

**STATEMENT
OF
THE NATIONAL NATIVE AMERICAN AIDS PREVENTION CENTER
TO
THE HOUSE ENERGY AND COMMERCE COMMITTEE
AND
SENATE HEALTH, EDUCATION, LABOR AND PENSIONS COMMITTEE
FOR
THE RYAN WHITE CARE ACT FEEDBACK MEETING
JANUARY 19, 2006**

**Part One
Presented by Brandy Tomhave, J.D.**

Native Americans are among the most needy in this country when it comes to health care. Their story of health disparity begins with an infant mortality rate that is 1.7 times greater than the rate for white infants and ends with a life expectancy that is six years less than that of other U.S. citizens. That is why, on behalf of the Native American AIDS Prevention Center, we thank you for this important opportunity to discuss the unmet needs of Indians with HIV/AIDS, and what you can personally do to help.

To provide context for our discussion, I would like to begin by answering 3 frequently asked questions, which you are probably wondering right now.

Is HIV/AIDS a problem within tribal communities?

While surveillance problems and racial misclassification mask the true scope of this disease' impact on American Indians and Alaska Natives, available data reveals that HIV/AIDS is a deadly serious problem within Indian Country-- 44% of known HIV cases in American Indians and Alaska Natives progress to AIDS within 12 months.

The Centers for Disease Control has determined that American Indians and Alaska Natives have the third highest rate of AIDS in the nation, 40% higher than the rate among Whites. The highest rate of increase is among Native women, for whom incidences of rape are 3.5 times higher than among all other racial groups, and their children, who have the second highest rate of infection, behind African American children. This is not surprising when you consider the risk amplifiers ravaging Indian Country-- there is more binge drinking and illicit drug use among Indians than any other racial or ethnic group, and the second highest rate of sexually transmitted diseases in the nation.

As you know, the difference between living with AIDS and dying from AIDS is access to treatment, which is all about available resources. Unfortunately, we do not have time here today to cite for you the statistics on the third world conditions you would find if you visited most

Indian reservations-- the lack of basic public health necessities that allow this disease to thrive. For that information, we direct you to the briefing book we have provided.

Suffice it to say that all of the essential infrastructure that most Americans take for granted-- running water, sewage, refrigeration, indoor power, paved roads, garbage collection and telephones-- are things that most Indian Reservations and Alaska Native Villages don't have. In this respect, Indian Country looks a lot like Sub-Saharan Africa, which has most of the world's AIDS cases today. The bottom line for you is this-- HIV has found its perfect incubator in Native American communities and will continue to explode if you continue to ignore this population.

Does the RWCA reach Indian Country?

With only few exceptions, the answer is "no." The Ryan White Care Act authorizes no direct HIV/AIDS treatment funds for the Indian Health Service, which is the primary health care provider for Indians on reservations and Alaska Native Villages. For many Natives, the local IHS clinic is their only source of medical treatment, from cradle to grave.

If you are a Native with HIV or AIDS, you face a one-two punch when you turn to IHS for medical treatment. First, IHS has no line item within its annual appropriation request for HIV/AIDS treatment. Second, IHS is excluded from the Ryan White CARE Act.

Why don't Indians just get HIV/AIDS treatment off-reservation?

American Indians and Alaska Natives are the only Americans who have been systematically denied treatment by Ryan White Care Act grantees for the past 15 years. When Indians go to the city to access the treatment they cannot get at their local IHS clinic, they are more often than not told that they do not qualify for treatment because of their race. They are told that Indians are supposed to get their medical treatment from IHS.

This situation has been so bad for so long that the Health Resource Service Administration has twice issued a restatement of its policy reaffirming that eligible American Indians and Alaska Natives are entitled to claim Ryan White CARE Act services from non-tribal grantees. Unfortunately, the Ryan White CARE Act provides no mechanism of accountability for, or sanction against, noncompliant grantees who withhold medical treatment from Native Americans.

Part II
Presented by Sharon Day

Booshoo Nindinwaymanidoog
Nagamoo Mahingen, Indishnikaz
Wahbizhwayzhi indodem
Ojibweequay indow
Indizhbeshego M'dewiwin

Greetings, my relatives
Singing Wolf is my name
I am of the Marten Clan
An Ojibwe woman
I am first degree M'dewiwin.

It is an honor for me to be here today to address this committee. I bring you greetings from my Nation, the Ojibwe People.

I am the Executive Director of the Indigenous Peoples Task Force. An organization that was created in 1987 to prevent the spread of HIV amongst our people and to provide care services to Indigenous People living with HIV and their family members.

I came to this work because my brother, Michael, and other Native people I know are living with this disease. In 1987, no organization existed nor were there any existing organization to provide culturally specific services to Native Americans. Over the past 19 years, we have seen the growth of this disease among Native communities across this country but we have not seen a growth in services. Because our prevention efforts are so small and ineffective, the average Native person will tell you that HIV is a gay white male disease and they are not at risk.

In the great state of Minnesota, 19 years hence, there is still only one organization providing culturally based case management services to Native people living with HIV with funds from the Ryan White Care Act, that is the Indigenous Peoples Task Force. We are located in Minneapolis. There are eleven reservations in Minnesota, seven which are located from 100 miles north to 500 miles north of Minneapolis. It is almost impossible for us to try to provide services to people living so far away.

Yet, we are always hopeful that we will make a difference for our people. We were happy when the CDC included Native Americans as a racial category in the surveillance system in 1990. We were happy to no longer be labeled "other." We thought this might bring a change in funding so we could better serve our people. We were happy when the Ryan White Care Act became law. We thought this might bring some funds to Native communities so we could provide care services to our people.

Alas, today, there are only five Native Programs in the entire United States that are directly funded by the CDC. There are only a handful of programs providing care services with funds from the Ryan White Care Act including Titles I, II, III or IV. What we need is a Title devoted to Native Americans, because tribal programs have no access to Title I, few tribal programs have access to Title II and there have only been a few Special Programs of National Significance funded for Native Americans since the beginning of the Care Act.

Some of the reasons why we have no culturally specific programs are because the planning committees operate in ways that are foreign to our people. They are politically motivated to continue the status quo. The majority of funds go to white/gay male organizations. I asked one of our clients recently, why don't you go over to the big HIV AIDs organization for transportation services because you are eligible? He looked at me and said, "because they treat us badly."

My organization which has won awards for the excellence in our work from the Surgeon General and HRSA struggles from year to year. In this past year, alone, our Title I funds went from \$27,450.00 to a meager \$15,300.00. When I chaired the Ryan White Care Title I Planning Committee in 1991, we received nominal funding for emotional support, transportation and case management.

Every time we are fortunate to receive some funding from CSAP or the CDC, the State of Minnesota's health and human services agencies reduce our Ryan White Care Act or Prevention funding. In a state where the reservations are so far apart, it would be impossible for us in the urban area to provide the necessary services on the reservations. We do not want to be the only organization to provide care services. We want the reservation clinics to have access to funds to provide the services locally.

Two years ago, we administered a state wide survey to the eleven reservations asking them if they provided prevention or care services. Nine of the eleven reservations responded to this survey. They are not providing services because they do not have the resources to provide either prevention or care services. Our clients who want to return to their reservation communities, to their homes, are unable to because there are no HIV health care services for them, no access to HIV medicines, and so they return to the cities.

Over the past ten years, we have lost many of our brothers and sisters to this disease. For what reason? In this land with all it's vast resources, why should we be the poorest of the poor? The sickest of the sick? And have to beg for health care services?

You have the power to change this at least as it relates to HIV and the Ryan White Care Act. Please do the right thing. Migwetch.....Niconidahnah.

Part III

Presented by Jeff Tomhave, J.D.

The Ryan White CARE Act is basically a spigot of resources for individuals with HIV/AIDS. Unfortunately, if it were a public drinking water fountain, the sign above it would read, "Indians Not Allowed." The only reason Indians have such a difficult time accessing medical treatment through Ryan White CARE Act provisions is because they are Indians.

HRSA, IHS and state departments of public health can argue all they want about payers of last resort. The fact is, they all refuse to be that payer. From our perspective, these excuses look like institutional racism.

The good news is that all it takes is common sense and common decency to fix this problem. The National Native American AIDS Prevention Center has forwarded its recommendations regarding CARE Act reauthorization to the President's Advisory Council on HIV/AIDS, the full text of which is included in your briefing book.

Here's how you can and should help save the lives of Native Americans with HIV/AIDS: apply the President's principles to Indians.

Serve the neediest first. Set aside 1% of annual RWCA appropriations for American Indians, the funds for which could be captured by eliminating waste from existing programs. While you are at it, make sure that funding formulas and criteria's include indices relevant to Native communities, such as epidemiological rates, rural socioeconomic data, and proof of cultural competency.

Focus on life saving and life extending services. Authorize the development of capacity building programs in Indian Country so that the best practice models the SPNS program has been funding can graduate to become permanent programs and be replicated. Be sure that Indians themselves are allowed to identify the essential elements of what for them are life saving and extending services.

Increase prevention efforts. Require Native American representation on all HIV/AIDS prevention and treatment advisory bodies. Identify and disseminate best practice programs specifically designed to change behaviors within tribal communities.

Increase accountability. At a minimum, authorize the development of sanctions against CARE Act grantees who wrongfully deny service to Native Americans. Program oversight and enforcement should be done by a body required to include Indian researchers and service providers.

Increase flexibility. Allow Indians to be Indians -- help support and sustain their cultures -- by authorizing a program for them to develop their own priorities and culturally competent program criteria. Remember, one size does not fit all minorities and local Native communities, just like

local African American and Hispanic communities, know best what they need to stay alive.

For your convenience, we have captured all of these recommendations in the draft bill called the Native Americans AIDS Assistance Act. We thank Senator Bingaman for his leadership on this effort. We have included this discussion draft in your briefing books because we look forward to working with each and everyone of you to incorporate the essence of the Native American AIDS Assistance Act into your Ryan White CARE Act reauthorization bill.

You may be wondering why we are coming to you with all of this rather than trying to affect change through the Indian Health Care Improvement Act or annual IHS appropriations. That is an excellent question. The answer is simple: Every year Congress ignores the health needs of Indian people by flat funding IHS and refusing to reauthorize the Indian Healthcare Improvement Act, effectively pulling the wheels off both legislative vehicles and leaving Natives stranded in a desert of healthcare disparity.

For example, the federal government spends twice as much on federal prisoner's health care than American Indians and Alaska Natives. The Department of Health and Human Services currently spends just over \$4,000 per capita on all Americans; the Indian Health Service spends less than half that. IHS considers funding medical treatment for AIDS a rationing issue because the agency struggles to operate at 57% of its budget needs.

Furthermore, Congress has failed to reauthorize the Indian Health Care Improvement Act since 1992. In so doing, Congress has failed to move the legislative vehicle that authorizes the legal and administrative framework for carrying out the federal government's trust responsibility to provide health care for American Indians and Alaska Natives. Jumping onto that vehicle would be like jumping onto a train that is not even on the tracks.

The United States Commission on Civil Rights issued a report in September, 2004 entitled, "Broken Promises: Evaluating the Native American Health Care System." The Commission called its report, "a clarion call to those who inexplicably fail to acknowledge the present state of Native American healthcare." Like the Commission on Civil Rights, the National Native American AIDS Prevention Center calls upon political leadership to "honor our nation's commitment to protecting the health of Native Americans."

You have the power to do the right thing for the most needy among us. While the rest of the population lives with HIV, Indians are dying from AIDS. You can fix the Ryan White CARE Act so that it no longer deprives American Indians and Alaska Natives of medical treatment. AIDS is not a gay issue, it is a family issue, and Indians are part of our American family. Thank you.