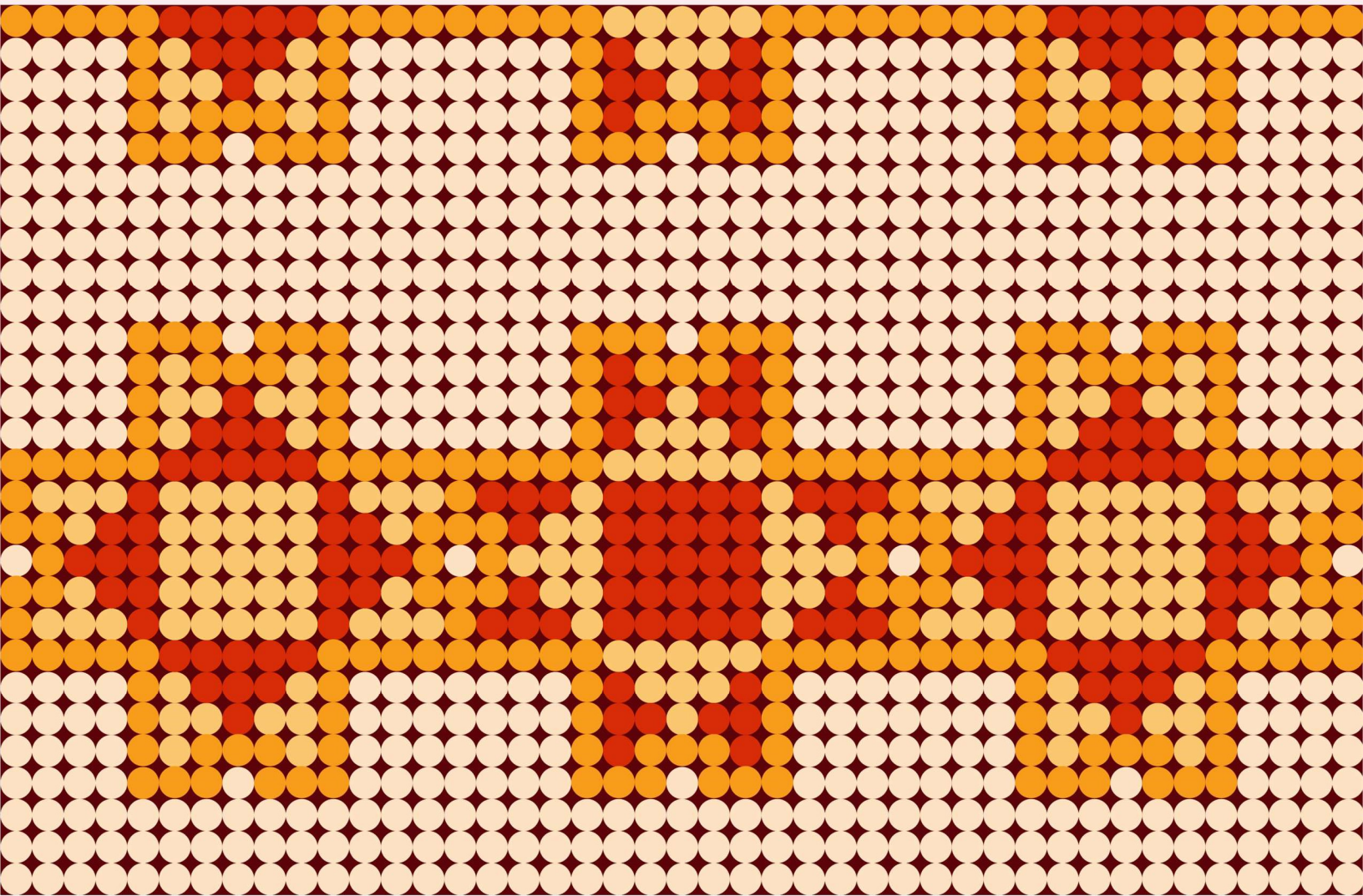


# Positively Native

## **FACILITATION GUIDE: A RESOURCE FOR LEADING DISCUSSIONS ON HIV/AIDS AND STIGMA IN AMERICAN INDIAN/ALASKA NATIVE COMMUNITIES**



**Urban Indian  
Health Institute**  
A Division of the Seattle Indian Health Board

**Our mission is to decolonize data,  
for indigenous people, by indigenous people.**

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## FOREWORD BY BILL HALL (TLINGIT)

The Positively Native project was created to provide community advocates with tools for starting conversations around the topic of HIV/AIDS stigma. In the accompanying twelve-minute video, three Native people (Bill Hall, Shana Cozad, and Hamen Ides) share their experiences with the stigma they have experienced as a result of living with HIV/AIDS. They share a powerful message: Native people can overcome HIV stigma by coming together to support one another.

It is our hope that this video will spark conversations about stigma as it relates to the individual's own beliefs on HIV/AIDS. If you come across a person living with HIV/AIDS, what is your first thought about that person? If it's a negative thought, that's stigma. The end goal of this conversation is what would it take for individuals (when they hear about the impact that stigma has on our community) to set aside those beliefs and be tested for HIV. You can have all the thoughts and beliefs you want on HIV, but are those thoughts and beliefs worth your life?

At this stage, there is no cure for this disease, and the sad reality is our people are still dying from this disease. We need to get to a place where we realize that AIDS is here; ignoring it won't make it go away. And the impact of becoming HIV Positive is life-altering. The thoughts you might have about people living with AIDS will now be the thoughts of others about you if we don't accept this disease for what it is, educate our family and friends about this, and take the necessary steps to protect ourselves. If everyone in this room takes this to heart and begins this difficult conversation with family and friends, we can change the face of AIDS and the impact it has on our people.

—Bill Hall (Tlingit)

# FACILITATOR INFORMATION

## Overview

### **Positively Native is a toolkit that includes:**

- A presentation on the basics of HIV, including transmission, prevention, treatment, stigma and discrimination, and epidemiology of HIV in American Indian/Alaska Native (AI/AN) communities.
- A short video in which three American Indian/Alaska Native people share their experiences with stigma and discrimination as a result of living with HIV.
- Discussion questions corresponding to the video.
- A facilitator's guide.

The toolkit is intended to be used in both urban and tribal American Indian/Alaska Native communities and may be used at community events and/or as part of already existing programs, like youth clubs and elder programs. Please consider using the toolkit to commemorate National Native HIV/AIDS Awareness Day (NNHAAD), which falls on March 20th of each year.

## Objectives

For participants to become informed about the transmission, prevention, and treatment of HIV.

Introduce participants to HIV stigma and discrimination through the stories of American Indian/Alaska Native people living with HIV.

To develop ideas on how participants can help stop HIV stigma and discrimination in their communities.

## Format

### **Present the basics of HIV PowerPoint (~10 minutes).**

- Presenter notes are included with the PowerPoint.
- In addition, there is space for the facilitator to make notes.
- As you present the PowerPoint, consider talking about local programs and resources available to community members (e.g. HIV testing, free condoms, needles exchanges, etc.) Watch the Positively Native Video (~12 minutes).
- Before the event begins, ensure that you can play the video embedded in the PowerPoint presentation.
- If the embedded video will not play, access the video from YouTube (see link below).

- In addition, ensure that your speaker sound is working prior to the presentation.
- Biographies of the people in the video are located in the appendix.

### **Facilitate the discussion (~20 minutes)**

- If there are more than 10 people in the audience, break up into groups of 5-6 people.
- In each group, there should be a facilitator and notetaker.
  - The facilitator and notetaker may be staff from your organization, trusted staff from partner organizations, or community members who are comfortable with facilitation and/or notetaking.
- The facilitator should have a copy of the discussion questions (located in appendix), and the notetaker should have a flipchart and marker. If flipcharts aren't available, use regular paper.

### **Report Back (~10 minutes)**

- Once groups are finished discussing the question, have each group select one person to report back to the larger group on the question.
- All groups don't need to report back on every single question.

### **Materials**

- Computer that is connected to working speakers
- [https://www.youtube.com/watch?time\\_continue=722&v=gZNMsyAswLo](https://www.youtube.com/watch?time_continue=722&v=gZNMsyAswLo) (Positively Native video)
- Copies of discussion questions for facilitators
- Flip chart or paper for notetakers
- Markers for notetakers

## FACILITATOR INFORMATION

### Notes

The components of the toolkit may be split up among different staff and community members. For example, if you work in a clinic, it may be useful to have a medical provider give the presentation on the basics of HIV, a social worker facilitate the video discussion, and a community member be the notetaker. However, please ensure that someone is in charge of keeping time, bringing materials, ensuring the computer sound and video work, etc.

If you find yourself with questions about HIV as you read through the facilitation guide, please see the resource list on pg. 12 for more information about HIV. If you have additional questions, please contact the Urban Indian Health Institute.

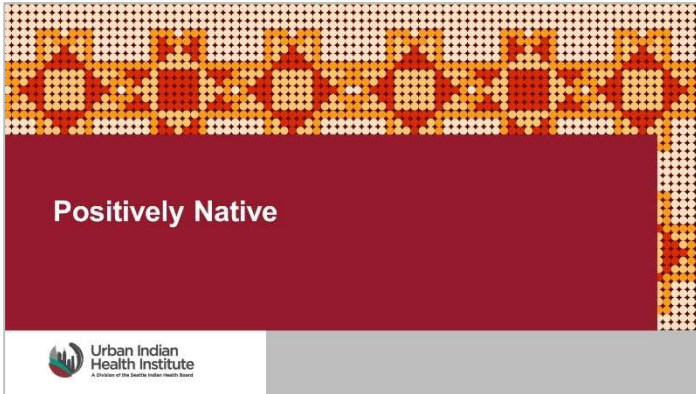
If you are using this toolkit as part of a community event for NNHAAD, consider the following:

- Open the event with a blessing.
- Serve a meal before or after the presentation, video, and discussion.
- Invite HIV-focused community organizations to participate in a resource fair.
- Have a raffle with prizes.
- Offer free hepatitis C and HIV testing. If your organization does not offer these services, invite another organization to do so.
- Offer free condoms.
- Encourage the leadership of your organization to attend.

# PRESENTATION NOTES

## Introduction

### Slide 1



- Welcome the audience.
- Introduce yourself, including your tribal affiliation (if applicable) and your role at your organization.
- Give a brief overview of the presentation, video, and discussion.
  - For example, “Today, we’re going to talk about the basics of HIV, watch a video about how stigma has impacted three American Indian/Alaska Natives living with HIV, and then we’ll have a chance to discuss the video.”

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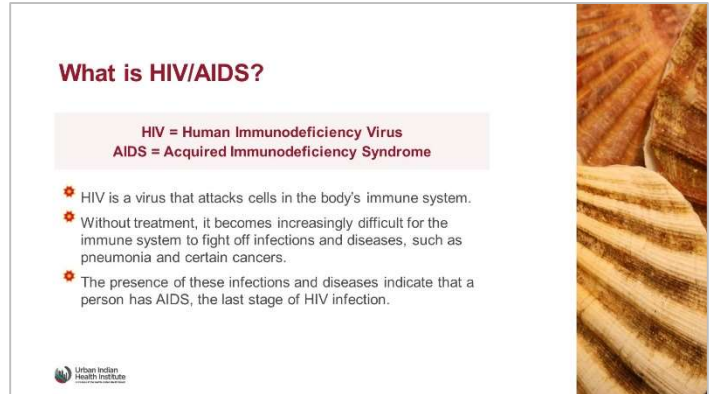
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## HIV Basics: What is HIV/AIDS (~10 minutes)

### Slide 2



Stages of HIV Infection include:

#### Stage 1: Acute infection

- People have a large amount of the virus in their blood at this stage and are highly contagious.
- Flu-like illness may be experienced by people with acute infection.

#### Stage 2: Clinical latency

- The HIV virus reproduces at low levels at this stage.
- There may be no symptoms.
- People who take their HIV medicine may stay in this stage for decades.

#### Stage 3: AIDS

- Marked by symptoms such as chills, fever, sweats, swollen lymph glands, weakness, and weight loss.

Notes Source: CDC (2019). HIV Basics: About HIV/AIDS. Retrieved January 29, 2020, from

<https://www.cdc.gov/hiv/basics/prevention.html>

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# PRESENTATION NOTES

## HIV Basics: Transmission

### Slide 3



Sexual contact and sharing needles to inject drugs are the most common ways AI/ANs are contracting HIV

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## HIV Basics: Prevention

### Slide 4



Everyone between the ages of 13 and 64 should be tested for HIV at least once.

**However, people with the following risk factors should be tested more often:**

- Men who have sex with men.
- Had sex with a partner who has HIV
- Had more than one partner since last HIV test
- Injected drugs or shared needles with others
- Exchanged sex for drugs or money
- Been diagnosed or treated for an STI
- Treated for hepatitis or TB

**Tips for condom use:**

- Check the expiration date
- Make sure there are no tears in the condom
- Store in a cool, dry place
- Use water or silicone-based lubricant to prevent tears.

Notes Source: CDC (2019). HIV Basics: Prevention. Retrieved January 29, 2020, from <https://www.cdc.gov/hiv/basics/prevention.html>

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# PRESENTATION NOTES

## HIV Basics: PrEP and PEP

### Slide 5

**PrEP and PEP**

**PrEP**

- Pre-exposure Prophylaxis (PrEP) is a **daily pill** that prevents HIV in people at risk of contracting HIV.
- PrEP can reduce the risk of contracting HIV by
  - 99% for sex
  - 74% for shared needles
- PrEP must be taken consistently to be effective

**PEP**

- Post-exposure Prophylaxis (PEP) is a pill taken after exposure to HIV to prevent HIV infection.
- PEP must be started within 72 hours of exposure.
- PEP is effective in preventing HIV, but not 100%.

Urban Indian Health Institute | Source: CDC (2019). HIV Basics: Prevention. Retrieved January 29, 2020, from <https://www.cdc.gov/hiv/basics/prevention.html>

PrEP and PEP are for all genders and sexes.

**In assessing eligibility for PrEP, the following risk factors will be considered:**

- Having a sexual partner with HIV in the past 6 months.
- Inconsistent condom use for the past 6 months.
- Having been diagnosed with an STD in the past 6 months.
- Having an injection partner with HIV.
- Sharing needles, syringes, or other equipment to inject drugs.
- Having a partner with HIV and are considering getting pregnant.

Notes Source: CDC (2019). HIV Basics: Prevention. Retrieved January 29, 2020, from <https://www.cdc.gov/hiv/basics/prevention.html>

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## HIV Basics: Treatment

### Slide 6

**Treatment**

- Antiretroviral Therapy (ART) is a combination of drugs taken to reduce the amount of HIV in blood and body fluids.
- ART can lower the amount of HIV in blood and body fluids to undetectable levels, making HIV untransmittable through sex.

**Undetectable = Untransmittable**



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While there is no cure for HIV, treatment is available that allows people to live long, healthy lives

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# PRESENTATION NOTES

## HIV Basics: Stigma and Discrimination

### Slide 7

### Stigma & Discrimination

- HIV stigma is negative beliefs, feelings, and attitudes about people living with HIV.
- Discrimination is the unfair and unjust treatment of someone resulting from those negative attitudes, feelings, or beliefs.
- Refusing housing, healthcare, or work to someone because they have HIV.
- Socially isolating a community member because they are living with HIV.



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When stigma is internalized, it can lead to feelings of shame, fear of disclosure, isolation, and despair. Unfortunately, such feelings can keep people from getting tested and treated for HIV.

Notes Source: CDC (2019). HIV Basics: Dealing with Stigma and Discrimination. Retrieved January 29, 2020, from <https://www.cdc.gov/hiv/basics/livingwithhiv/stigma-discrimination.html>

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## HIV Basics: HIV in AI/ANs

### Slide 8

### HIV in American Indians/Alaska Natives

	# of Cases	Rate
<b>Number of HIV Diagnoses (2017)</b>		
AI/AN	212	8.8
White	10,048	5.1
<b>Number of AIDS Diagnoses (2017)</b>		
AI/AN	72	3.0
White	4,321	2.2

\* Rate is per 100,000 people

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Source: CDC (2019). HIV Surveillance Report 2017. 29. Retrieved from <https://www.cdc.gov/hiv/reports/national-surveillance/pdf/10surveillance-report-2017-vol-29.pdf>

In 2017, the crude number of HIV and AIDS diagnoses were higher in whites than in American Indians/Alaska Natives. However, when you take population size of each race group into account, meaning the white population being much larger than the AI/AN population, the rate of HIV and AIDS is higher in AI/ANs than in Whites.

It's important to mention that racial misclassification, which is when a AI/AN person is often classified as white in their healthcare record, definitely plays a role here, most likely making the number of diagnoses in AI/AN higher than what is reported here in these numbers.

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# PRESENTATION NOTES



## HIV Basics: HIV in AI/ANs

### Slide 9

#### HIV in AI/ANs (Cont.)

- It is estimated that 3,600 AI/ANs are living with HIV in the US.
- However, this number is most likely higher due to AI/ANs being misclassified as another race.
- From 2010 to 2016, the annual number of HIV diagnoses increased 46% among AI/AN.
- Among gay and bisexual AI/AN men, the number of HIV diagnoses increased by 81%.



Source: CDC (2018). HIV Surveillance Report, 2017, 29. Retrieved from <https://www.cdc.gov/hiv/pdf/library/reports/surveillance/cdc-hiv-surveillance-report-2017-vol-29.pdf>



## Positively Native Video (~12 minutes)

### Slide 10

#### Video



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From 2010 to 2016, AI/ANs were only one of two racial groups to see an increase in HIV infections (the other was Asians; however, Asians have the lowest rate of HIV infection among all racial and ethnic groups).

Notes Source: CDC (2018). HIV Surveillance Report, 2017, 29. Retrieved from <https://www.cdc.gov/hiv/pdf/library/reports/surveillance/cdc-hiv-surveillance-report-2017-vol-29.pdf>

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# PRESENTATION NOTES

## Discussion Questions (~20 minutes) and Report Back (~10 minutes)

### Slide 11

**Discussion Agreements**

- Introduce yourself
- Listen respectfully, without interrupting
- Allow everyone a chance to speak
- Stay on topic
- Any others?

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Once the video is over, go through agreements before beginning discussion or breaking into groups.

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### Slide 12

**Discussion Questions**

- What are your first thoughts after watching the video?
- Do people in your community talk about HIV and how to prevent it?
- What can you do to help stop stigma and discrimination in your community and beyond?
- How will you continue this discussion moving forward?
- I learned, I hope, or I feel....

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#### As a reminder:

- If there are more than 10 people in the audience, break up into groups of 5-6 people.
- In each group, there should be a facilitator and notetaker.
  - The facilitator and notetaker may be staff from your organization, trusted staff from partner organizations, or community members who are comfortable with facilitation and/or notetaking.
- The facilitator should have a copy of the discussion questions (located in appendix), and the notetaker should have a flipchart and marker. If flipcharts aren't available, use regular paper.
- Once groups are finished discussing the question, have each group select one person to report back to the larger group on the question.
- All groups don't need to report back on every single question.

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# PRESENTATION NOTES

## Closing

### Slide 13



Answer any questions the audience may have and thank them for coming to the event.

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## ADDITIONAL RESOURCES

### General HIV

#### HIV Basics (CDC)

<https://www.cdc.gov/hiv/basics/index.html>

#### HIV Overview (National Institutes of Health)

<https://aidsinfo.nih.gov/understanding-hiv-aids/fact-sheets/19/45/hiv-aids--the-basics>

#### About HIV and AIDS (HIV.gov)

<https://www.hiv.gov/hiv-basics/overview/about-hiv-and-aids/what-are-hiv-and-aids>

### HIV and AI/ANs

#### HIV/AIDS (IHS)

<https://www.ihs.gov/hiv/aids/>

#### Project Red Talon

##### (Northwest Portland Area Indian Health Board)

<http://www.npaihb.org/project-red-talon/>

#### HIV Among AI/ANs (CDC)

<https://www.cdc.gov/hiv/group/raciaethnic/aian/index.html>

### Youth HIV/STI Education

#### Native Voices

##### (Northwest Portland Area Indian Health Board)

<https://www.healthynativeyouth.org/curricula/native-voices>

### HIV Stigma

#### Facts about HIV Stigma (CDC)

<https://www.cdc.gov/hiv/basics/hiv-stigma/index.html>

#### HIV Stigma and Discrimination (Avert)

<https://www.avert.org/professionals/hiv-social-issues/stigma-discrimination>

### Pre-Exposure Prophylaxis (PrEP)

#### Pre-Exposure Prophylaxis (CDC)

<https://www.cdc.gov/hiv/risk/prep/index.html>

#### Ready, Set, PrEP (HIV.gov)

<https://www.hiv.gov/federal-response/ending-the-hiv-epidemic/prep-program>

#### Cyber Tipi of PrEPahHontoz

<https://prepahontoz.com/>

## APPENDIX

### Bios

#### **Bill Hall (Tlingit)**

Bill Hall, a member of the Tlingit tribe of Southeast Alaska, has been living with HIV for more than three decades in which time he has become a courageous advocate sharing his experience as an HIV+ Native individual and honestly detailing his battles with depression and cancer. Bill serves on the community advisory board (CAB) of DefeatHIV, is a member of the Multicultural HIV and Hepatitis C Action Network (MHHAN) and is a tireless community partner and advisor of Seattle Indian Health Board and Urban Indian Health Institute. He is unyielding in his hope for a cure for HIV and resolute in his belief that reducing stigma is fundamental to improving the health outcomes and lives of those living with HIV. He has touched countless lives throughout Indian Country and beyond. Each month he hosts and cooks a homemade meal for Defeat HIV's CAB meeting!

#### **Shana Cozad (Kiowa)**

Shana Cozad is a full-blooded Native American enrolled with the Kiowa Tribe of Oklahoma. Shana has been a noted, recognized public speaker and HIV/AIDS prevention educator since 1994. Shana has spoken at numerous schools, universities, AIDS memorials, AIDS Walks and World AIDS Day events. Some highlights of their advocacy include being featured in POZ Magazine, Keynoting for the 3rd Annual Circle of Harmony Conference, and being on the Keynote Panel for the National Native American AIDS Awareness events around the country. Shana's story is also among the women's voices in River Huston's book "A Positive Life." She has been interviewed numerous times throughout the years by television, newspaper, and national radio sources. She won the Richard Shackleford Memorial Award for outstanding service and care within the HIV community in Tulsa, Oklahoma. She serves as a member and advisor with various HIV coalitions and HIV planning committees, particularly in Native American communities.

#### **Hamen Ides (Lummi)**

Hamen Ides is a member of the Lummi Nation of Washington, with ties to the Makah Nation on the Olympic Peninsula. Hamen is a Founder and Executive Director of Ti-Chee Native AIDS Prevention.