



NATIVE AMERICAN  
ENDING THE HIV/AIDS EPIDEMIC  
IN NEW YORK STATE  
ADVISORY GROUP

BLUEPRINT IMPLEMENTATION  
STRATEGIES



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## NATIVE AMERICAN ENDING THE EPIDEMIC ADVISORY GROUP

### Advisory Group Chairs:

**Pete Hill (Cayuga, Heron Clan)**, Native American Community Services

**Talia Shenandoah (Mohawk, Bear Clan)**, ACR Health

### NYS Department of Health AIDS Institute Staff:

**Bethsabet de Leon Stevens**, Director, Community Based Services

**Maryline Alexis Philippe**, Assistant Director, Community Based Services

**Laura Trolio**, Senior Program Coordinator, Office of Planning and Community Affairs

### ADVISORY GROUP MEMBERS (ALPHABETICAL ORDER):

**Norine Borkowski**, Native American Community Services

**Curtis Davia (San Carlos Apache)**, American Indian Community House, Executive Director

**Paula Collins (Shinnecock)**, Indian Health Service

**Jennifer E. Cuffee-Wilson (Shinnecock/Montauk)**, Blossom Sustainable Development on the Shinnecock Nation

**Pamela Everingham (Onondaga, Snipe Clan)**, Onondaga Nation Health Services / Upstate Medical University

**Shirley Farmer-Tyner (Cayuga, Wolf Clan)**, NYS Department of Health, AIDS Institute

**Barbara Johnson (Onondaga, Snipe Clan)**, CirCare Agency

**Heather LaForme (Onondaga, Beaver Clan)**, NYS Office of Children & Family Services

**Michael Martin (Onondaga, Beaver Clan)**, Native American Community Services, Executive Director

**Sheldon Raymore (Cheyenne River Sioux)**, American Indian Community House

**Star Wheeler (Seneca, Turtle Clan)**, Native American Community Services

### SPECIAL ACKNOWLEDGEMENTS

**Michèle Hamel**, NYS Department of Health, Office of Minority Health and Health Disparities Prevention

**Julie Harris**, NYS Department of Health, AIDS Institute

**Chief Beverly Cook (Mohawk)**, Saint Regis Mohawk Tribal Council

**Jajaida Corchado, NYS Department of Health**, AIDS Institute Office of Planning and Community Affairs

## MESSAGE FROM THE ADVISORY GROUP: CULTURAL GROUNDING AND CONTEXT

While HIV impacts virtually every community throughout New York State, it is critical to begin with a foundation of recognizing the unique histories, community dynamics, and cultures of Indigenous people who live in these lands that are currently known as New York State, long before the arrival of Europeans and peoples from across the globe. These issues collectively create specific, additional challenges and demands if Ending the Epidemic (ETE) efforts are to effectively reach and support Indigenous people today. Although a complete history of Indigenous peoples and a description of the cultures and communities they represent are outside of the scope of these ETE recommendations, there are specific issues which need to be understood so that all efforts intended to reach Native populations can offer the greatest opportunities and the best chances for success.

For Indigenous communities, all ETE implementation strategies that address the New York State Blueprint to End the Epidemic by 2020 (for more information on the NYS ETE Blueprint, please visit [https://www.health.ny.gov/diseases/aids/ending\\_the\\_epidemic/docs/blueprint.pdf](https://www.health.ny.gov/diseases/aids/ending_the_epidemic/docs/blueprint.pdf)) must recognize that Indigenous peoples in the Americas, United States, and New York State have a unique cultural heritage that speaks of sovereignty, culture, language, community protocols, traditional medicines, and a wide range of related strengths and assets. This cultural heritage is critical to recognize as this cultural grounding must be acknowledged in order to engage many Native and Indigenous communities, nations, tribes, families, and individuals more successfully in HIV/AIDS ETE efforts. Peace, health, respect, pride, love and gratitude are a few of the major assets and concepts that are engrained within these Native cultures. These traditional teachings and cultures have served as the foundation for many Indigenous peoples since the beginning of our existence.

Yet, at the same time, the stark reality facing Native peoples is that Indigenous peoples have long been the focus of attempts of genocide as defined by the United Nations' definition—either the physical genocide of wiping Indigenous peoples out or the cultural genocide of forced assimilation. Centuries-long efforts of removing the “Indian problem” by the United States government have resulted in significant health disparities among many Native people and communities. Suicide, incarceration, substance abuse, risk factors for HIV/AIDS, and a range of health issues impacts many Native people at very high rates. Several historical underpinnings (such as the systems of residential boarding schools, federal and state policies of termination, forced assimilation, campaigns of war and attempted extermination of Native peoples and their Nations) have all contributed to these health disparities. Issues of mistrust, anger, and a general lack of engagement among many Native people and communities in government-funded programs are all critical to recognize as being relevant when considering the implementation of HIV related interventions which prioritize Native people. Therefore, a framework which considers these historical underpinnings and related factors and seeks to reduce health disparities and inequities must be a priority for this community.

There are additional cultural perspectives that are critical to recognize as well. Many Native Americans claim and support the sovereignty of their respective Native Nations, which has been a fundamental concept and principle that has guided interactions between Indigenous peoples and Europeans, European-Americans, and Non-Native peoples since 1492. Many traditional Native people do not claim citizenship in the United States and/or maintain that the New York State can actually be considered as a “foreign government.” Some Native governments may not accept state or federal funding, while others do. When referring to Native people, the extensive diversity of Native peoples, communities, nations and tribes must be acknowledged and respected.

Thus, each Native government has its own unique relationship(s) with state and federal governments. Each Indigenous Nation also has its own specific organizational structure, array of health services, and cultural norms. It is incorrect and inappropriate (if not offensive) to consider that all Native Nations ancestral to these lands now referred to as New York State are the same and can be treated as such.

It is also important to recognize that, on average, approximately 70% of Native people do not live on the Native Nations. Rather, most Native people live in cities, rural areas, and off-Nation territories and many have various relationships with the Native nations. Some people are fully engaged with the services and cultural resources provided through the Native nations in New York State, while others have only occasional to no connection with these Native nations. New York is also the home of several thousands of Indigenous peoples whose ancestries originate in other areas of the US, as well as Canada and other areas of the Americas.

While some HIV and viral hepatitis services are provided through the Indian Health Service (IHS) on some Native nation lands, there are very few, if any, IHS facilities that provide HIV-related services in the cities or urban areas. (Please recognize the health clinics that are on territories are funded by New York State Department of Health and American Indian Health Program, in addition to IHS.) As a result, Native people may seek and access services through local community-based organizations and health centers (outside tribal nations) or not at all.

For many Native peoples, the traditional Native American cultures have also been recognized as an extremely powerful source of resilience, survival, and identity. Native people and communities are currently striving to rebuild and reconnect with their traditional cultures, languages, and teachings to help reclaim their cultural identity. Some Native people have theorized that these traditional teachings and cultures are the factors that have assisted Indigenous peoples to withstand the centuries-long efforts of cultural and/or physical genocide.

At the same time, because of historical underpinnings such as the systems of residential boarding schools, federal and state policies of termination, forced assimilation, campaigns of war and attempted extermination of Native peoples and their Nations, there are Native people who do claim citizenship in the United States and New York State. Similarly, the varying extent of personal identity and affiliation

with Native American cultures and traditional practices is also a factor when working with Native people. Some Indigenous people identify very strongly with their traditional cultures and may respond to culturally-grounded messaging, perspectives, and approaches while many others do not. Many other Native people may not value or be completely unaware of these traditional cultures. The cultural identity and strength of their connections to their own cultures are extremely diverse.

Recognizing the issues of historical traumas, external factors, and cultural norms of Native people and communities are critical to understanding and developing more effective methods and strategies to engage Native peoples in ending the HIV/AIDS epidemic. Furthermore, given the extensive array of varying relationships of Native Nations and Tribes with state and federal government, health departments, and most “mainstream” organizations, as well as the diverse connections that Native people have with their own cultures, a strong grounding and foundation in Native American cultural competency is critical.

Another aspect of this cultural grounding relates to the data used to determine how HIV/AIDS related funding is administered. First, Native people are often excluded from many data sources reporting on race and ethnicity due to a wide range of issues. Misclassification, stereotypical images of Native peoples, and not even being listed as an option on intake forms are among the factors that contribute to this exclusion of Native people from many data sources. Furthermore, data that shows raw numbers of HIV cases of Native people (compared to Communities of Color and/or diverse populations) may indicate that Native people are not greatly impacted by this epidemic. However, if data is used that reports rates per population size (rates per 10,000, rather than just numbers of people in various communities), a much different picture can be seen. Native people have similar rates of a range of HIV-related issues and disease as African-Americans and Latinx.

Understanding the experiences and needs of the Native American communities overall and all the diversity among Native peoples (such as Two Spirit persons, bi-racial, multi-racial people, enrollment or non-enrollment in Native nations or tribes) communities can help health care providers improve outcomes in this patient population, including HIV/STI/HCV related outcomes. Culturally-competent technical assistance and related trainings are key to thoroughly understanding this report and implementing the recommendations and statements contained herein. Such trainings and technical assistance should be provided through experienced organizations that have a demonstrated track record of providing effective trainings and technical assistance.

Another area that undergirds any HIV-related services relates to Two Spirit persons and the unique challenges that they face, even compared to other LGBT+ persons of color. According to a report focusing on Two Spirit persons<sup>1</sup>, “LGBT American Indians found a high rate of HIV prevalence.... strong

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<sup>1</sup> Frazer, M. Somjen and Pruden, Harlan. (2010). Reclaiming Our Voice: Two Spirit Issues & Human Service Needs in New York State. NYS DOH AIDS Institute: Albany, NY

relationships between discrimination and physical pain, impairment, and poor health.” Other studies report “high rates of victimization, child abuse, historical trauma, problems with mental health.”

Even an understanding of the term “Two Spirit” requires some explanation, as the impacts of residential boarding schools, the history of the highest rates of US military service among Native peoples, and the promotion of Christianity (while encouraging Native people to abandon their own cultures), health and human services that are designed for the wider LGBT+ population may not serve the needs of Two Spirit persons. There have been documented cases of outreach racism, failure to provide culturally-sensitive services by such human services, and lack of understanding of pressing health issues and needs in physical, mental, emotional, and spiritual areas of health. While these issues relate to many Native people, Two Spirit persons have additional challenges to their health, requiring more informed and culturally competent services. Native American LGBT+ persons report experiencing higher rates of insufficient access to mental health specialists, depression, significant amounts of violent homophobia among some segments of Native communities, isolation, transphobia, and lack of cultural programming for Two Spirit persons.

It should also be noted that while racism towards Indigenous people has not only been a factor of historical traumas, racism continues to be a significant issue for many Native peoples. Many of these racist ideas stem from stereotypes found in many mainstream media, outdated “cowboy and Indian” films, and sports teams that use Native people or words as mascots. Racism also is a factor for Indigenous peoples who have multiple ancestries, as many are not accepted as being Native but are presumed by other, Non-Native people as being Black, African-American, Asian, Hispanic, Latino, or another identity. Racism also influences many Non-Native people and organizations, albeit sometimes it is unintentional or unrecognized. Cultural competency trainings that address racism and its many forms are critical to help organizations and individuals who are funded to support Native people and provide HIV-related services.

Another source of traumas and challenges impacting HIV risk taking among some Native communities involves issues of human trafficking, sex work, and epidemics of missing and murdered Native women (as well as men and Two Spirit or LGBT+ persons). Several communities are dealing with these serious issues, and each of these issues deserves to be examined more closely to work towards ending the HIV epidemic for Native peoples. Yet these threats to Native wellbeing are not always being addressed or understood fully, as many persons who are impacted by these issues are not always welcomed, acknowledged, and/or included in many Native communities. Plus, authorities are not always recording, tracking, and/or properly reporting these incidents impacting Native people. All HIV-related efforts towards ending the HIV epidemic must take these issues into consideration so that all Native American community members are included.

In addition to completing and receiving cultural competency and technical assistance trainings as outlined herein, organizations that serve Native American populations should be held accountable for

ensuring that the recommendations provided through these trainings are implemented in ways that can be documented and demonstrable.

The Native American ETE Advisory Group respectfully presents this document which highlights the concerns as well as the implementation strategies that will need to be considered to inform future HIV/STI/HCV programming for Native American communities and peoples in New York State.



## OUR JOURNEY

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In 2017, a group of diverse statewide leaders, community representatives and providers working with Native American communities and subcommunities participated in a gathering call. The purpose of the dialogue was to understand the community's perspective, experience and priorities related to HIV/STI and prevention, support and medical care. The community's input was critical to help the AIDS Institute gain a better understanding of the community needs and challenges that exist with the goal of working together to develop and implement solutions for improving Human Immunodeficiency Virus (HIV), Sexually Transmitted Infections (STI), Hepatitis C (HCV) programs and services for New York Native American communities.

Many common themes emerged during the gathering call. Most importantly, the need for the AIDS Institute to actively engage the Native American community in further discussions about New York State's Ending the Epidemic (ETE) efforts and facilitate the creation of customized strategies to implement Blueprint recommendations based that are responsive to the needs of each nation and community.

On April 9, 2018, the Native American ETE Advisory Group first met to begin its work to develop culturally responsive recommendations that aligned with the implementation of the ETE and the Blueprint. The advisory group convened and has met for over a twelve-month period via conference call and face to face in different cities across NYS, including:

### In-person meetings:

- |                               |                                    |                                |
|-------------------------------|------------------------------------|--------------------------------|
| - May 22, 2018<br>(Albany)    | - September 24, 2018<br>(Syracuse) | - February 12, 2019<br>(Islip) |
| - August 8, 2018<br>(Buffalo) | - December 6, 2018<br>(Albany)     |                                |

### Conference calls:

- |                 |                    |                   |
|-----------------|--------------------|-------------------|
| - April 9, 2018 | - July 11, 2018    | - January 7, 2019 |
| - June 21, 2018 | - November 6, 2018 | - April 3, 2019   |

The first, full meeting was a face-to-face meeting of the advisory group to introduce the members to each other, to nominate and select Co-Chairs for the Advisory Group, and to share the vision and the goals for the committee based on the three pillars of the New York State Ending the Epidemic Blueprint:

1. Identify individuals with HIV who remain undiagnosed and link them to health care;
2. Link and retain individuals diagnosed with HIV in health care to maximize virus suppression so they remain healthy and prevent further transmission; and
3. Facilitate access to Pre-Exposure Prophylaxis (PrEP) for high-risk individuals to keep them HIV negative.

## INTRODUCTION AND BACKGROUND

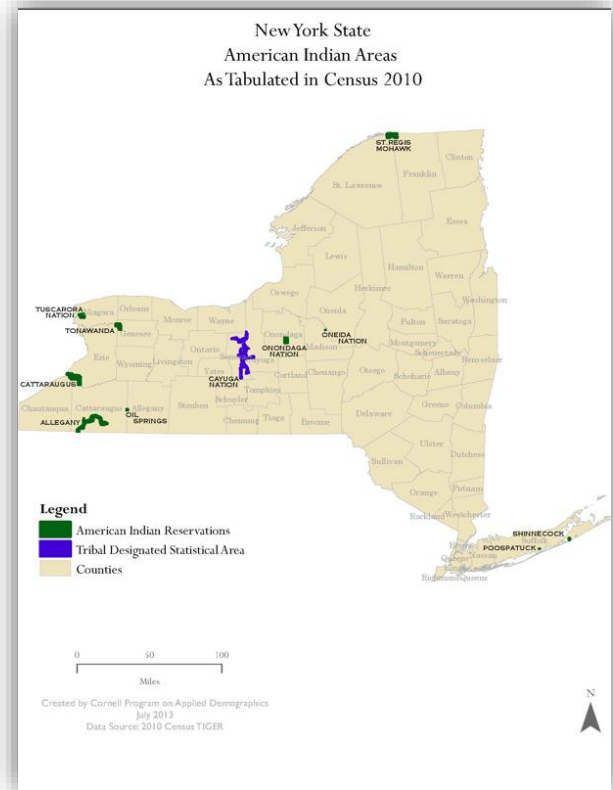
### Native Americans in New York State<sup>2</sup>

New York State (NYS) is the ancestral home to Native people from the arctic to the most southernmost communities of Mexico and South America. The Native nations or tribes that are indigenous to these lands include Cayuga Nation, Oneida Nation of New York, Onondaga Nation, Poospatuck or Unkechaug Nation, Saint Regis Mohawk Tribe or Akwesasne Mohawk Nation, Seneca Nation of Indians, Shinnecock Indian Nation, Tonawanda Band of Seneca and Tuscarora Nation. It is also critical to recognize the sovereignty of the Haudenosaunee Confederacy which includes the Mohawk, Oneida, Onondaga, Cayuga, Seneca and Tuscarora Nations.

According to a Population and Area Profile report by Cornell University<sup>3</sup>, which used 2010 Census data, there were a total of 221,058 Native American individuals residing in the state (date includes American Indian and Alaska

Native -alone or in combination with another race, all counties), accounting for 1.1% of NYS population. About 107,000 individuals (48.4%) self-identified as American Indian and Alaska Native alone. The total NYS population grew by 2.1%, from 18,976,457 in 2000 to 19,378,102 in 2010. In comparison, the American Indian and Alaska Native alone-or-in-combination population increased by 28.8%, from 171,581 in 2000 to 221,058 in 2010.

In addition, it is estimated that 70% of Native Americans do not live on their nation territories. Rather, most Indigenous people live in the cities and other suburban and rural areas. The cities of Buffalo, Syracuse, New York City, Rochester, and Albany all have significant numbers of Native people. Issues for Native Americans who live off their nation territories may include the levels of cultural connections, assimilation, isolation, loss of traditional Native cultures, being impacted and/or influenced by Non-



<sup>2</sup> Statistical reports use the term American Indian and Alaskan Native to comply with Office of Management and Budget federal standards for the reporting of race and ethnicity data. During the course of this process, the ETE advisory group used the term Native American. Therefore, this report uses AI/AN when referencing data from federal reports such as the Census. Otherwise, the community is referred to as Native American.

<sup>3</sup> American Indian & Alaska Native Population and American Indian Areas – Population and Area Profiles 2013. Cornell Program on Applied Demographics. <https://pad.human.cornell.edu/profiles/AIAN.pdf>

Native communities and cultures, tenuous connections with their ancestral territories, and many related issues. The needs of the urban Native communities may not always be met by their Nations and/or tribes, nor are their needs met by Non-Native organizations and service providers.

**NOTE:** Whenever data relating to Native people are discussed, it is important to recognize that there are some significant concerns with data that stems from the US Census. Many Haudenosaunee persons do not participate in the census and cite to the “Two Row Wampum Belt,” a historic treaty between the Haudenosaunee Confederacy and Europeans and later the United States), which is often interpreted as a recommendation that Haudenosaunee people should not participate in American governmental or political activities. As this Two Row Wampum Belt is often referenced as the reason why many Native (particularly, the Haudenosaunee) may not vote in American political systems. It is often considered that up to 70% of Native people do not participate in the Census and data from the census may likely be significantly underestimated.

The 2009-2011 American Community Survey reports that the American Indian and Alaskan Native communities in NYS experience significant disparities related to various Social Determinants of Health, such as in education, employment status, household income, health insurance status, disability, and poverty, when compared to the NYS population:

- 15.2 % of the NYS population aged 25 and older did not complete high school. In comparison, 26.1% of American Indian and Alaska Native alone (or 21.0% of American Indian and Alaska Native alone or in combination) did not complete high school. About 33% of the NYS population aged 25 and older had a bachelor’s degree or more education. In comparison, 17% of American Indian and Alaska Native alone (or 22% of American Indian and Alaska Native alone or in combination) had a bachelor’s degree or more education.
- 6% of the NYS population aged 16 and older in the civilian labor force were unemployed. In comparison, 8.8% of American Indian and Alaska Native alone (or 10.2% of American Indian and Alaska Native alone or in combination) were unemployed.
- The median household income for the NYS population was about \$56,000. In comparison, the median household income for the American Indian and Alaska Native alone population was significantly lower at \$36,400 (or \$39,000 for American Indian and Alaska Native alone or in combination population).
- Less than 12% of the New York State civilian noninstitutionalized population did not have any health insurance coverage. In comparison, over 22% of American Indian and Alaska Native alone population (or 18% of American Indian and Alaska Native alone-or-in-combination population) lacked health insurance coverage.

- Less than 11% of the NYS civilian noninstitutionalized population reported a disability. In comparison, over 16% of American Indian and Alaska Native alone population (or 18% of American Indian and Alaska Native alone-or-in-combination population) reported a disability.
- About 18% of NYS families with children under the age of 18 were living below the poverty level. In comparison, 31% of American Indian and Alaska Native alone families with children under 18 (or 27% of American Indian and Alaska Native alone-or-in-combination families) were living below the poverty level.

It is not possible to effectively address HIV transmission or medical care engagement without also addressing disparities and social determinants of health, such as the ones noted above. Because of these many co-occurring issues, it is important to employ a holistic (biological, psychological and social) approach to HIV prevention and care that extends beyond an individual's risk behaviors. Moreover, understanding complexities such as the tremendous diversity of this community, issues of sovereignty, economic development, self-sufficiency, and interdependence is critical to partnership building and the development of an effective framework to reduce the risk of HIV transmission not only at the individual level, but also at the community and ultimately achieve the goals of Ending the Epidemic in NYS by 2020.

#### **HIV EPIDEMIOLOGY: United States and New York State**

**Overview:** Surveillance data do not necessarily reflect the extent of HIV/AIDS morbidity among Native Americans. Several factors contribute to the underreporting of Native American individuals. For instance, racial/ethnicity misidentification of Native American individuals may lead to the undercounting of this population in human immunodeficiency virus (HIV) surveillance systems (i.e., individuals who are Native American being 'categorized' as White or another racial group). This misclassification leads to undercounting of cases among Native Americans. Other factors are tied to sovereignty (that is, that some Native nations may collect HIV-related data but may be reluctant to share them with NYS, or "data sharing") and to social determinants of health and inequities such as access to culturally appropriate services. Additionally, stigma and concerns about confidentiality often dissuade some people from getting tested and learning their HIV status or accessing health care services. The undercounting is an important point because it may contribute to the underfunding of culturally appropriate interventions and services, as well as a general lack of recognizing how severe these health concerns and disparities are for Native people.

Another major concern from this group relates to the misclassification of Native American individuals in HIV surveillance systems. In recognition of these concerns, the NYS DOH AIDS Institute Bureau of HIV/AIDS Epidemiology (BHAIE) recently conducted a study to explore Native American race reporting in NYS HIV surveillance data. The project looked at methodologies estimating the number of Native Americans living with HIV in NYS. Findings from the study show that the true number of Native

American persons living with diagnosed HIV is likely to be **2-5 times greater** than the number produced by the current CDC method. The findings from NYS BHAЕ provide published research indicating documented racial misclassification of Native Americans in the US Surveillance System. It also underscores the need for more accurate representation of this community to ensure that adequate funding and resources are established to provide population specific and targeted HIV prevention interventions and health care services that are culturally tailored and appropriate. The study and findings were presented at the 2019 National HIV Prevention Conference<sup>4</sup>.

Nevertheless, available data show that early intervention is needed to ensure that Native people are aware of their HIV status, are fully engaged in medical care and treatment and are aware of latest prevention science (both behavioral and biomedical). More importantly, the need to promote overall health and wellness is critical.

**United States:** National level data from the United States Census and other sources demonstrate that HIV is a public health issue among Native Americans, who represent about 1.3%<sup>5</sup> of the U.S. population. Overall, diagnosed HIV infections among Native Americans are proportional to their population size. The rate of diagnosis of infection among Native Americans in 2016 (10.2 per 100,000 population) was the fourth highest among seven racial/ethnic groups in the United States; the number of diagnoses of HIV infection among Native American individuals increased by 70%, from 143 in 2011 to 243 in 2016<sup>6</sup>.

In terms of risk factors for HIV, for every 100 Native Americans living with HIV in 2014, 58 received some HIV Care while only 47 were retained in care and 47 were virally suppressed. Incidence of Acute Hepatitis C among Native people was the highest among all racial and ethnic groups in the United States from 2001-2016<sup>7</sup>. Rate of Hepatitis C deaths for Native Americans was 10.75, compared to 2.7 among the general population in 2016. Finally, rates of Gonorrhea and Chlamydia for Native Americans was second highest among all racial and ethnic groups from 2013 – 2017<sup>8</sup>.

Below is a summary of the national numbers specific to HIV:

- Of the 39,782 HIV diagnoses in the United States in 2016, 1% (243) were among Native American. Of those, 81% (198) were men, and 19% (45) were women.

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<sup>4</sup> Yao Y, Patterson W, Swain CA, Gunn JKL, Anderson BJ, Tesoriero JM. Exploring Native American Race Reporting in New York State HIV Surveillance Data. 2019 National HIV Prevention Conference, Atlanta, GA. March 2019.

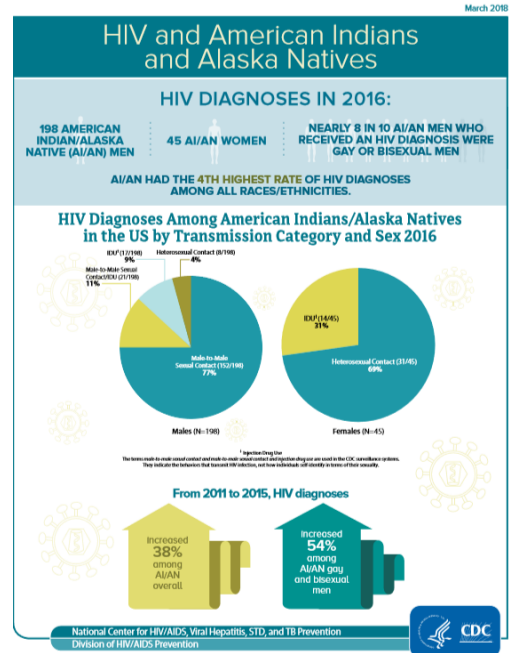
<sup>5</sup> US Census Bureau. QuickFacts United States: American Indians and Alaska Natives. Accessed January 26, 2018. American Indian/Alaskan Native is a CDC Surveillance designation. For the purposes of this report, Native American is utilized.

<sup>6</sup> Baugher AR, Beer L, Bradley HM, Evans ME, Luo Q, Shouse RL. Behavioral and Clinical Characteristics of American Indian/Alaska Native Adults in HIV Care — Medical Monitoring Project, United States, 2011–2015. *MMWR Morb Mortal Wkly Rep* 2019;67:1405–1409. DOI: <http://dx.doi.org/10.15585/mmwr.mm675152a1>.

<sup>7</sup> [www.ihs.gov/hiv/ids/stats/](http://www.ihs.gov/hiv/ids/stats/)

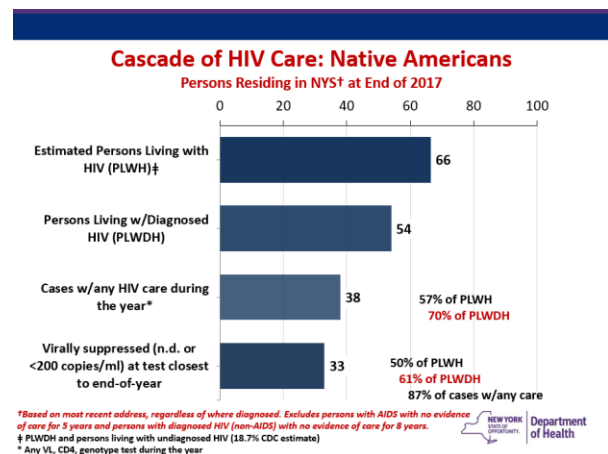
<sup>8</sup> CDC, National Notifiable Diseases Surveillance System (NNDSS), 2001 – 2016.

- Of the 198 HIV diagnoses among Native American men in 2016, most (77%; 152) were attributed to male-to-male sexual contact.
- Most of the 45 HIV diagnoses among Native American women in 2016 were attributed to male-to-female sexual contact (69%; 31).
- From 2011 to 2015, the annual number of HIV diagnoses increased 38% (from 143 to 197) among Native American overall and 54% (from 74 to 114) among Native American gay, bisexual, and Two Spirit men.
- In 2016, 102 Native Americans were diagnosed with AIDS. Of them, 75% (77) were men and 24% (24) were women.



**New York State:** The 2017 Cascade of HIV Care for Native Americans<sup>9</sup>, shown below, indicates that:

- There is an estimated number of 66 Native Americans living with HIV in NYS in 2017, of which 54 have been diagnosed.
- Of those diagnosed, 70% had HIV care (as measured by a viral load, CD4 or genotype test result) in 2017 and 61% were virally suppressed at their last viral load test in 2017.



Again, it must be stated that the data reporting Native American HIV/AIDS issues should be closely examined as many data underestimate these and other rates, due to issues of Native people being misclassified as a different race or ethnicity, the resistance of many Native people to get tested for HIV, and the frequent omission of Native peoples in various data sources. This workgroup believes that

<sup>9</sup> Bureau of HIV/AIDS Epidemiology, NYS DOH AIDS Institute.

these issues may result in the lack of a full understanding of the impact of HIV among Native populations, as stated throughout this report.

## FOCUS AREA 1: HIV TESTING

The Native American ETE Advisory Group recognizes that it is important for everyone to know their HIV status. *Individuals who do not know they have HIV cannot take advantage of HIV care and treatment. For many, HIV is the first entryway into vital treatment and essential social support services.*

While some Native Americans receive HIV/AIDS and viral hepatitis services through the Indian Health Service (IHS), not all Nation territories and tribes provide services through the IHS. Moreover, over 70% of Native Americans live off-reservation and reside in urban or suburban environments where there are no IHS facilities or do not reside near an IHS facility. Health clinics that are on territories are funded by New York State Department of Health and American Indian Health Program, in addition to IHS. As a result, Native individuals seek and access services through local programs. However, there is a lack of community based and culturally tailored HIV prevention and health services<sup>10</sup>.

The Native American ETE Advisory group identified several contributing factors that pose barriers and may lead to delays in testing, diagnosis and treatment: historical trauma, distrust of government, stigma, confidentiality, lack of insurance, absence of culturally relevant services, unemployment, substance use, educational level, and low health literacy. To address these barriers, culturally tailored interventions to increase access to HIV testing and awareness of transmission risk must be developed.

### BP1: MAKE ROUTINE HIV TESTING TRULY ROUTINE

#### IMPLEMENTATION STRATEGIES

1. Issue a formal press release from the NYS DOH AIDS Institute to promote **National Native American HIV/AIDS Awareness Day**, March 20<sup>th</sup>. The press release should include information about the availability of routine HIV testing as well as where to access tailored culturally appropriate targeted HIV testing.
2. Use Organizational Cascade Data, AIRS data and other information available to identify entities that provide medical care services to Native American communities and issue an annual “Dear Colleague Letter” from the State Health Department Commissioner to emphasize the importance of culturally appropriate HIV testing, prevention and treatment.



<sup>10</sup> American Indian & Alaska Native Population and American Indian Areas – Population and Area Profiles 2013. Cornell Program on Applied Demographics. <https://pad.human.cornell.edu/profiles/AIAN.pdf>

3. Continue to support NYS DOH funded health services provided to Native nations that do not receive Indian Health Services (IHS) funding, American Indian Health Program, and/or other sources, as these funds allow for the implementation of routine HIV testing.
4. Collaborate with IHS, nation/tribal leaders, and urban Native leadership who are willing to engage in discussions to identify concerns and guide the implementation of scalable, effective prevention strategies that reach those at greatest risk for HIV within their community.
5. Increase provider knowledge regarding the concerns that hinder access to and compromise the quality of health care for diverse and vulnerable Native American individuals, families, and communities (e.g., historical trauma, stigma, discrimination/bias, substance use) through technical assistance and cultural competency training and accountability as referenced earlier in this document.
6. Recommend that AI funded prevention and health care organizations that serve Native American communities and subcommunities are appropriately trained in the provision of culturally appropriate services (e.g., Clinical Education Initiative and other training and technical assistance provided from Native organizational perspectives).
7. Fund/support the capacity of community-based programs and grass roots initiatives/projects that serve Native American communities to provide free and low-cost confidential HIV services, as well as to increase opportunities to expand STI and Hep C screening programs.
8. Fund peer-delivered services such that agencies can hire Native American community members to do HIV testing and outreach to Native Americans on and off the nation territories and/or reservations across New York State.
9. Fund/support special evaluation projects/studies that addresses racial/ethnic misclassification issues. Use results to improve HIV surveillance data and develop a *Cascade of Care* that more accurately represents the percentages of undiagnosed/HIV tested Native American individuals as well as other Cascade outcomes (e.g., special project from BHAЕ referenced in the Introduction section).

## BP2: EXPAND TARGETED TESTING

### IMPLEMENTATION STRATEGIES



1. Fund culturally tailored HIV targeted testing and prevention interventions which prioritize Native American individuals.
2. Support the use of existing Indigenous cultural/traditional events or gatherings to provide education and resources and build community support for eliminating barriers to prevention and care, when appropriate.
3. Promote non-traditional/flexible service hours to improve availability and ensure greater access to culturally tailored services.
4. Support demonstration projects such as HIV Home Testing for Native American individuals and Peer Syringe Exchange programs.

#### BP4: IMPROVE REFERRALS AND ENGAGEMENT

##### IMPLEMENTATION STRATEGIES

1. Support the creation and maintenance of a multilevel directory/database or mobile application of agencies which specialize in serving Native Americans to facilitate linkages to culturally appropriate services.
2. Fund the implementation of interventions which employ an indigenous perspective, recognizing the principles of autonomy and self-determination to ensure successful referrals and care engagement (e.g., socio-cultural model, coping-stress model, trauma informed approaches).
3. Promote a culturally competent workforce (e.g., traditional and non-traditional) to improve the outcome of referrals and care engagement activities.
4. Support integrated screening practices for Mental Health and Substance Use peer-delivered services to help more Native Americans achieve improved health outcomes, including viral suppression.

#### FOCUS AREA 2: HIV CARE, TREATMENT AND RETENTION

*“Developing models of competent care that treat the whole person, as well as the virus, is crucial. People living with HIV—after being diagnosed, entering the healthcare system, and being prescribed treatment —require supports to remain engaged in care. Helping persons to enroll in and navigate health care coverage or medical assistance programs that provide HIV care or cover costs of care and treatment may be needed to support retention in care. Equally important is the need to re-engage people diagnosed with HIV who have subsequently fallen out of care”. “In addition to benefiting their*

*own health and longevity, people living with HIV who adhere to effective antiretroviral therapy and have suppressed viral load can reduce the risk of sexual transmission of HIV by 96 percent”.<sup>11</sup>*

In January of 2019, the CDC published a Morbidity and Mortality Weekly Report which summarized results from a Medical Monitoring Project that examined the Behavioral and Clinic Characteristic of American Indian/Alaskan Native (Native American) Adults in HIV Care in the US, 2011-2015<sup>12</sup>. The report findings indicate that to improve the health of Native American patient with HIV infection, it is *“important for health care providers, tribal organizations, and state and local health departments to consider the sociodemographic and behavioral barriers to achieving viral suppression for this community and design care plans that seek to eliminate those barriers.”*

Factors such as depression, historical trauma, distrust of government, stigma, alcohol use, confidentiality issues, lack of insurance, absence of culturally relevant services, unemployment, substance use, educational level, and poverty all present barriers to engagement in care and to achieving viral suppression for this community.

## BP5: CONTINUOUSLY ACT TO MONITOR AND IMPROVE RATES OF VIRAL SUPPRESSION

### IMPLEMENTATION STRATEGIES

1. Develop/adopt the use of trauma informed care models and frameworks that include concepts of historical and community-wide trauma specifically tailored to working with Native American individuals living with HIV for medical and non-medical providers with the goal of improving HIV and other health outcomes.
2. Support the hiring of Native American care coordinators and peer navigators. This practice increases cultural responsiveness, sensitivity to traditions and language appropriate services among HIV prevention and health services providers, and public health officials.
3. Create and maintain a directory of community-based agencies/providers that provide culturally tailored services to the Native American community. A complete directory of these agencies and contacts must be easily accessible online and in print form.

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<sup>11</sup> <https://www.hiv.gov/federal-response/national-hiv-aids-strategy/nhas-update>

<sup>12</sup> <https://www.cdc.gov/mmwr/volumes/67/wr/mm675152a1.htm>

## BP6: INCENTIVIZE PERFORMANCE

### IMPLEMENTATION STRATEGIES

1. Establish a list of approved patient incentives for providers (e.g. provide transportation access, grocery store gift cards for viral suppression, paid peer navigator positions, routine care incentives including rewards).
2. Utilize Value Based Payments to incentivize physicians that care for Native Americans living with HIV to promote sustained engagement in care.
3. Partner with agencies that serve and are trusted by Native American individuals and fund the use of incentives to promote care retention and viral load suppression.

## BP8: ENHANCE AND STREAMLINE SERVICES TO SUPPORT THE NON-MEDICAL NEEDS OF ALL INDIVIDUALS WITH HIV

*“Structural approaches can reduce risk of HIV transmission at community and societal levels. It is imperative that the conditions in which people live, learn, work, play, and pray facilitate—rather than detract from—their ability to lead healthy lives. Such conditions include the background prevalence of HIV in sexual and drug networks as well as housing, education, employment, and family and social support systems. It has become abundantly clear that these social determinants of health are significant factors in the ability to meet the goals of the National HIV/AIDS Strategy”. These goals are aligned with NYS’ Ending the Epidemic efforts.*

### IMPLEMENTATION STRATEGIES

1. Support the implementation of trauma informed care approaches that are inclusive and integrate concepts of historical and community-wide traumas in health care settings where Native American individuals access services.
2. Promote innovative and culturally tailored models for engaging Native American individuals with low levels of viral suppression or those who are treatment naïve.
3. Implement a holistic approach to wellness which addresses all aspects of health and recognizes that body, mind and spirit are connected (e.g., integrated and patient-centered HIV and related screening STI screening, substance use, mental health, intimate partner violence, viral hepatitis infections) and linkage to basic services (housing, education, employment). Native concepts of the Medicine Wheel, expanding silos, and similar teachings should be included with all cultural competency trainings.

## FOCUS AREA 3: BIOMEDICAL INTERVENTIONS (PREP AND PEP)

*“Studies have shown greater than 90 percent effectiveness of PrEP to prevent HIV infection when it is taken regularly. U.S. Public Health Service clinical practice guidelines were released in 2014 to assist clinicians in providing PrEP and associated services to their patients at substantial risk for HIV infection. Biomedical interventions should also be accompanied with behavioral interventions that support engagement in care and support medication adherence for those using PrEP”. “There are also specific HIV medications (PEP) that a person can take immediately after being exposed to HIV that can reduce the risk of HIV infection”<sup>13</sup>*

As with previous focus areas, the Native American ETE Advisory group identified several contributing factors that pose barriers to PrEP/PEP engagement including lack of awareness, absence of appropriate educational materials, limited access to or knowledge of PrEP prescribers, insurance challenges/cost, and stigma associated with being on or in need of PrEP and PEP. A partnership approach is critical to ensure prevention approaches are culturally tailored to the needs of the Native American community and people.

### BP11: UNDERTAKE A STATEWIDE EDUCATION CAMPAIGN ON PREP AND PEP

#### IMPLEMENTATION STRATEGIES

1. Use AIRS data and other data platforms/information available to identify entities where Native people are accessing services. Training should be provided by established, known training organizations to these entities to ensure the delivery of culturally appropriate services.
2. Partner with Native American community representatives and gatekeepers to create messages, materials and information about biomedical strategies such as Treatment as Prevention, PrEP and PEP for dissemination through print, web-based and mobile platforms. The goal is to implement a “For Us, by Us” approach to education and awareness activities.
3. Develop and conduct provider trainings on comprehensive sexual health conversations which are culturally sensitive and consider the diversity of the Native Americans, the impacts of historical as well as individual trauma, cultural resiliency, and self-determination of the community.

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<sup>13</sup> <https://files.hiv.gov/s3fs-public/nhas-update.pdf>

## BP12: INCLUDE A VARIETY OF STATEWIDE PROGRAMS FOR DISTRIBUTION AND INCREASED ACCESS TO PREP AND PEP

1. Support culturally appropriate HIV prevention interventions developed and delivered by Native Americans. Recognize, acknowledge, and incorporate when possible the many 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.
2. Fund/support PrEP/PEP programs that partner with the Native American community (community agencies, IHS, tribal nations, stakeholders, etc.) for community engagement and outreach activities. This approach ensures the delivery of culturally relevant client engagement activities. The goal is to improve access and sustained engagement in preventive services
3. Partner with IHS to promote PrEP/PEP access within the Native nations and tribes, as appropriate.
4. Support community-based Native people PrEP navigators in areas of NYS with large numbers of Native people in the cities and urban areas of NYS, as well as the Nation territories, when possible
5. Thoroughly review data sources to determine the completeness of such data and to ensure that any data used is the most accurate as possible.
6. Use such acceptable, accurate data to guide programmatic activity and ensure access to PrEP, PEP and preventive care in geographic areas with large numbers of Native people and access services at local hospitals, community-based organizations, STI/sexual health clinics, community health centers, etc.
7. Reach out and provide services to areas where there are low numbers of Native people. While supporting the concept that funding should be effective in creating the largest impacts, it is equally important that individual Native persons also have access to critical HIV-related services, regardless of how many Native people live in specific areas.

## BP25: TREATMENT AS PREVENTION INFORMATION AND ANTI-STIGMA MEDIA CAMPAIGN

*“Stigma and discrimination must be eliminated in order to diminish barriers to HIV prevention, testing, and care. HIV-related stigma can be confounded by or complicated with stigma*

*related to substance use, mental health, sexual orientation, gender identity, race/ethnicity, or sex work. Stigma can lead to many negative consequences for people living with HIV. It is imperative that all levels of government recognize that these various biases exist and work to combat stigma and discrimination in order to reduce new infections and improve health outcomes for people living with HIV. In the legal arena, this requires ensuring that all Federal and state criminal laws regarding HIV transmission and prevention are scientifically based, and that prosecutors and others in law enforcement have an accurate understanding of transmission risks”.*<sup>14</sup>

## **IMPLEMENTATION STRATEGIES**

1. Create a statewide health and wellness awareness and anti-stigma campaign that is relatable, culturally appropriate and responsive to the diverse needs of all Native American communities. Select art work and any images for Health Department materials in consultation with members of Native communities who are representative and inclusive of all Native “communities within communities.”
2. Provide networking opportunities for Native people and communities by supporting a statewide gathering or learning collaborative to address such issues as stigma and its impact on HIV prevention and treatment.
3. Include representatives from Native American communities in educational campaign planning processes to gain input on barriers and effective strategies to seeking prevention/sexual health services and medical care (e.g., leaders, elders, key stakeholders – both tribal and urban).

## **FOCUS AREA 4: FUNDING AND DATA COLLECTION/REPORTING**

*The lack of accurate data due to the misclassification of Native American individuals, particularly in government data systems is a significant concern as it may lead to misconceptions about the true burden of disease for this vulnerable population, and thus the inadequate allocation of resources. Although state laws about reporting new HIV diagnoses apply to providers and laboratories serving AI/AN tribal and urban facilities (as they do to other licensed providers), tribal facilities on sovereign nations may not be legally required to report infectious diseases (NOTE: Pam felt that the on-territory health clinics ARE required to report infectious diseases). While relatively few people may be tested in Native-focused hospitals and clinics on Native territories, racial misclassification is another potential concern with the use of HIV/AIDS surveillance data, as many Non-Native providers may often assign an incorrect race/ethnicity for Native American clients, clients may lack awareness, or they may intentionally identify themselves other than Native American due to concerns about confidentiality.*<sup>15</sup>

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<sup>14</sup> <https://files.hiv.gov/s3fs-public/nhas-update.pdf>

<sup>15</sup> <https://www.nastad.org/blog/addressing-hiv-and-viral-hepatitis-among-native-gay-men-and-two-spirit-people>

The Native American ETE Advisory group identified several issues which need immediate attention by the AIDS Institute which pertain to the two blueprint points noted below. It is the opinion of this Advisory group that these are intertwined.

**BP28: EQUITABLE FUNDING WHERE RESOURCES FOLLOW THE EPIDEMIC.**

**BP29: EXPAND AND ENHANCE THE USE OF DATA TO TRACK AND REPORT PROGRESS.**

### **IMPLEMENTATION STRATEGIES**

1. Cease using terms such as “Other” or “Statistically Insignificant” when referencing Native American data or information.
2. Utilize Request for Application (RFA) eligibility criteria requirements which are specific and ensure that agencies which demonstrate a commitment to providing culturally appropriate and trauma informed services to Native Americans are funded.
3. Utilize special projects/studies to provide a more accurate representation of the HIV burden in the Native American community in NYS (BHEA project).
4. Educate and foster a community dialogue about the importance of accurate data (e.g., appropriate identification by the medical provider in chart) to ensure adequate funding and resources for Native American communities and people.
5. Implement a statewide needs assessment to examine the needs of Native American communities, risk and protective factors, sources of health care and healing, explore concerns of historical trauma and stigma, as well as other socio-cultural-economic aspects that affect the health and wellbeing of this community and how these factors influence cross-cultural services, outreach efforts, and related programs.
6. Restore funding for community-based HIV prevention and support services that prioritize Native American communities in areas where they live (both urban and rural). Agencies should have an intimate understanding of Native American community needs, history, culture and socio-economic factors.
7. Fund/support community participatory research to develop innovative strategies to prevention and care which prioritize Native American communities.
8. Because of their unique experiences and perspectives, the input of Native people HIV/STI/HCV prevention and care program planning/resource allocation is essential. Therefore, the AI must actively involve Native people in planning bodies and advisory groups.

9. Advocate for changes at the national level about the impact of the CDC method for classifying race/ethnicity which leads to the underrepresentation of Native peoples in HIV surveillance data.

#### LESSONS LEARNED: EXCERPT FROM THE 2010-2015 COMPREHENSIVE PLAN, NYS PREVENTION PLANNING GROUP

The NYS HIV Prevention Planning Group (PPG) and the NYS Department of Health AIDS Institute (AI) developed the following factors or strategies for consideration when working with Native American Communities from: 2010-2015 PPG Comprehensive Plan. This “Lessons Learned” document was developed based on a three-day presentation by Native American members of the PPG in 2014. As it is the feeling of the Native American ETE Advisory Group that these considerations/lessons learned still apply today, the group is including in this report.

NOTE: As many Indigenous nations maintain their sovereignty as independent nations, some may not consider themselves as being part of the “jurisdiction” as stated below as this implies some level of hierarchy or authority over these nations. “Service areas” is a more appropriate phrase to use when considering services provided by state departments and offices.

- Identify HIV and AIDS cases by a separate category. Do not categorize Native Americans and Alaskan Natives under “Other” or “Unknown”.
- 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 the NYS DOH AIDS Institute’s 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 have not 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/Hawaiian Natives/Alaskan Natives 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. Be mindful of the impact of social, economic factors of oppression and historical events that have contributed to “mistrust” of governmental program and traditional health care institutions.
- 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 in addressing the 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 (e.g., 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.

**Acknowledgments:** *These "Considerations" are based upon experience working collaboratively with members of Native American communities in New York State. This list was prepared with benefit of guidance and insights provided by Native Americans and Native American service providers.*

*The following individuals reviewed and commented on this checklist in 2005: Cissy Elm (Onondaga, Snipe Clan), Ken Dunning (Onondaga, Beaver Clan), Pete Hill (Cayuga, Heron Clan), Shirley Farmer-Tyner (Cayuga, Wolf Clan), Barbara Johnson (Onondaga, Snipe Clan) and Norine Borkowski, Native American Community Services.*