot address the wide cultural variation between Native Americans. Rather, the focus is on some of the basic similarities found among many Native Americans and to which a care provider should be sensitive.

This Guide introduces service goals and interventions to address the challenges posed by Native American cultural amplifiers. While not all of your Native American clients will manifest many of these amplifiers, much less all of them, keeping these cultural amplifiers in mind will facilitate your treatment and care of Native Americans living with HIV.





CULTURAL AMPLIFIERS

A cultural amplifier is a cultural factor that magnifies the difficulties faced by Native Americans living with or at risk for HIV.

CIRCULAR MIGRATION

Depending on distance, many Native Americans may migrate daily, weekly or several times a year from reservation/rural areas to urban areas. Migrations occur for many reasons, including family visits, tribal ceremonies, job and educational opportunities, substance abuse, and illness. An individual may travel a long distance to an urban area to work or to obtain an education since the opportunities are more limited in reservation/rural communities. A substance user may travel to an urban area to access alcohol or drugs. Some reservations are "dry" meaning that alcohol is prohibited from being sold or used on the reservation. A substance abuser may be required to leave a reservation/rural area to enter a drug or alcohol treatment program that is located in an urban area. An ill individual living in an urban area may return home to receive care from family or community members, and simultaneously, have access to more traditional healing methods. Conversely, an individual may travel or relocate from a reservation/rural area to an urban area to receive more comprehensive health care services. The circular migration of Native American people also means that disease can be easily carried from urban areas to reservations, with a tremendous potential to achieve epidemic proportions on reservations.

HOLISTIC APPROACH TO HEALTH

Many Native Americans believe in a holistic approach to health. Health is synonymous to the harmony of mind, body and spirit

with nature. Illness implies an imbalance within the individual and between the individual and his or her universe. Many Native Americans also believe that an imbalance can occur through "bad medicine" or a spell from someone who may want to cause harm. Because of this, the whole individual must be treated and not merely one physical segment of the body. Better results can be obtained for a Native patient if his/her physical, emotional, mental, and spiritual needs are addressed in the care and treatment plan.

TRADITIONAL HEALING

Each Native American tribe has distinct ceremonies and medicines, although overlaps exist in certain regions. Native American patients who access traditional medicine and ceremonies report physical relief as well as an overall increase in his/her sense of well-being. For many Native Americans the practice of traditional methods of healing can contribute to a sense of empowerment. An individual living on a reservation would have better access to traditional medicines and ceremonies than an individual living off the reservation. Due to this distinction, an individual living in an urban area may return home for traditional medicine and ceremonies. In some settings, access to traditional healing services can be obtained in urban contexts.

DISTRUST OF AUTHORITY

Native Americans have a long history of mistrust of the government as a result of broken treaties, lost land, reservations, boarding schools, and the urban relocation program, as well as ongoing experiences with racial and ethnic discrimination. This mistrust extends to public health officials, as a result of specific tribal histories of poor health care and deliberate infection. Most Native Americans are familiar with the government's "gift" of blankets to many tribes, which were infected with small pox. This history is well recognized



throughout the Native community, and often translates into a level of mistrust of health care providers in contemporary settings.

FEAR OF BREACH OF CONFIDENTIALITY

Breaches of confidentiality have been a serious issue in many Native American clinics. This transgression often occurs in reservation/rural communities where rumors can spread quickly, although comparable breaches also occur in urban clinics. In Native American communities, it is not uncommon for a patient to have relatives, friends, or acquaintances who are employed at the Native American clinic. These individuals, therefore, may have access to confidential information about a patient. Any breach of confidentiality by a clinic employee, or anyone else, can lead to shame and isolation from the community especially when the information is about a socially stigmatized problem such as HIV. In 1991, a study by the National Commission on AIDS found that Native Americans were concerned "over the inability of the Indian Health Service to protect the confidentiality rights of patients, evidence of breaches of confidentiality, and the lack of anonymous test sites."

COMMUNICATION STYLE

Some Native Americans exhibit a style of communication that is reserved and may be interpreted as unfriendly. When addressed, a Native American may look away or down to defer to another person's authority. In some tribes direct eye contact is considered disrespectful. Many Native Americans speak in a slow and deliberate manner which is often interpreted as the individual being uneducated or ignorant. For some of these individuals, English is their second language and/or their way of speaking was learned within their families and communities. Many Native American people also exercise caution in personal communication with others. Information or problems about oneself and one's family is not voluntarily shared. Contributing fac-

tors to the nondisclosure of information are the inherent distrust of authority and the fear of breach of confidentiality. Native Americans are usually careful listeners and perceptive observers of nonverbal communication, such as facial expressions, gestures, or verbal tones. A Native American patient not volunteering information should not be interpreted as an indication that there is nothing wrong. A patient is more likely to share information if trust is developed between the provider and the patient.

MODESTY

Most Native Americans are modest about their bodies and find it uncomfortable to discuss their bodies or perform self-examinations. Consequently, an individual may not notice or wish to discuss personal bodily changes. This same modesty, in fact, may extend to discussing sex and sexual behaviors, especially homosexuality, and may even present great discomfort. Health care providers should learn how to discuss the body, sex and sexuality in a non-offensive manner. For example, in encouraging your patient to conduct physical self-examinations suggest that your patient examine his/her body in the shower. Since a shower involves touching one's body, a patient may feel more comfortable with this suggestion.

LANGUAGE AND CULTURE

Many cultural elements are contained within the context of a Native American language. Many words and concepts are not easily translated into English, and some cannot be translated. The language of each tribe describes and identifies its speakers. Every Native language contains the key to that tribe's view of the universe. Even if a non-Native learned the language, some of the cultural elements would be lost in the translation. When the BIA attacked Native languages in its boarding schools, the BIA attacked the culture of all tribes. Native Americans



strive to preserve and restore their respective tribal languages and culture. Because of their history, Native Americans may not share their culture, including traditional methods of healing, with people outside of their tribe.

FAMILY AND COMMUNITY ROLE

The importance of the extended family is crucial in understanding the relationship of an individual to family and community. Aunts are often considered mothers, uncles are often considered fathers, and cousins are often considered brothers and sisters. Members of the same clan, or even related clans, may be considered relatives. In this social structure, some Native children are raised by an extended family without a formal adoption process. The community, urban and reservation, is a valuable resource for a Native person in need. An individual may turn to the community for financial, emotional, or spiritual support. That individual is committed in the same way to others in the community.

ORIENTATION TO THE PRESENT

Many Native Americans are more oriented to living in the present than the future which is often emphasized in Western culture. Since the future is vague and ambiguous, it is not unusual for the focus to be on immediate gratification. Many Native American tribes emphasize living each day as it comes. This perspective could influence how Native patients adhere to pharmacotherapies, for example, when they are feeling well or poorly on any given day. Health care providers need to explain and emphasize how HIV progresses in the body, and how antiretroviral therapies work over time.

MORTALITY

High rates of mortality are a part of most family and community experiences for Native Americans. According to the Indian Health Service's annual report on mor-

tality rates, Native Americans consistently have higher than national average death rates due to automobile accidents, liver disease, homicide, suicide, and diabetes. It is not unusual for an individual to have someone in his or her family commit suicide, be a victim of a homicide, or lose a relative in a fatal automobile accident. Not infrequently, a community may experience several deaths over a short period of time. This experience may impact an HIV-infected Native American, possibly altering his or her own desire to extend life by means of antiretroviral therapies.

SEXUAL ORIENTATION

Many tribes have a pre-Columbian history of acceptance of alternative gender roles and sexualities. However, European arrival brought Christianity which influenced these social systems and indigenous beliefs that alternative gender roles and sexualities were not an anomaly. In some tribes there is no historical record that these alternative gender roles and sexualities ever existed, which again, may have been destroyed with European arrival. 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 people and communities are just as likely to exhibit the same type of homophobia prevalent in mainstream society. Some gay, lesbian, bisexual and transgendered Native Americans identify as "two spirit." The term "two spirit" is a fairly new term that originated from the organizing efforts of gay, lesbian, bisexual and transgendered Native Americans to distinguish themselves from mainstream gay and lesbian culture. The "term two spirit" attempts to reclaim and honor the historical roles and traditions of individuals within many tribes that were at one time inclusive of alternative gender roles and sexualities.





SERVICE INTERVENTIONS

The service interventions presented in this section address the service needs of Native Americans living with HIV and are adaptable to also address the service needs of Native Americans at risk for HIV. A patient at risk for HIV may have sex with more than one partner, have an infected partner, have a history of sexually transmitted diseases, and/or use or have a history of substance abuse. For these reasons, it is critical to conduct a thorough patient sex and drug history, risk assessment, and physical examination to determine if the patient has placed himself/herself at risk for infection. The provider should also discuss the HIV testing procedure with the patient and provide pre- and post-test counseling services.

The information in this Guide presents service interventions which encourage and support a strong and trusting patient-provider relationship whether the patient is living with HIV, or at risk for HIV.

TEACH AND OFFER A BICULTURAL APPROACH TO CARE

Native American patients bring their personal history, including their cultural values and beliefs to the health care system. Learn about your patient, and the Native American community you are serving, in order to teach and offer a bicultural approach to care. Be aware of the important aspects of Native American history and the cultural amplifiers that may affect the relationship between you and your patient. Get to know your patient. When compiling a patient history find out what tribe(s) your patient is from, and where he or she was raised. Ask your patient without requesting details, if they use traditional healing services and medicines. Refrain from judgment when the patient is sharing information about the

traditional healing services and medicines they have accessed. A judgmental response could harm the trust and confidence you have established with your patient. Discuss Western medicine and its uses, and encourage the use of both Western medicine and traditional medicine whenever possible. Emphasize to your patient that traditional healing and Western medicine are more effective together, than separate. Encourage and validate your patient's effort to access Native-specific resources.

CREATE AN EMPOWERMENT NARRATIVE

By knowing your patient's history, you can easily create an empowerment narrative. A comprehensive patient history and notes documenting your patient's successes will make this process easier. Assist your patient in dealing with any current issues related to his or her HIV status by recounting their success in overcoming past issues.

Often a patient will feel as though they have no control over their health care. Whenever possible, give the patient options, discuss the pros and cons, and let the patient make a decision based on the information presented. Involve the patient in every step of their care and treatment plan.

ESTABLISH PEER INTERVENTION

Connect your patient with support groups, or other services, where your patient can meet other HIV-infected individuals. An HIV-infected Native American may feel isolated and alone especially if HIV support services are not available in his/her area. If possible, create these support systems within your clinic in a safe environment where confidentiality will not be breached.

TEACH PATIENTS ABOUT THE STRUCTURE OF THE MEDICAL CARE SYSTEM

Many Native Americans are most familiar with Indian Health Service (IHS) clinics or tribal clinics that are available on reservations and in some urban areas. A Native



American patient may become overwhelmed by other medical care systems. Assist your patient in understanding how the medical care system works. If possible, provide your patient with a diagram or directory of available services at your clinic. Explain the provider/patient relationship, your roles in the relationship, and the roles of other providers within the clinic involved in your patient's care and treatment. Encourage your patient to advocate for him or herself and question provider/authority figures.

Often a patient's medical insurance plan will dictate how the patient will access services and receive referrals to specialists. Direct your patient to the benefits coordinator at their place of employment, or have your clinic insurance specialist explain what he/she knows about the patient's plan.

PRACTICE DIRECT COMMUNICATION

Teach and practice direct communication with your patient. In general, most Native Americans are not comfortable with, and do not engage in, direct communication. Become familiar with the communication style of Native Americans discussed in the cultural amplifier section. Your patient may exhibit this type of communication requiring you to read between the lines. Explain to your patient that you will ask direct questions to help you better assess and serve his/her needs, and that it is not your intent to be insensitive or offensive when asking questions. To help your patient identify the difference, give examples of direct and indirect questions and answers. When questioning your patient use the formal medical terminology followed by any known "slang" terminology used within the community. Encourage your patient to ask questions if they are not familiar with formal medical terminology. Emphasize to your patient that he/she is allowed to ask direct questions, and respond directly to questions, without

feeling embarrassed or ashamed. Validate your patient when he/she uses direct communication.

SHOW RESPECT FOR TRADITIONAL APPROACHES TO HEALING

A provider can acknowledge and encourage the use of traditional medicine. Discuss Western Treatment options with your patient and show respect for traditional methods of healing. Your patient's health and well-being may be supported by traditional healing methods.

ASSESS INTEGRATION OF HIV DIAGNOSIS INTO IDENTITY

When a patient is advised of his/her HIV diagnosis it takes time to integrate the HIV diagnosis into his/her identity. This process follows a continuum throughout the patient's life. A newly diagnosed patient may be in denial about his/her HIV status, may not want to share their HIV status with others, or may not access any HIV services. A patient that has been aware of his/her HIV diagnosis for several years accesses HIV specific services, has familial and community support, attends HIV-support groups and is involved in an HIV-case management program; this person has incorporated HIV into most aspects of his/her life.

Keeping this continuum in mind, questions to assess your patient's integration of HIV into his/her life should be direct. Avoid open-ended questions about your patient's thought process and feelings until the relationship is established. The following initial questions to the patient may prove helpful:

- Where do you access your primary HIV medical care? Have your experiences been positive or negative?
- What do you know about your diagnosis?
- What treatments or services have you sought since you were diagnosed (including traditional treatments)?
- Do you dialogue with your doctor



- about treatment options?
- Are you involved in an HIV-case management program?
- Do you know about federal or state benefit programs?
- Who knows about your diagnosis?
- Do you try to avoid thinking of HIV or find that you can't stop thinking about HIV?
- Do you practice safer sex?

DEVELOP AN ALLIANCE

Take the time to know and understand your patient. Share your experience in working with HIV-infected individuals as a way of gaining your patient's trust. Emphasize that you will work with your patient towards maintaining his/her health and well-being. Discuss care and treatment options with your client and involve him/her in the decision-making process. A provider-patient relationship based on trust and direct communication will support your patient's adherence to his/her care and treatment plan.

LINK PATIENT TO SOCIAL SERVICE PROVIDER

A patient may need additional support from other social service providers, especially Native American service programs/providers. Find out about available resources for Native Americans in your area. Link your patient to an HIV-case management program, support groups, substance abuse programs, or other resources. Your patient will gain invaluable support from social service providers who will advocate for your patient's physical, mental, emotional and spiritual well-being. Social service providers also act as intermediaries to interpret and support your patient's care and treatment plan.

ESTABLISH A MULTIDISCIPLINARY CARE TEAM

Discuss the multidisciplinary care team approach with your patient. A patient who trusts his/her provider will tend to trust any providers you recommend.

Introduce or schedule a meeting to transition your patient to a new provider. Keep apprised of the care and treatment delivered by other providers, including social service providers. Emphasize to your patient that his/her care team is working together to maintain his/her health and well-being.

EDUCATE PROVIDERS ABOUT CULTURALLY SENSITIVE SERVICES

Share this Guide with other providers and discuss the content. It is important to engage in discussion with other providers and share their success in incorporating culturally sensitive services with patients. A colleague may have an approach that has worked with his/her Native American patients. Talk to Native American providers that may provide additional strategies to working with your patient.

PACE THE DELIVERY OF INFORMATION

Medical terminology can be intimidating, foreign, and overshadowed by psychosocial issues related to integration of HIV into a patient's identity. Provide the information to your patient in increments, and confirm that your patient knows and understands the information before proceeding. Too much information at once can cause a patient to shut down and isolate oneself from the medical care system. Being patient and showing acceptance is critical in supporting your patient's adherence to his/her care and treatment plan.





SERVICE GOALS FOR NATIVE AMERICANS LIVING WITH HIV

TREATMENT ADHERENCE AND HOPE

Native Americans' cultural beliefs, history, and daily experiences have the potential to make treatment adherence a challenge. Native Americans deal with death all too frequently within their communities, an experience that can foster feelings of hopelessness and resignation. Fear, shame, and a source of disappointing one's family and community due to being HIV-infected only magnify these feelings. A patient may turn to alcohol or other substances, which further inhibit a patient's ability to adhere to his/her treatment regimen. Draw on the strengths of Native American holistic approaches to health and encourage your patient to access services that will maintain his/her physical, mental, emotional and spiritual well-being, and foster a sense of hope.

INTERVENTIONS

- Teach patients about the structure of the medical care system
- Create an empowerment narrative
- Establish a multidisciplinary care team
- Establish peer intervention

LINGUISTICALLY AND CULTURALLY SENSITIVE CARE

A Native American patient may experience alienation in the medical care system when accessing services. Whenever possible, connect your patient with a Native American provider or know the information in this Guide when working with Native American patients. Involve a social service provider (case worker, social worker or peer advocate), preferably Native American, in the patient's care. A Native American provider would be able to interpret information to the patient and advocate on the patient's behalf.

Let the patient choose his/her social serv-

ice provider. The fear of breach of confidentiality is real for many Native Americans in both small and large communities and it is important that your patient have control over how much information is shared with anyone involved in his/her care.

INTERVENTIONS

- Link patient to social service provider
- Educate providers about culturally sensitive services
- Establish a multidisciplinary care team

BELIEF IN WESTERN TREATMENT AND TRADITIONAL METHODS OF HEALING

Some Native Americans access traditional healing services to heal from mental, emotional, physical, and spiritual imbalances or ailments. Encourage your patient's use of Western medicine as a part of the holistic approach to health underlying traditional methods of healing. Your patient's belief in, and incorporation of, Western medicine into a holistic healing approach will encourage your patient to adhere to his/her treatment regimen.

Many Native American traditional methods of healing have survived for hundreds of years despite historical attempts to abolish these practices. Native Americans protect and preserve these traditions, and may not be allowed to share details of their traditional methods of healing. If your patient is accessing traditional healing services through their tribe or a Native American program, refrain from asking for details and imposing your judgment or religious beliefs. Your interest and support in your patient's use of traditional healing methods will strengthen the provider/patient relationship, and does not indicate a compromise in a provider's own belief system.

INTERVENTIONS

- Educate providers about culturally sensitive services
- Teach and offer a bicultural approach



to service access

- Show respect for traditional - approaches to healing -

INTEGRATE HIV INTO IDENTITY

A patient commonly responds to an HIV-positive diagnosis with denial or avoidance. For Native Americans, this reaction is compounded by a fear of rejection by family and community, and possibly a fear of disclosure of sexual behaviors and substance abuse. An HIV-positive patient may also feel that he/she will not be able to fulfill his/her family and community obligations. Connect your patient to resources that provide support for your patient to openly discuss his/her HIV-diagnosis. A patient who integrates his/her HIV-diagnosis into his/her identity can better seek and maintain participation in treatment.

INTERVENTIONS

- Create an empowerment narrative
- Teach patients about the structure of the medical care system
- Practice direct communication
- Teach and offer a bicultural approach to care

INTERVENTIONS

- Assess integration of HIV diagnosis - into identity -
- Pace delivery of information
- Develop an alliance
- Establish peer intervention

SENSE OF CONTROL OVER TREATMENT AND SERVICES

Native American patients may distrust the Western medical care system, feel inundated with information from their providers, isolated from their family and community, and have a general sense of hopelessness. For these reasons, it is imperative for a provider to gain the trust of his/her patient, and build on this trust to connect the patient to other providers and available resources. Whenever possible, a provider should involve his/her patient in making decisions about his/her care and treatment plan. Present your patient with options for discussion, and assist the patient in his/her decision-making process.





CASE STUDY 1: FRANK

PATIENT HISTORY

Frank is a 26-year old man with AIDS who identifies as gay. Frank's first language is his tribal language and he speaks with a slight accent; however, Frank speaks English fluently. Frank left the reservation when he was 17-years old because he was harassed and physically assaulted in his community for being gay. Frank has been living in Phoenix intermittently for the past nine years. You have treated him at the reservation clinic for the past five years when he returns home to visit his family or for care.

Frank was hospitalized two months ago in Phoenix for a bacterial pneumonia and was then placed in a treatment program for his alcohol abuse. Over the past two years, Frank has been to three treatment facilities for his alcohol abuse. Frank is now back on the reservation with his family and has started a new antiretroviral regimen. When Frank is using he does not adhere to his regimen.

Frank has now tried several regimens. His poor adherence when he is using alcohol has caused some treatments to fail and he is now resistant to many related drugs. Frank's new regimen has been giving him nausea and diarrhea. Frank's mother and grandmother have been caring for him since he was released from the hospital. They believe that the medication Frank is taking is making him more ill and they do not want him to take any more prescribed medication. Frank's grandmother would like him to go through a healing ceremony instead.

BELIEF IN WESTERN TREATMENT AND TRADITIONAL METHODS OF HEALING, TREATMENT ADHERENCE AND HOPE

- Show respect for the Frank and his family's approach to healing, and encourage integration of their approach with Western medicine. Talk with Frank and his family, without asking for details, about what traditional methods of healing they would like Frank to utilize.
- Use an empowerment narrative. Remind Frank about previous struggles he has had in balancing traditional ways with Western ways, and the methods he used for overcoming these struggles. Discuss Frank's sobriety, and how he attended a Native-specific recovery program but also attended Alcoholics Anonymous meetings for additional support when he was in Phoenix.
- Link Frank to a Red Road program, Alcoholics Anonymous or some other support system to maintain his sobriety in the area. This is important since Frank's adherence to his antiretroviral therapy is affected by his alcohol abuse.
- If possible, link Frank to an HIV support group, preferably with other Native Americans, so that he does not feel alone and has others to talk to with similar struggles and experiences.
- Talk with the family about a bicultural approach to healthcare. Work



collaboratively with them to identify ways that traditional medicine and Western medicine may be beneficial to Frank.

LINGUISTICALLY AND CULTURALLY-SENSITIVE CARE

- If you do not speak Frank's tribal language and/or have knowledge about his tribe, link Frank and his family to a social service provider who speaks his language, is from the same tribe, or from another Native American tribe.
- If the social service provider is unfamiliar with medical and psychosocial aspects of HIV disease, connect the provider with a sensitivity training program about HIV disease. Make sure the training program has a component on the importance of provider-patient confidentiality.
- If Frank is agreeable, work with the social service provider to establish and maintain an ongoing relationship with the family.

INTEGRATE HIV INTO IDENTITY

- Assess where Frank is on the continuum of incorporating HIV into his life. You know that Frank's family knows his HIV status, what about other community members?
- Determine if Frank understands how his HIV treatment regimens have been affected when Frank uses alcohol. How involved has Frank been in the past in choosing his treatment options?
- Ask Frank if he was involved in an HIV case management program in Phoenix. What support services did he have access to in Phoenix that may

be available on the reservation?

- Discuss Frank's safer sex practices.

SENSE OF CONTROL OVER TREATMENT AND SERVICES

- Use an empowerment narrative. Emphasize Frank's success in getting through other difficult times, for example, Frank's continued attempts to recover from his alcohol use despite his two relapses. Help Frank identify strengths that got Frank through these difficult times.
- Teach and practice direct communication with Frank and his family. Encourage questions and complaints the family may have. Emphasize that any information they share will be kept confidential.
- Educate the family about HIV and the importance of Frank adhering to his medication, the role sobriety plays in his adherence, and the potential side effects of the medication he is presently taking. Ask a social worker or a nurse practitioner to play this ongoing role.
- Emphasize that traditional and Western medicine can work together to improve Frank's health and overall well being. Support his grandmother's request for a healing ceremony.





CASE STUDY 2: LEONA

PATIENT HISTORY

Leona is a 24-year old married woman with a three-year old son. Leona's husband Danny tested positive for HIV over a year ago. Since then, Leona has used condoms with her husband, but refuses to get tested. She knows that she is at high risk for HIV infection or that she may already be infected. Her son has been tested and he is negative.

For the past several months, she has had recurrent vulvovaginal candidiasis. She has tried several over-the-counter medications with minimal relief.

Leona is a competition jingle dancer and her husband Danny sells jewelry at powwows, fairs and exhibits. Leona and her husband traveled all over the United States before they met at a powwow over five years ago. In their travels, Leona and Danny attended many powwows and enjoyed many "49s" (an after-powwow gathering).

Her husband's health has been good so over the past several months they have continued to travel and sell jewelry. Lately Leona has been tired and she did not accompany her husband on his last two trips.

She returns to your office two months later with another episode of vulvovaginal candidiasis. The medication she was prescribed did not heal her infection. She is now considering being tested for HIV. She is afraid to find out her HIV status and feels that this is only the beginning of what she will endure if she is HIV positive. She is depressed about the future. What concerns her most is that her son may be

left without a mother and father if she is HIV positive.

She shares that she is considering moving back to her reservation with her husband and son. She wants to make sure her son has a home, and she knows that her mother would care for him. However, she is concerned that others may discover her husband's HIV status since he would likely get his care and treatment from the reservation clinic.

INTEGRATE HIV INTO IDENTITY

- Determine what Leona knows about HIV.
- Although Leona has known about her husband's HIV status for a year, Leona is at the beginning of the continuum in incorporating HIV into her life as it relates to her husband.
- Discuss her participation in a support groups for families affected by HIV.
- Discuss how it is not uncommon for partners or family members of an HIV-infected person to feel depressed and isolated, and how support groups, therapy or traditional counseling could be beneficial.

HELP THE PATIENT MAINTAIN A SENSE OF CONTROL

- Encourage Leona to get tested. By discovering her HIV status, she will be able to make important decisions for herself, her husband and her son. Explain that if her HIV status is pos-



itive early intervention is critical in maintaining her health and well-being whether through antiretroviral therapies or other medical or social services she may need.

- Utilize an empowerment narrative. Remind her of the previous challenges she has successfully negotiated, (i.e. discovering her husband's HIV diagnosis.)
- Utilize the alliance that you have developed with her. Confirm your commitment over the past year to help maintain confidentiality for her family.
- Encourage Leona to continue practicing safer sex. Until she knows her HIV status, it is important that she protect herself from infection, or reinfection if her HIV status is positive.
- Assess her understanding of the connection between her depression and isolation surrounding HIV. Discuss the potential benefits of support groups, therapy or traditional counseling.
- Provide Leona with contact names and information about the local HIV-case management program or other HIV/AIDS services in the area.





CASE STUDY 3: THOMAS

PATIENT HISTORY

Thomas is an 18-year old "urban Indian" who recently tested positive for HIV. Thomas's maternal and paternal grandparents were relocated to a major city during the government's relocation program in the 1950s. Thomas's parents were married for ten years, but have been separated for just as long. Since their separation, Thomas has lived with his mother and two siblings. Thomas has accessed services, including health care, from the Native American programs in the area throughout his life. Thomas knows most Native people in the community.

Thomas was informed of his HIV-diagnosis on his last visit to the Native American health clinic. HIV has been Thomas's worst fear. He has heard people in the community talk about HIV and AIDS as a "gay disease" and he knows his mother thinks similarly. Although his mother has suspected Thomas is gay, he has not "come out" to her. Thomas has tried to mask his sexual orientation by having girlfriends while he has had a sexual relationship with a 23-year old man for the past two years. Thomas is not ready to tell his mother that he has sex with men, and much less his HIV status. He is worried that his status may be disclosed to her or to others in the community because he knows many of the Native people that work in the clinic.

Since Thomas still lives at home, he does not want to start treatment because his mother or siblings would see the medications and find out his HIV status. He also does not understand why he needs to begin treatment when he does not have

any symptoms.

INTEGRATE HIV INTO IDENTITY

- Determine what Thomas knows about his HIV diagnosis.
- Assess where Thomas is on the continuum of incorporating HIV into his life. Thomas is at the beginning of the continuum and needs more support services to help him in the process of accepting and incorporating his HIV diagnosis into his life.
- Discuss his enrollment in an HIV-case management program and the services that would be available to him (support groups, therapy, housing, and other referrals).
- Discuss how being involved in an HIV-positive support group, or a gay youth support group, would be beneficial for Thomas in coming to terms with not only his HIV status, but also his sexual orientation.
- Is Thomas practicing safer sex?

HELP THE PATIENT MAINTAIN A SENSE OF CONTROL

- Treat Thomas with respect and pace the information when explaining medical information and treatment options. Practice direct communication with him and encourage him to ask questions. Ask Thomas what he knows about HIV disease and treatment.
- As an adolescent, Thomas is in the



process of developing an identity as an individual. Treat Thomas as an adult, and involve him in making decisions about his care and treatment plan. This will give Thomas a sense of control.

- Link Thomas to an HIV-case management program, gay youth support groups, HIV support groups, and any other services that are available for positive youth.
- Emphasize that his HIV status, and your discussions, are confidential and that it is safe for him to talk to you.

CULTURALLY SENSITIVE CARE

- Develop your alliance with Thomas by demonstrating your understanding and interest in the cultural and generational gap between him and his mother. While building an alliance, be sure to ask Thomas questions in a non-judgmental tone about his experience.
- Link Thomas with a social worker, case manager, peer advocate, or counselor who ideally has had experience working with Native Americans and/or gay youth.

HELP THE PATIENT MAINTAIN HOPE

- Link Thomas to a peer group of individuals living with HIV to keep Thomas from feeling isolated and alone. Importantly, Thomas will meet individuals throughout the continuum of HIV identity integration. In this process, Thomas will have the opportunity to hear and exchange experiences, and help him maintain a sense of hope. This group may be predominantly made up of youth, gay youth or Native Americans.





RESOURCES

NATIONAL

National Council of Urban Indian Health
Washington, DC
202-659-9159
www.ihs.gov/NonMedicalPrograms/Urban/ncuih/index.html

National Indian Health Board
Denver, CO
303/759-3075
www.nihb.org

National Native American AIDS
Prevention Center
Oakland, CA
510/444-2051
www.nnaapc.org

EAST COAST

American Indian Community House
New York, NY
212/598-0100
www.aich.org

Catawba Indian Nation
Catawba, SC
803/366-6721

North American Indian Center of
Boston, Inc.
Jamaica Plains, MA
617/232-0343
www.bostonindiancenter.org

GREAT LAKES

American Indian Health and Family
Services of Southeast Michigan
Detroit, MI
313/846-3718

Inter-Tribal Council of Michigan, Inc.
Sault Ste. Marie, MI
906/635-4208

(cont.)
www.itcmi.org

MIDWEST

Ahalaya Native Care Center, Inc.
Oklahoma City, OK
405/235-9988

Ahalaya Native Care Center, Inc.
Tulsa, OK
918/834-8136

American Indian Health Service of
Chicago, Inc.
Chicago, IL
773/883-9100

Dallas Inter Tribal Center
Dallas, TX
214/941-1050

Gerald L. Ignace Indian Health Center, Inc.
Milwaukee, WI
414/383-9526

Hunter Health Clinic
Wichita, KS
316/262-3611
www.hunterhealthclinic.org

Indian Health Board of Minneapolis, Inc.
Minneapolis, MN
612/721-9800

Indigenous People's Task Force
Minneapolis, MN
612/870-1723

Native American Health/AIDS Coalition
Kansas City, KS
913/342-5400

Oklahoma City Indian Clinic
Oklahoma City, OK
405/948-4900
United Amerindian Center, Inc.
Green Bay, WI
920/436-6630



PACIFIC

Ke Ola Mamo
Honolulu, HI
808/550-0885

Life Foundation
Honolulu, HI
808/521-2437
www.lifefoundation.org

Maui AIDS Foundation
Wailuku, HI
808/242-4900
www.mauiaids.org

PLAINS

Denver Indian Health and Family Services
Denver, CO
303/781-4050

Helena Indian Alliance
Leo Pocha Clinic
Helena, MT
406/449-5796

Indian Family Health Clinic
Great Falls, MT
406/268-1510

Indian Health Board of Billings, Inc.
Billings, MT
406/245-7318

Missoula Indian Center
Missoula, MT
406/329-3373

Nebraska Urban Indian Health Coalition
Lincoln, NE
402/434-7177
www.nuimc.org

North American Indian Alliance
Butte, MT
406/782-0461
South Dakota Urban Indian Health, Inc.
Pierre, SD
605/224-8841

SOUTHWEST

All Indian Pueblo Council, Inc.
Albuquerque, NM
505/884-3820
www.aipcinc.com

First Nations Community Health Source
Albuquerque, NM
505/262-2481

HIV Center for Excellence
Phoenix Indian Medical Center
Phoenix, AZ
602/263-1502
www.ihhs.gov/MedicalPrograms/AIDS/index.asp

Inter Tribal Council of Arizona, Inc.
Phoenix, AZ
602/258-4822
www.itcaonline.com

Inter-Tribal Health Care Center
Tucson, AZ
520/882-0555

Native American Community Health Center
Phoenix, AZ
602/266-6363

Navajo AIDS Network, Inc.
Chinle, AZ
928/674-5676
www.navajoaidsnetwork.org

Navajo Nation AIDS Office
Window Rock, AZ
520/871-6250

WEST COAST

Alaska Native Health Board
HIV/AIDS Project
Anchorage, AK
907/562-6006
www.anhb.org



American Indian Health & Services
 Santa Barbara, CA
 805/681-7356

www.ihs.gov/NonMedicalPrograms/Urban/aihs/

Chugachmiut
 Anchorage, AK
 907/562-4155
www.chugachmiut.org

Fresno Indian Health Association
 Fresno, CA
 559/222-9865

Indian Health Center of Santa Clara Valley, Inc.
 San Jose, CA
 408/445-3415
http://www2.ihs.gov/SantaClara/contact_info.asp

Native American AIDS Project
 San Francisco, CA
 415/552-4246

Native American Health Center
 Oakland, CA
 510/261-0524
www.uihbi.org

Native American Health Center
 San Francisco, CA
 415/621-8051
www.uihbi.org

NARA of the NW
 Indian Health Clinic
 Portland, OR
 503/230-9875

Northwest Portland Area Indian Health Board
 Portland, OR
 503/228-4185
www.npaihb.org

Nevada Urban Indians, Inc.
 Reno, NV

(cont.) -
 775/788-7600 -

Sacramento Urban Indian Health Project, Inc. -
 Sacramento, CA -
 916/441-0918 -

San Diego American Indian Health -
 Center -
 San Diego, CA -
 619/234-2158 -
www.sdaihc.com -

Seattle Indian Health Board -
 Seattle, WA -
 206/324-9360 -
www.sihb.org -

United American Indian Involvement, -
 Inc. -
 Los Angeles, CA
 213/353-9429 -

CANADA
 Canadian Aboriginal AIDS Network
 Ottawa, ON
 613/567-1817
www.caan.ca

Healing Our Nations
 Atlantic First Nations AIDS Task Force
 Halifax, NS
 902/492-4255
www.healingournations.ca

Healing Our Spirit
 BC First Nations AIDS Society
 North Vancouver, BC
 604/879-8884
www.healingourspirit.org

Manitoba Aboriginal AIDS Task Force
 Winnipeg, MB
 204/772-6800



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<http://hab.hrsa.gov>
<http://www.nnaapc.org>





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CLINICIAN'S GUIDE

WORKING WITH NATIVE AMERICANS
LIVING WITH HIV

