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# Prevention of HIV/AIDS in Native American Communities: Promising Interventions

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## S Y N O P S I S

**Objective:** This article presents the latest data on trends in AIDS prevalence among Native American men and women and discusses problems of classification, data collection, factors that contribute to high risk, and factors that affect prevention and intervention. It presents a model for building effective prevention and intervention strategies.

**Observations:** The number of people in the United States diagnosed with AIDS has risen by less than 5% per year since 1992, and the slowdown is estimated to continue in coming years. Among Native Americans, however, the number of people diagnosed with AIDS rose 8% in 1997, and nonwhites accounted for more than one-half of all reported AIDS cases through December 2000. For Native Americans, the rate of growth in AIDS prevalence has been steadily increasing since the early 1980s, and AIDS is now the ninth leading killer of Native Americans between the ages of 15 and 44. Factors that contribute to high risk include poverty, homophobia, denial, and mistrust.

**Conclusions:** Effective strategies must include efforts to reduce the risk factors for AIDS. Future research should honor and celebrate diversity among people as an empowering force that facilitates collaboration and shared learning with tribes.

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## INTRODUCTION

**Prevalence of HIV/AIDS Among Native Americans.** The number of people diagnosed with AIDS in the United States has risen by less than 5% per year since 1992, and the slowdown is estimated to continue in the coming years. However, the increases in AIDS are higher in some population groups. Among Native Americans, the number of people diagnosed with AIDS rose 8% in 1997. Non-whites accounted for more than one-half of all reported AIDS cases through December 2000.<sup>1</sup> While the proportion of cases among whites decreased from 60% in 1985 to 43% in 2000,<sup>1,2</sup> the prevalence of AIDS has been steadily increasing among Native Americans since the early 1980s. AIDS is the ninth leading killer of Native Americans between the ages of 15 and 44.<sup>3</sup>

AIDS is reported to affect less than 1% of the Native American population, with just 205 new cases (137 males and 68 females) reported in 2000.<sup>1</sup> These low numbers are viewed with skepticism for several reasons, including racial misclassification, underreporting, poor reporting from various health clinics to states, coding errors, inclusion of insufficient numbers of Native Americans to formulate conclusions, regional limitations on data collection that cannot be generalized to all Native Americans in the United States, and the omission of data on Native Americans in urban areas.<sup>3</sup> The issue of poor reporting and ways to improve it are currently being addressed by the National Native American AIDS Prevention Center, which seeks to ensure that the collection of accurate data will be adequate to set health priorities and develop innovative health programs for Native Americans.<sup>4</sup>

In 1984 the Centers for Disease Control Surveillance Report recorded just two cases of AIDS among Native Americans; through December 2000 the cumulative number of cases among Native Americans was 2,336 (1,897 males and 439 females). Changes in the reporting system can account for some but not all of this increase. Underreporting could lead Native Americans to be complacent when, in fact, many are at high risk for infection.

**Factors Contributing to Risk.** The increase of reported HIV/AIDS cases among Native Americans can be attributed to various classes of factors, including biological, economic, and social factors, and high-risk behaviors, such as alcohol and substance abuse. While these factors may vary somewhat among communities, it is likely that many of them exist in most areas. The identification of specific factors is very important to

developing prevention and intervention efforts. Effective strategies must include efforts to reduce risk factors. For example, critical behavioral factors are alcohol abuse and intravenous drug use.<sup>5,6</sup> Under the influence of alcohol, protective behaviors, such as condom use, are forgotten or ignored, and judgment about high-risk behaviors becomes impaired.

Poverty may contribute to the prevalence of HIV/AIDS.<sup>7</sup> HIV prevalence is disproportionately high in poor communities in the United States.<sup>7</sup> Since many Native American communities are poor, those communities may be at risk for an epidemic of HIV.<sup>8</sup> During 1997-99, 25.9% of the Native American population lived below the poverty line—more than twice the rate among all other races (11.8%). When poverty is prevalent, health education, access to good health care, and proper medical treatment are low priorities.<sup>7</sup> Yet these are the very elements that can significantly affect the prevention and treatment of HIV/AIDS.

Poverty also has a powerful effect on social behavior. Poverty keeps many Native Americans at home, sometimes in violent and abusive situations that are related to other high-risk behaviors. Condom use is a complex issue in sexual relationships and is tied to poverty, self-esteem, the desire to preserve relationships, and preventing abuse, rejection, and abandonment.<sup>9</sup>

Homophobia is a social factor that may increase HIV infection. Levels of acceptance, tolerance, and discrimination toward gay and bisexual tribal members may vary somewhat from location to location, but in many Native American societies the treatment of gays coincides with the attitude of the dominant society—discrimination. When associated with homosexuality, HIV/AIDS can become hidden, with devastating results. These results include participating in risky sexual behavior because of a lack of information about the risk, failure to seek medical treatment, and spreading the disease unknowingly. To address homophobia, Native American communities will need to change community norms and attitudes; that is a difficult task.

Denial and mistrust are other social factors that may lead to the spread of HIV in Native American communities. Denial that HIV/AIDS is a problem in Native American communities continues to be an issue in urban, rural, and reservation communities. Many still believe that it is a “gay man’s disease.” In fact, rates of sexually transmitted disease, substance and alcohol abuse, and poverty clearly indicate that Native Americans are at risk for HIV infection.

Mistrust is an important factor because it prevents Native Americans from trusting public health officials.

Sadly, this mistrust is well founded in tribal histories documenting “gifts” of blankets infected with smallpox and the sterilization abuses of the 1970s.<sup>10,11</sup> Native American mistrust extends to the Indian Health Service, where issues of confidentiality have been questioned, the quality of care has been debated, and depersonalization issues have been prominent. These are particularly important issues for Indian Health Service offices which are located in small, tight-knit communities, where rumors and innuendo are common. This history of distrust inhibits some from seeking diagnosis, assistance, and medical attention.

**Research on Prevention and Intervention.** Despite the proliferation of studies on HIV/AIDS in the United States, little research has been done on prevention and intervention in Native American communities. No book has been published on interventions specific to Native Americans and HIV/AIDS, and a review of recent literature describes only a handful of such studies. Several articles do examine the rise of HIV/AIDS in Native Americans and their high-risk behaviors,<sup>5,6,11,12-16</sup> and several studies examine particular tribal groups or geographic areas and their specific pathways to infection, as well as prevention strategies.<sup>17-24</sup> But given the number of federally recognized tribes (more than 500) and the differences among Native American communities, the volume of research is insufficient.

Minority communities have been encouraged to develop effective prevention programs and initiatives to eliminate disparities in HIV/AIDS,<sup>2</sup> but many Native American communities lack the resources to do so. Feasible, effective, and culturally specific approaches are needed to educate Native Americans in rural, reservation, and urban minority communities about the extent to which HIV/AIDS is a very real threat. It is important to encourage and, more important, to engage tribal communities to invest in and initiate local prevention efforts.

In 2001 the National Native American AIDS Prevention Center (NNAAPC) attempted to address the issue of prevention in Native American women. NNAAPC proposed a workshop entitled “Native American Women, HIV and Wellness: Is There a Role for HIV Prevention Case Management?” to be held at the United States Conference on AIDS, in Miami, Florida, in September 2001. The participant work groups were to present information on Native American women and HIV/AIDS, HIV prevention case management, and ideas on HIV prevention case management programs in rural and urban communities.

Because of the events of September 11, however, the workshop was cancelled.

Although some Native American agencies are moving toward more medical self-sufficient lifestyles (services and programs created by Native Americans that are culturally sensitive and appropriate for tribal people), the task remains difficult given the scarcity of resources and model programs. Little is known about cultural barriers to recognition of the problem and the need for more traditional methods of intervention and prevention. If cultural barriers are not understood and not incorporated into approaches, effective prevention may not be possible in Native American communities.

### PROMISING COMMUNITY MODELS OF PREVENTION AND INTERVENTION WITH HIV/AIDS

**The Community Readiness Model.** One model that offers promise is the Community Readiness Model developed at the Tri-Ethnic Center for Prevention Research.<sup>27-31</sup> The Community Readiness Model is a nine-stage model that assesses a community’s level of readiness to develop and implement prevention programming. It identifies specific characteristics related to different levels of problem awareness and readiness for change. The model is based on the idea that interventions must be consistent with the awareness of the problem and the level of readiness for change among community residents. The interventions must be culturally and community specific and utilize local resources.

The Process of Community Readiness begins by identifying the issue to be addressed. Whatever health issue is addressed, it must be specific so that the questions may be adapted accurately. The next step is to define “community.” The community may be adolescents, a specific subpopulation, a neighborhood, or even an organization. When the questions have been adapted and pilot tested, interviews are conducted with key informants within the identified community. The interviews are scored, and readiness is assessed using the nine-stage model.

The application phase begins by using the knowledge gained in the readiness stage to develop strategies specific to the stage. This is best done in a workshop attended by community members from various segments of the community. The result is expected to be community change. The knowledge gained from this experience can then be applied to another issue in the community. Through this process, the Community Readiness Model assesses the level of

readiness of a community to develop and implement prevention programming.

The Community Readiness Model can be used as either a research or an evaluation tool to assess change in readiness from pre- to post-intervention (figure 1). The model can also be used as a community diagnostic tool that identifies the level at which to intervene and the interventions that are appropriate to the stage of readiness. The model acts as a guide in developing prevention efforts at the community level.

Although the Community Readiness Model was originally developed to address community alcohol and drug abuse prevention efforts, it has been applied successfully to a variety of health problems (sexually transmitted diseases, head injury, heart disease and diet, drug use, HIV/AIDS prevention); environmental issues (water and air quality, nuclear waste, results of atomic testing); and social issues (poverty, homelessness, child abuse, teen pregnancy, cultural competency, teen suicide, violence). The model has been very well received in communities. Communities that have reported back to NNAAPC about their experience have expressed a high level of satisfaction with the model. Examples of successful applications of the model are described below.

*Alcohol use.* In a community with extensive alcohol abuse problems, one woman used the model to develop community support to reduce public alcohol use and violence related to alcohol abuse. After four years, more than one-fourth of the adults in the community had entered treatment. The community voted into its bylaws that people in positions of authority cannot be chronic alcohol abusers.

*Intimate partner violence.* One southern community identified significant problems with intimate partner violence, but the problems were not being addressed by law enforcement or any other agency in a constructive manner. Two women used the model to garner support within the community to actively address the issue. A direct result of their efforts was a change in the elected law enforcement officials. The newly elected officials were more supportive of domestic violence intervention and created a domestic violence advocate position within the department. The local newspaper now publishes the names of domestic violence offenders as well as resources available for victims and perpetrators, and the community holds an annual domestic violence conference. It took this grassroots group only two years to move this community from denial to preparation.

The community is currently at a stabilization stage and still moving forward.

*Suicide.* The NNAAPC was recently approached by a woman seeking help for her community. After hearing about the model at a conference, she immediately contacted NNAAPC for more information. Her community of approximately 600 people had documented 18 suicides over the previous 6 months. She wanted someone to come to her community and train people to use the model to prevent more suicides. Center staff went to the community expecting no more than 15-20 people to attend the training session. They were overwhelmed when almost 100 people, both young and old, showed up. The occasion marked the first time that six small towns had come together to work on a problem. They did so because they did not want to lose another teenager to suicide.

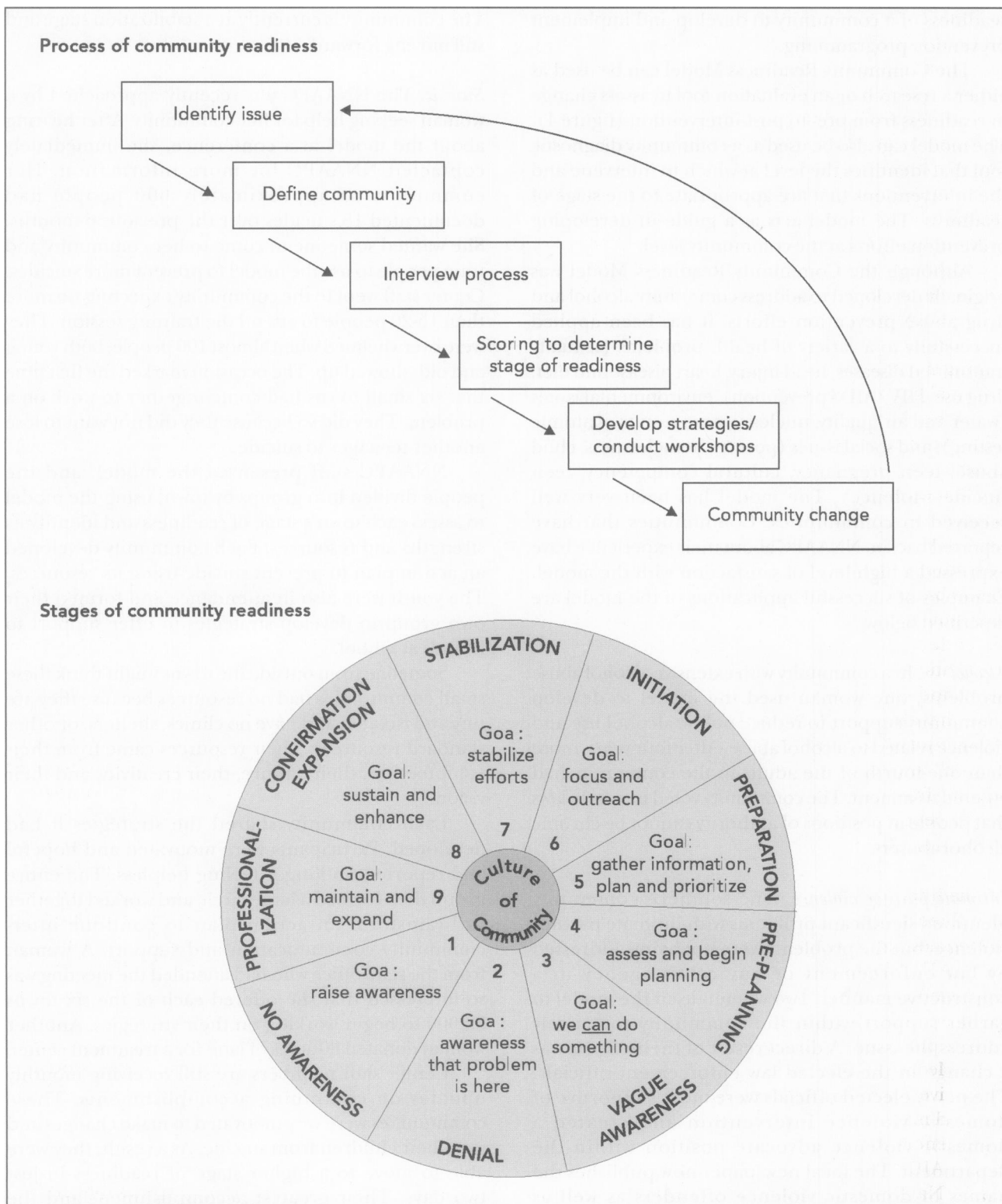
NNAAPC staff presented the model, and the people divided into groups by town, using the model to assess each town's stage of readiness and identify its strengths and resources. Each community developed an action plan to prevent suicide using its resources. The youth were also in attendance and formed their own group to develop strategies to offer support to friends at school.

Someone from outside the towns might think these small communities had no resources because they are tiny and isolated and have no clinics, shelters, or other standard resources. Their resources came from their volunteerism, their culture, their creativity, and their vision.

Each community shared the strategies it had developed. Participants were motivated and hopeful and reported no longer feeling helpless. The entire group then formed a large circle and worked together to brainstorm an action plan to continue inter-community communication and support. A woman from the state office who had attended the meeting was so impressed that she offered each of the six towns \$2,000 to begin working on their strategies. Another woman donated 80 acres of land for a treatment center.

Center staff members are still receiving monthly updates on continuing accomplishments. These communities were very motivated to make changes and save their children from suicide. As a result, they were able to move to a higher stage of readiness in just two days. Their greatest accomplishment and the source of their greatest joy is that they have had *no* suicides since they developed their action plans.

The Bureau of Indian Affairs was concerned enough about the risk of HIV/AIDS to administer a



**Figure 1. Community Readiness Model**

Source: Tri-Ethnic Center for Prevention Research.

national survey to high schools under its jurisdiction. More than 5,000 students anonymously completed the survey on health risk behaviors. The results indicated that many students engage in behaviors that increase their risk for HIV infection. In fact, 63.3% of students reported having had sexual encounters, 14% by age 13. Of the students who reported sexual intercourse, only slightly more than one-half had used a condom during their last encounter. More than one-half of them reported using alcohol during the three months before the survey, and 6% reported ever having injected illegal drugs. As a result of the findings, the Bureau of Indian Affairs supported the need for effective programs and activities to reduce risky sexual behaviors and drug use among the students. Clearly, accurate assessment is an essential first step in effecting positive change.

Other Native American communities, such as the Diné, have already begun to work as communities to change policy by training people, sponsoring presentations, and establishing a multidisciplinary team to reduce the risk for sexually transmitted disease and HIV infection. This type of collaboration and community involvement also resulted in a change in the Tribal Code and Policy. This policy, Title 13, serves as a guide to schools, tribal programs, health care providers, and organizations serving at-risk populations.<sup>30</sup>

Another reservation community, in Washington State, has also recognized the need for prevention and early intervention. It has mandated that its Tribal Council and all tribal employees receive HIV/AIDS training from certified trainers. These trainers also train young people enrolled in summer training or involved in tribal employment programs.<sup>31</sup>

**Media Interventions.** The media have long been used to influence public behaviors, sometimes successfully, sometimes not.<sup>32,34</sup> Media efforts focused on preventing HIV/AIDS have been effective in reaching the population at large.<sup>35,36</sup> Such efforts have only recently been produced for Native Americans. In 1993 Mona Smith, project coordinator for the National Indians AIDS Media Consortium, noted that “prevention of HIV in Native America demands Native-produced HIV-focused materials that speak to the shared values and experiences of Native people.”<sup>37</sup> Before her call, a few Native AIDS videos had been developed; after her call, more Native and non-Native producers created culturally specific AIDS videos.<sup>38</sup> The Native American Prevention Project Against AIDS and Substance Abuse created several videos in the early 1990s targeting Native American teenagers. They used a multicomponent

preventive intervention curriculum based on social action theory, which they adapted to Native American reservation and border town environments.<sup>18</sup>

In media studies at the Tri-Ethnic Center, two types of projects have laid the groundwork for developing materials. The first was a project to develop a survey to assess local drug use and to create methods to communicate information about local drug use to community members in a way that would stimulate drug prevention efforts.<sup>39</sup> This project worked with communities that were usually at the pre-planning or preparation stage of community readiness. It proposed using a wide range of methods for communicating with various community audiences, including newspaper articles, radio spots, presentation scripts, and color graphics.

The second project initiated at the Tri-Ethnic Center used this local survey assessment to develop a communication intervention for children and adolescents.<sup>40</sup> Broad-based media campaigns were tailored for small towns. The media materials and messages reflected local community needs to reduce alcohol and drug involvement. The materials were computer generated to include local references. The project also created newspaper advertisements and articles, radio spots, billboards, pamphlets, a presentation series for adults and young people, and a poster competition.

Providing local information on drug use stimulated local drug prevention efforts, as demonstrated by anecdotal evidence and an increase in newspaper stories. After hearing about the survey results through local newspapers and presentations to community members, many schools and agencies upgraded their adolescent drug programs. They brought more education programs into the schools, sought funds for other programs, and organized parent groups to work against drugs. The media project demonstrated that the level of community readiness could be systematically increased through such efforts and that use of local site-specific people and resources increased and stimulated prevention efforts.

The results of these projects suggest that media specific to Native American communities would be effective for HIV prevention efforts.

## DISCUSSION

Effective prevention requires collaborative efforts from all segments of the community, from initial assessment and accurate surveillance to program implementation. The research community must also use collaborative efforts to implement effective prevention efforts for

specific populations. To meet the needs of Native Americans, they must successfully link those efforts to a holistic research model based on Native American concepts. This model has been used successfully in other communities to reduce health disparities and has specific application to Native American communities.

Future research should honor and celebrate diversity among people as an empowering force that

facilitates collaboration and shared learning with tribes to deal with HIV/AIDS. Researchers who are tribal members should draw on the strength and resiliency that comes from Native traditions, languages, and the models of health and healing that already exist in tribes. These strengths have supported Native Americans in the past and will do so in the future.

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