

HIV/AIDS AMONG AMERICAN INDIANS/ALASKA NATIVES LIVING IN MONTANA: A DESCRIPTIVE STUDY

K. Ann Sondag, PhD, CHES and Carrie Strike, MS

Abstract: This study examined the epidemiology of HIV among AI/ANs in Montana. Barriers to HIV testing and motivations to test also were explored. Analysis of data revealed that there were no significant changes in regard to HIV/AIDS case rates, demographic characteristics, or risk behaviors of AI/ANs infected with HIV/AIDS since reporting began in 1985. Barriers to testing included low perception of risk and fear of people finding out about the test. Despite major barriers to testing identified in this study, AI/ANs appeared to be testing at a higher rate than Whites.

INTRODUCTION

The HIV/AIDS epidemic has been one of the defining features of the past quarter-century. By the end of the 2006, over one million people in the U.S. alone had been infected with HIV. Three racial and ethnic minorities in the U.S.—African Americans, Hispanics/Latinos, and American Indians/Alaskan Natives (AI/ANs)—account for a greater proportion of HIV/AIDS cases than would be expected for their proportion of the population (Centers for Disease Control and Prevention [CDC], 2008). Despite the increased rates of infection in these populations, there is a lack information about how HIV/AIDS affects them and their communities. This lack of information is evident in AI/AN communities where many AI/ANs have expressed specific concerns about the quality of HIV/AIDS data that currently is available (National Alliance of State and Territorial AIDS Directors [NASTAD], 2008). This concern exists, in part, because the relatively low numbers of reported HIV/AIDS cases among AI/ANs nationwide belie the many factors that put them at increased risk for infection.

Vernon and Jumper-Thurman (2005) reviewed factors that may contribute to high rates of HIV infection among AI/ANs. Most salient are biological factors, such as increased rates of sexually transmitted diseases; social factors, such as homophobia and distrust in health systems; economic factors, such as poverty, which can inhibit access to good health care and health education;

socioeconomic factors related to gender inequality and violence; and substance use factors, which often are not direct routes of HIV transmission but do influence risky behaviors such as unprotected sex. While the combination of these factors has the potential to lead to high rates of infection (NASTAD, 2008; Hamill & Dickey, 2005; Bertolli et al. 2004), the reported rates of HIV among AI/ANs are not dramatically higher than those among Whites (CDC, 2010).

Many health professionals estimate the number of HIV/AIDS cases among AI/ANs to be much higher than what statistics currently report. Data sharing issues, racial misclassification, and misidentification and underreporting of HIV tests have been cited as possible reasons that national statistics regarding AI/AN populations may not reflect the extent of HIV/AIDS morbidity (NASTAD, 2008; Hamill & Dickey, 2005)—reasonable assumptions in light of the high prevalence of risk factors and risk behaviors within these populations.

One avenue for obtaining more accurate information about the prevalence of HIV/AIDS in AI/AN communities is to increase the numbers of individuals who get tested for HIV. The CDC (2010) estimates that one in five (21%) persons in the U.S. who are HIV-positive have not been tested and do not know their status. Nearly half (46.4%) of AI/ANs report they have never been tested for HIV (CDC, 2010). Unfortunately, numerous barriers inhibit people from being tested. There are individual factors (fear and discrimination); program policy or law factors (named reporting and inability to afford treatment); and counseling and testing factors (dislike of counseling, anxiety waiting for results, and venipuncture) that must be considered when determining why an individual might not go to a health facility to be tested (Spielberg et al., 2003). Using a rapid assessment model, Burks, Robbins and Durtchi (2010) explored barriers to testing among AI men identifying as gay, bisexual, or two-spirit or who had same-sex experiences. Barriers identified by individuals in this study included: limited hours of availability and inconvenient locations of testing sites; fear that “everyone is going to know” if one gets tested; not wanting to know one’s HIV status; shame and stigma associated with being HIV positive; and the belief among young people that they are invulnerable to HIV/AIDS.

These barriers are not new. Over a decade ago, research regarding HIV testing barriers specific to AI/AN populations revealed similar results—lack of knowledge about available testing services and inconvenient office hours at testing sites; concerns about lack of confidentiality; low perceived risk for getting HIV; and mistrust of local health departments (Duran et al., 2000; Mochi, 1997).

While HIV testing data and epidemiologic information about AI/ANs living with HIV/AIDS provide some insight into who is infected with HIV, there is a need to investigate these sources of information more closely. By examining 23-year trends found in HIV/AIDS epidemiologic data, gathering information about the demographic characteristics and risk behaviors of individuals

who have been tested for HIV, and examining barriers to testing among a convenience sample of Montana's AI/AN populations, we hope that this study will not only add to the understanding of the distribution of HIV/AIDS among Montana's AI/AN communities, but also illuminate the barriers to HIV counseling and testing (HIV C&T).

BACKGROUND

There are seven federally recognized reservations representing 11 different tribes in Montana: Blackfoot, Crow, Confederated Salish and Kootenai, Assiniboine, Gros Ventre, Sioux, Northern Cheyenne, Little Shell, and Chippewa-Cree (Montana Office of Public Instruction, 2009). AI/ANs living on the seven reservations and in urban areas represent approximately 6.4% of the nearly 975,000 individuals living in Montana (U.S. Census Bureau, 2010). Despite the size of Montana's AI/AN population, prior to this study, no formal assessment of the impact of HIV/AIDS among AI/ANs had been conducted in the state. Therefore, Montana's state HIV Prevention Community Planning Group (MT CPG), under the auspices of the Montana Department of Public Health and Human Services (MTDPHHS), contracted with researchers from The University of Montana to explore the feasibility of gathering information that would contribute to an understanding of the impact of HIV/AIDS among AI/ANs. The MT CPG membership has a strong AI/AN constituency. At the time of the assessment, 10 of the 35 members identified as AI/AN and were representative of tribes and communities throughout the state. In planning for the assessment, the researchers, in conjunction with the MTDPHHS, scheduled three meetings with the AI/AN members of the MT CPG. Six to eight AI/ANs representing five of Montana's seven reservations were present at the meetings. The goals of the series of meetings were to determine the specific purpose of the assessment; to decide who should lead and direct the assessment; and to determine how, when, and where data collection should take place. The group determined that the researchers would gather preliminary information and bring it to subsequent meetings.

Preliminary informal data gathering efforts included phone calls to all seven Indian Health Service (IHS) clinics in Montana. Researchers spoke with public health nurses at six of the seven clinics and explained that the purpose of the phone call was to inquire about the feasibility of working with IHS clinics to gather HIV testing information. Testing information would be used to assist the MT CPG in developing HIV prevention interventions for AI/ANs in Montana. Specific information about testing was not solicited at this time. Nurses were asked, however, for their "best guesses" regarding numbers of HIV tests given annually at the clinics. Estimated numbers of tests conducted at each clinic varied greatly from clinic to clinic. This information, along with information about teen pregnancy and STD rates among AI/ANs, was brought back to the group during the third meeting.

AI/AN MT CPG members organized a fourth meeting to discuss their role, and the role of the researchers, in the data collection process. During this meeting, the AI/AN MT CPG members decided that data gathering efforts would be best received by IHS and tribal leaders if representatives from each reservation took ownership of the process and gathered testing information specific to the reservation where they resided. As a result of this decision, the researchers chose to focus their efforts on collecting information from urban Indian centers and from state-funded testing sites with a history of testing high numbers of AI/ANs. The present assessment, therefore, was not designed to be a comprehensive examination of “all testing sites” in Montana. Rather, it was designed as an examination of state-funded sites that were required to report test results directly to the state public health department. The purpose of this assessment was to use multiple sources of information to contribute to an understanding of the distribution of HIV/AIDS among the AI/AN communities in Montana and to illuminate some of the challenges AI/ANs encounter when seeking to know their HIV status.

METHODS

To construct a more in-depth picture of the demographic characteristics and risk behaviors of individuals who were being tested for HIV, data from three existing sources and one new source were used. First, information from the CDC standardized counseling and testing intake forms for the year 2007, and from the 2007 Montana Behavioral Risk Factor Surveillance Survey (BRFSS), were examined. State of Montana epidemiological data were used to enhance understanding of the demographic characteristics and risk behaviors of AI/ANs living with HIV/AIDS in Montana. And finally, data from the 2008 Barriers to HIV Testing Questionnaire were examined. Approval from The University of Montana’s Institutional Review Board was obtained prior to data collection.

The Barriers to HIV Testing Questionnaire developed for this study included three sections: 1) demographic questions, 2) questions about barriers to HIV C&T, and 3) questions about motivations for seeking an HIV test. Categories and wording for demographic questions were taken directly from the MTDPHHS HIV C&T forms. Questions regarding barriers to and motivations for accessing an HIV test were adapted from an earlier University of Montana study assessing the barriers to HIV testing among four high-risk groups in Montana (Mochi, 1997), as well as from a review of the literature regarding barriers to HIV testing. The instrument was reviewed by staff at the MTDPHHS STD/HIV Prevention Section and by staff at each of the nine HIV testing sites chosen to distribute the questionnaires. A few minor edits were made to the questionnaire following the review. However, no major adaptations to the questionnaire were suggested by the reviewers.

Data Collection

The Barriers to HIV Testing Questionnaire was distributed to four MTDPHHS-funded testing sites. The state-funded sites were chosen based on numbers of AI/ANs who sought HIV C&T services in 2007; the five sites with the highest numbers were chosen. One site, however, declined to participate in the study. Staff at the MTDPHHS-funded sites asked all eligible AI/ANs over the age of 18 who came in for an STD and/or HIV test to volunteer to complete the questionnaire.

All five urban Indian centers in Montana also were asked to assist with questionnaire distribution. The HIV/STD Section Supervisor at the MTDPHHS sent an introductory letter to the urban Indian centers explaining the purpose of the assessment and asking clinics to participate. Following the letter, a researcher visited in person with staff at each of the centers to explain the purpose of the assessment, to describe procedures for distributing questionnaires, and to request the center's participation. Staff at the five urban Indian centers agreed to participate and consequently asked all individuals over the age of 18, regardless of the purpose of their health care visit, to volunteer to complete the questionnaire.

At all questionnaire distribution locations, individuals who chose to participate were given a packet containing an informed consent form, a two-dollar incentive, and a self-addressed pre-paid envelope. Participants were invited to complete the questionnaire at the clinic or finish it at a time more convenient for them and mail it to the researchers in the provided envelope.

Information for this assessment also was collected from three existing data sources. First, this study utilized information from existing HIV C&T intake forms. Montana HIV testing contractors utilize standardized machine-readable intake forms that were developed by the CDC in 1990 and revised in 2007. (The older version of the form, used through 2007, was the version included in this study.) Montana collects HIV C&T data, which are submitted directly to a CDC database via scanning software. These data are used to facilitate program monitoring and evaluation at the local, state, and national levels. Data taken from the form included: 1) client demographics, 2) HIV testing information, including specific test technology and test specimen type, 3) test results, and 4) client risk behaviors.

Second, information from the 2007 Montana BRFSS was analyzed. The BRFSS is a randomized telephone survey and is the primary source of state-based information on health risk behaviors among adult populations. For over 20 years, the BRFSS has been used to gather information from U.S. adults about a wide range of behaviors affecting their health, with a primary focus on behaviors that are linked to leading causes of death, including HIV/AIDS (CDC, 2009). The MT BRFSS includes three questions specific to HIV. The questions are: "Have you ever been tested for HIV?" "Where did you have your last HIV test?" and "Was it a rapid test where you could get

your results within a couple of hours?” Responses to the first two questions were used to provide a more comprehensive picture of HIV testing among AI/NA populations.

Finally, state epidemiologic data specific to AI/ANs were made available to the researchers. HIV/AIDS epidemiologic data are collected by the MTDPHHS on an ongoing basis. The state HIV epidemiologist worked with researchers to examine 23-year trends in the incidence and prevalence of HIV/AIDS among Montana’s AI/ANs.

A synthesis of information from all four data sources is provided in this paper. We report results, discuss key findings, and offer recommendations based on the conclusions drawn from this study.

DATA ANALYSIS

The study was intended to be descriptive; therefore, complex statistical analyses of the data were not performed. Rather, the researchers looked at actual counts and frequency of responses.

The researchers entered primary data from the Barriers to HIV Testing Questionnaire into the SPSS database for Windows. The demographic characteristics, barriers to HIV C&T, and motivations for testing reported by AI/ANs seeking health services at specific MTDPHHS-funded sites and urban Indian centers in Montana are reported descriptively. Actual counts and percentages are reported for all forced-choice questions. Information from open-ended questions was qualitatively analyzed using a content analysis method. Themes that arose from the content analysis of open-ended questions are reported along with supporting quotations from respondents.

Secondary data gathered from the standardized HIV C&T intake forms also were entered by the researchers into the SPSS database for Windows. The demographic characteristics and risk behaviors reported by AI/ANs seeking testing at specific MTDPHHS-funded sites are reported by actual count and percentage. In addition, data from two of the three HIV testing-related questions on the BRFSS were taken directly from the state Web site and used to provide information about the numbers of AI/ANs who reported receiving an HIV test and where they received the test. And finally, epidemiologic data were used to provide a more comprehensive picture of the incidence and prevalence of HIV/AIDS among Montana’s AI/ANs, and to provide additional information regarding the demographic characteristics of individuals living with HIV/AIDS. The state epidemiologist provided incidence and prevalence data for a 23-year period, as well as information regarding the risk behaviors of AI/ANs infected with HIV and living in Montana. Because actual case numbers were very low, data were aggregated into two- to five-year units to ensure confidentiality.

RESULTS

Primary Data

Barriers to HIV Testing Questionnaire Results

A total of 275 questionnaires were distributed among the nine sites. The number of questionnaires delivered to each site was based on site staff members' estimate of the number of questionnaires they might be able to distribute in a four month time period. Urban Indian centers requested a total of 175 questionnaires and returned 103 for a return rate of 59%. State-funded sites requested a total of 100 questionnaires and returned 54 for a return rate of 54%. Overall, of the 275 questionnaires distributed to sites, 161 were completed. Four questionnaires were removed from the analysis because the respondents did not meet the criteria of being over the age of 18, leaving 157 valid questionnaires for a total return rate of 57%.

Demographic characteristics

Females (n = 89) returned the questionnaire at a higher rate than males (n = 68). Ages ranged from 18 to 75 years, with the largest represented age group being 45 years or older (37%). Of all respondents, 90% reported being heterosexual. The remaining 10% reported their sexual orientation as bisexual, homosexual, uncertain, or other. The vast majority of the respondents (82%) reported living off reservation. Nine tribes were represented by the 137 respondents (87%) who reported being enrolled members of a tribe.

Barriers to HIV testing

The questionnaire's main purpose was to assess both real and perceived barriers to getting tested for HIV in Montana. The statement on the questionnaire read, "My reasons for NOT getting tested, or for waiting until today to get tested for HIV, include: (check all that apply)." This statement was followed by a comprehensive list of 26 barriers that was compiled from earlier studies. Barriers reported among both males and females were similar. The five barriers that were checked most frequently were:

- I am at low or no risk (reported by 43%);
- I am in a monogamous relationship (reported by 18%);
- I usually practice safe sex (reported by 14%);
- Fear of people finding out (reported by 14%); and
- I always practice safe sex (reported by 13%).

Three main themes evolved from responses to the open-ended question, “Can you suggest some ways in which this clinic could make it easier for American Indians to get tested for HIV/AIDS?” The themes are described below:

- Confidentiality was the number-one suggestion respondents wrote on the questionnaire. Most respondents simply wrote the word “confidentiality.” Some, however, expanded on the issue and explained why confidentiality was a barrier to testing. One respondent summed up the issue of confidentiality with these words: “Confidentiality is a huge issue. Any town in Montana is a fairly small community, smaller in Indian circles and you are bound to be related to or know someone who works at the clinics. I personally don’t use any services at the Indian center just because as soon as you walk in you see someone you know and they immediately start questioning your reason for being there. I get calls from my family members asking why I was there because they’ve already heard about it.”

- The need to promote HIV testing also was a common response to the open-ended question. Several respondents mentioned the need to “get the word out” about where, when, and who should be tested. One person wrote, “There needs to be more TV ads, magazine ads, etc. for Indian country.” Another said, “Post notes and fliers at the colleges of upcoming events and clinics. Some Indian students from out of town might not know where the Indian center is or might not know there is one.”

- The importance of incentives as a motivating factor, the need for rapid testing technology, and the need to offer HIV testing during the annual exam to make it more accessible, also were offered as suggestions. One respondent wrote, “Indians love free incentives! Nobody likes to pay, but we love free stuff.” Another individual wrote, “Offer the test for free or ask during annual exams or physicals.”

In an effort to determine if barriers to HIV testing in Montana had changed over time, data from this study were compared with the only other available information specific to AI/AN testing barriers in Montana. Mochi, in 1997, distributed approximately 600 questionnaires to AI/AN health educators in four regions of the state. The health educators were asked to give the questionnaires to a convenience sample of AI/ANs over the age of 18 who were living on reservations in those regions. Completed questionnaires were mailed directly to the researcher in a self-addressed, stamped envelope that was provided. The number of questionnaires that were actually given to members of the target population was not recorded; however, sixty-seven were completed and returned to the researcher. Table 1 below illustrates the percentage of individuals who reported each barrier in 1997 and 2008, and adds to our awareness of the changing nature of HIV testing barriers in Montana over the past 14 years.

Table 1
Barriers to Testing: Comparison of 1997 and 2008 Results*

Barriers to Testing*	1997 Questionnaire (n = 67)	2008 Questionnaire (n = 157)
I am not at risk for HIV/AIDS	56.0% (38)	43.2% (68)
I always practice safe sex	25.4% (17)	13.0% (20)
I usually practice safe sex	34.3% (23)	13.7% (21)
Fear of people finding out	25.4% (17)	13.7% (21)
Not sure where to get tested	23.9% (16)	9.7% (8)
Do not trust Health Department	23.9% (16)	5.5% (8)
In a monogamous relationship	23.9% (16)	18.1% (28)

*Respondents were asked to "check all that apply"

Motivation for testing

Thirty-seven individuals who visited the MTDPHHS-funded sites and completed the Barriers to HIV Testing Questionnaire indicated on the questionnaire that the purpose of their visit was to receive an HIV test. Those individuals were asked to report their motivation for seeking the test. The five most frequent responses are listed below. Respondents were asked to "check all that apply."

- Knowing my status helps me feel safe (reported by 50%);
- I had unprotected sex (reported by 38%);
- I am getting paid to test (reported by 16%);
- It is part of my yearly checkup (reported by 8%); and
- I am pregnant (reported by 5%).

SECONDARY DATA

HIV C&T Intake Forms Results

All HIV C&T intake forms submitted by testing sites to the state from January 1, 2007 through December 31, 2007 were made available to the researchers by the HIV/STD Section of the MTDPHHS. All forms indicating "AI/AN" as race (992 of 5,630 total) were sorted and used to extract demographic and risk behavior information of AI/ANs who received an HIV test from state-funded sites. Of the 992 testing forms available, 756 (76%) indicated the name of the testing site. An examination of the number of tests administered at each site revealed that four sites administered 83% of 756 tests given to AI/ANs. The testing site at Salish Kootenai College on the Flathead

Reservation administered the greatest number of tests (248). Two testing sites in Yellowstone County—RiverStone Public Health Department and the Yellowstone AIDS Project—administered 140 and 102 tests, respectively, and the Cascade City-County Health Department administered 135 tests. The remaining 13 testing sites recorded significantly smaller numbers of tests for individuals who identified as AI/AN – numbers of tests for those sites ranged from 1 to 40.

Demographics

Males comprised a larger percentage of the total tests than females, with 53% of tests indicating male and 47% of tests indicating female at state-funded sites in 2007. Ages ranged from 14 to 78 years. The mean age of those tested was 32, while the most frequently reported age was 26. Fifty-eight percent of all respondents had been tested for HIV in the past.

Risk Behaviors

Only 10% of those being tested did not report engaging in behaviors that put them at risk for HIV; 90% had participated in one or more behaviors placing them at a higher risk for infection. The majority of individuals, both male and female (53%, n = 521), reported having sex with a person of unknown HIV status as the biggest risk factor for HIV/AIDS. Table 2 below identifies the ten most frequently reported risk behaviors.

**Table 2
Risk Behaviors**

Risk Behaviors	Male (n = 521)		Female (n = 469)		Total (n = 990)	
	%	n	%	n	%	n
Sex (vaginal or anal) with male	18%	95	93%	436	54%	531
Sex (vaginal or anal) with female	76%	396	10%	47	45%	443
Sex with a person of unknown HIV status	51%	269	53%	252	53%	521
Sex while intoxicated and/or high on drugs	49%	254	49%	230	49%	484
Sex with an anonymous partner	29%	149	27%	128	28%	277
Sex with a person who is an injection drug user	19%	97	25%	115	21%	212
Injection drug use	17%	91	20%	94	19%	185
No risks identified	11%	59	10%	48	10%	107
Sex in exchange for drugs or money	9%	48	7%	33	8%	81
Sex with a person who exchanges sex for drugs or money	6%	36	7%	32	7%	68

Risk behaviors most frequently associated with HIV infection in Montana include being male and having sex with men (MSM), injection drug use (IDU), both MSM and IDU (MSM/IDU), and having sex with someone who injects drugs (MTDPHHS, 2009). Percentages of AI/ANs who reported those behaviors and were tested at public testing sites are listed below:

- 18% (n = 95) of males reported MSM
- 19% (n = 185) of individuals reported IDU
- 21% (n = 212) of individuals reported having sex with a person who uses injection drugs.

Monetary Incentives to Test

Of the 975 forms that indicated whether an incentive was offered to encourage people to be tested for HIV, 516 (53%) indicated that the person who received the test was offered an incentive. The testing site at Salish Kootenai College conducted nearly 30% of the total number of tests reported to the MTDPHHS that were received by AI/ANs in 2007. Incentives were offered to 98% of individuals who were tested at that site. Incentives were advertised through posters and electronic social networking systems (e.g., Facebook), and consisted of gift cards valued at \$10 to \$20 for area discount or grocery stores. Individuals were given the incentive after completing both the HIV test and an exit survey (N. Graham, personal communication, February 16, 2011).

Behavioral Risk Factor Surveillance System Results

The BRFSS slightly oversampled AI/ANs to ensure that the weighted frequencies approximated the population proportion. Data for 2007 were obtained to determine the number of AI/ANs who reported having been tested at all testing sites, whether public or private. Information from the BRFSS indicated that AI/ANs were testing at a greater rate than were Whites (39% vs. 31%, respectively). In response to the question “Where did you have your last HIV test?” over 80% of Whites and AI/ANs reported receiving their tests at one of four major sites. Percentages of individuals tested at those sites are listed in Table 3 below (MTDPHHS, 2007).

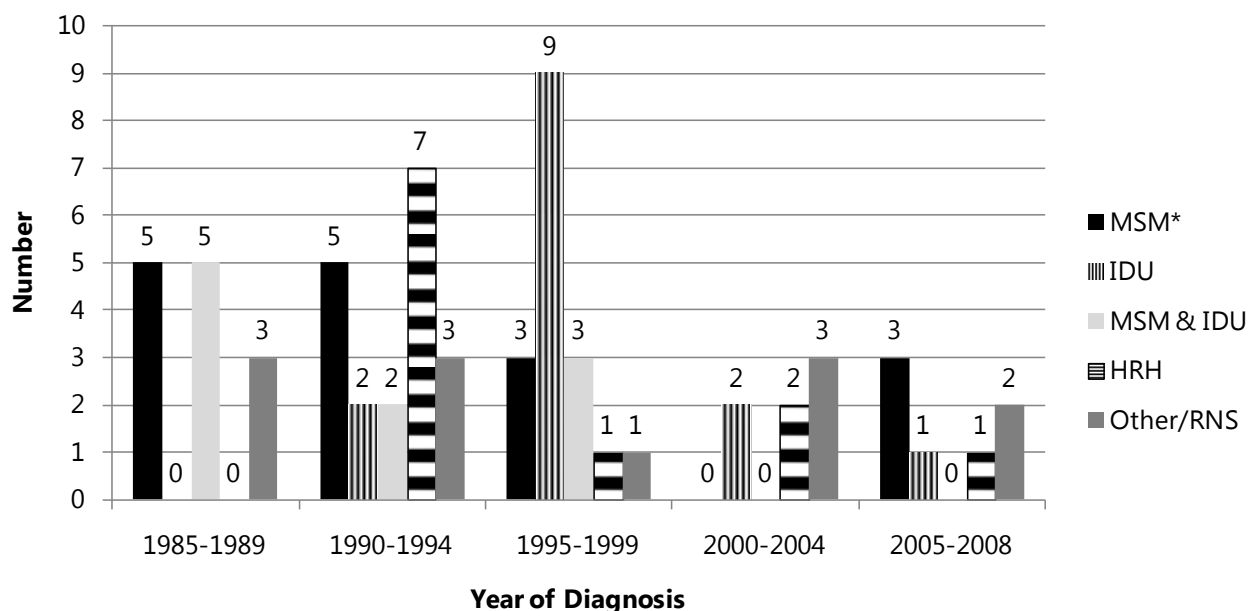
**Table 3
Testing Sites**

HIV Testing Site	AI/AN		White, Non-Hispanic	
	%	n	%	n
Clinic	32.4%	49	29%	297
Hospital	28.8%	35	17.1%	203
Private Doctor or HMO	19.9%	20	29.6%	347
Drug Treatment Facility	8.7%	10	1.7%	13

Epidemiological Data Results

As of December 31, 2008, a total of 895 cases of HIV/AIDS had been reported to the MTDPHHS; of those, 63 were among AI/ANs or mixed-race AIs. Of those 63 cases, 33 people are currently living. Males comprise 71% (n = 45) of the cumulative cases, with MSM representing the highest percentage (58%) of the male cases. Females comprise 29% (n = 18) of the cumulative cases, with “risk not specified” representing the highest percentage (55%) of the female cases (MTDPHHS, 2009). Because of the low numbers of cases per year, Figure 1 shows the combined 4- and 5-year rates of HIV by mode of exposure.

Figure 1
Number of Reported HIV/AIDS Cases - Mode of Exposure, 1985-2008



* MSM = Men who have sex with men; IDU = Injection drug Use; HRH = High-risk heterosexual; RNS = Risk not specified

From 1985 to 2008 the number of individuals newly diagnosed with HIV decreased from ten between 1990 and 1992 to five between 2006 and 2008. Epidemiologic data indicate that the mode of exposure to HIV among AI/ANs has remained relatively constant. Table 4 compares cumulative cases (1985 to 2008) to current living cases and reveals no noteworthy changes in the epidemic in the past 23 years (J. Frazier, personal communication, October 10, 2008).

Table 4
Comparison of Cumulative and Living HIV/AIDS Cases

Epidemiological Report: HIV/AIDS Cases	Cumulative Cases (n = 63)	Living Cases (n = 33)
Age:		
25 to 44 years old	60%	58%
Gender:		
Male	71%	67%
Mode of exposure:		
Male - MSM and MSM/IDU*	58%	54%
Female - HRH and RNS*	83%	72-100%**
Montana counties w/greatest # of positive reported cases	Yellowstone Missoula	Yellowstone Missoula

*MSM = Men who have sex with men; IDU = Injection drug use;

HRH = High-risk heterosexual; RNS = Risk not specified

**Note: If frequency <5, specific numbers are not reported and percentages are approximate

DISCUSSION

One of the primary purposes of this study was to add to the understanding of the distribution of HIV/AIDS among Montana’s AI/AN communities. The following section highlights information from state epidemiologic data that contributes to our knowledge of the infection among AI/AN people in Montana.

Prevalence of HIV/AIDS among AI/ANs in Montana

Current Montana epidemiologic data indicate that HIV/AIDS does not appear to have a disproportionate impact on Montana’s AI/AN populations (MTDPHHS, 2009). While the national case rates of HIV/AIDS among AI/ANs have increased slightly each year since 2003 (NASTAD, 2008), the number of cases reported among AI/ANs in Montana has annually remained constant or shown a slight decline each year since 1990. Montana’s relatively low case rate and the decline in cases since 1990 have led many health professionals to speculate that there is substantial underreporting of HIV/AIDS cases in these populations. One explanation for this potential underreporting may be that significant barriers to HIV testing exist among AI/ANs in rural areas (Rural HIV/STD Prevention Workgroup, 2009, pg. 39). Low testing numbers among AI/ANs could result in undetected cases of HIV/AIDS and, thus, in deflated case rates. The current study explored

this supposition by examining data regarding barriers to testing from the Barriers to HIV Testing Questionnaire, the HIV C&T intake forms, and the BRFSS Survey.

HIV C&T among AI/ANs in Montana

Examination of HIV C&T intake forms for the year 2007 revealed that, of the 5,630 total HIV tests administered at Montana's state-funded public testing sites, 18% (992) were administered to individuals who indicated AI/AN as their race. This finding was unexpected and indicated that the rate of testing at state-funded sites was approximately 16 per 1000 for AI/ANs, in contrast to a rate of approximately 5 per 1000 for Whites. It is important to note, however, that the HIV C&T forms represent tests conducted only at state-funded public HIV testing sites. To more accurately estimate the rate of testing among AI/ANs, it was necessary to account for individuals who were tested at private health care settings. Fortunately, the BRFSS asks respondents about HIV testing at all sites, both private and public. Information from the BRFSS was consistent with national data (CDC, 2010) and data from the HIV C&T forms in that it indicated that the rate of HIV testing reported among AI/ANs was higher than the rate reported among Whites. Interestingly, approximately one-third of both AI/ANs and Whites reported receiving their last HIV test at a clinic. One slight difference in reported testing sites, as might be expected, was that a greater proportion of Whites tested at private doctors' offices or HMOs, while AI/ANs had proportionately higher testing rates at hospitals (MTDPHHS, 2007). Unfortunately, data from tribal clinics and IHS testing sites on the reservations were unavailable. It is likely, however, that the random sample survey methods employed by the BRFSS captured some of the individuals who tested at tribal and IHS clinics. It appears, therefore, that AI/ANs are not underrepresented in the HIV C&T data that are reported to the state public health department in Montana.

Members of Montana's State HIV Prevention Community Planning Group have expressed concern that HIV testing efforts throughout the state are not reaching the populations most at risk for infection (L. Kops, personal communication, February 4, 2008). In this study, information taken from the HIV C&T forms was used to examine that concern. Approximately 90% of individuals who completed the state HIV C&T testing form in 2007 reported engaging in at least one behavior that put them at risk for HIV infection. Nearly 20% reported engaging in behaviors that placed them in one of the top four behavioral risk categories for HIV infection: MSM, IDU, MSM/IDU, and sex with someone who uses injection drugs (MTDPHHS, 2009). Nearly 30% of individuals who tested at public sites reported engaging in anonymous sex. Even though the C&T intake forms do not distinguish between protected and unprotected sex, there appears to be a substantial number of individuals who are getting tested for HIV and who are reporting multiple risk factors, including injection drug use and/or engaging in risky sexual behavior.

HIV C&T Barriers among AI/ANs in Montana

A second major purpose of this study was to explore the barriers to HIV testing. It is especially critical to break down barriers to testing in AI/AN communities because of the health care disparities they face. A study conducted by Kaufman et al. (2007) showed that testing is particularly important among AI/ANs, as these populations experience a faster progression from HIV diagnosis to AIDS than any other racial group in the U.S. They also experience some of the lowest survival rates after diagnosis. In 2001, 48% of AI/ANs diagnosed with HIV were subsequently diagnosed with AIDS within 12 months, compared with 40% for the general population (Kaufman et al., 2007). One potential explanation for this phenomenon is that AI/ANs delay HIV testing until they develop symptoms associated with AIDS. Early testing for HIV could improve survival rate of AI/ANs infected with the virus. It is important, therefore, to assess the barriers to testing and reduce or eliminate those barriers if possible.

In the present study, the number-one barrier to testing, as reported by the 157 individuals who completed the Barriers to HIV Testing Questionnaire, was “not being at risk for HIV/AIDS.” Interestingly, 14 years ago, the only other study that examined barriers to HIV testing on Indian reservations in Montana also found that “not being at risk for HIV/AIDS” was the number-one barrier to testing (Mochi, 1997). This perception may be reasonable given the relatively low incidence of HIV/AIDS among AI/ANs in Montana. One major difference between the barriers reported in the 1997 study and in the current study related to distrust of the health department. In 1997, nearly 24% of the respondents reported that they did not trust the health department, while in the current study, only about 6% reported distrust as a barrier to receiving an HIV test. This difference may reflect a more positive relationship between AI/ANs and county public health departments in the past 14 years, or it may reflect current respondents’ reluctance to admit to a distrust of public health departments. More likely, however, it reflects a difference in the populations that were assessed in the two studies. Participants in the 1997 study lived on reservations, while most of the participants in the current study lived in more urban areas. It seems plausible, therefore, that AI/ANs living off reservation may have greater exposure to and contact with the majority culture, and may have adapted their behavior and thinking to more closely match the prevailing view that health departments are safe places to receive preventive health services. Acculturation may be responsible, not only for the possible greater trust in health departments, but also for the dramatic decrease from 1997 to 2008 in the percentage of individuals who reported “not knowing where to get tested.”

Another interesting change in the past 14 years is in the number of people who reported “usually or always practicing safe sex” as barrier to testing. In 1997, approximately 60% of questionnaire respondents reported that they did not seek an HIV test because they “usually or

always practice safe sex.” In 2008, the percentage of individuals reporting the same barrier declined by nearly one half. There are several ways to interpret this difference. It may simply be that since 1997 fewer AI/ANs are practicing safe sex, or that AI/ANs living on reservations are more likely to practice safe sex than individuals living off reservations. An equally reasonable explanation, however, is that the actual rates of AI/ANs practicing safe sex have not changed significantly over time, but respondents in the 2008 study simply did not indicate on the questionnaire that “usually or always practicing safe sex” was a reason to forgo HIV testing.

Examination of HIV C&T forms revealed a surprising number of HIV tests administered at state-funded sites to individuals who identified as AI/AN. The fact that many AI/ANs choose to get tested at state-funded sites may be related, in part, to the barrier “fear of people finding out.” This fear appears to be common in smaller communities—both on and off reservations. “Fear of people finding out” was mentioned as a barrier to getting an HIV test by many individuals who completed the Barriers to HIV Testing Questionnaire. It makes sense, therefore, that three of the four sites recording the greatest number of HIV tests administered to AI/ANs were located in the largest cities in Montana’s Yellowstone and Cascade counties. These more urban HIV testing sites provide much-needed anonymity for individuals who reside in small rural communities in Montana.

In addition to reducing barriers to testing, it is also important to understand an individual’s motivation for seeking an HIV test. Of the respondents in this study who visited an urban Indian or a public health clinic for testing and completed the Barriers to HIV Testing Questionnaire, nearly half reported they tested because “knowing their status helped them to feel safe.” Over one-third of the questionnaire respondents were motivated to test after having unprotected sex, while nearly one-sixth reported being motivated to test because they were offered an incentive. The important role of incentives as a motivating factor in seeking an HIV test is most apparent in the data gathered from the HIV C&T intake forms, where approximately half of individuals who tested at state-funded sites reported being offered a monetary incentive to test. Seventy percent of those incentives were given to individuals who were tested for HIV at the Salish Kootenai College testing site on the Flathead Reservation—a site that administered approximately one-third of all tests given to AI/ANs at state-funded sites. While receiving a gift certificate to a discount and/or grocery store, in and of itself, may motivate individuals to get an HIV test, it is possible that receiving an incentive encourages individuals to get tested because it reduces the stigma of HIV testing. If individuals are asked by family or friends why they were motivated to test, they can attribute their motivation to their desire for an incentive rather than to their participation in high-risk behaviors such as injection drug use or unprotected sex. Awareness of both motivations for and barriers to testing can be useful for health professionals who are developing interventions designed to increase the number of AI/ANs who are knowledgeable about their HIV status.

LIMITATIONS OF THE STUDY

There are several important limitations regarding the data collected for this study.

Barriers to Testing Questionnaire

Data collected from the questionnaires were self-reported. Information was dependent upon participants' memory of previous experiences and willingness to answer questions honestly. Furthermore, distribution of questionnaires was dependent on health clinic workers at the participating sites. The questionnaire only represents responses of the volunteers and cannot be applied to AI/AN populations as a whole. Data also do not represent all possible testing sites available in Montana.

HIV C&T Intake Forms

The HIV C&T intake forms were supplied by the HIV/STD Section of the MTDPHHS. Individuals who conduct tests at state-funded sites are required to complete the forms to comply with the CDC surveillance regulations. Individuals who perform tests at IHS sites or tribal health clinics on reservations, as well as those who perform tests at private sites both on and off reservations, are not required to complete the CDC forms. Thus, data from the forms do not represent all AI/ANs who received an HIV test in 2007. Nor do the forms provide information about respondents' area of residency; therefore, we were unable to determine whether urban, rural, and reservation residents face different barriers to testing. Further research is recommended to investigate this possibility. In addition, the accuracy of the information on the forms is dependent on clients' ability and willingness to self-report past behaviors.

Behavioral Risk Factor Surveillance System

The BRFSS is an ongoing telephone survey conducted by the MTDPHHS in collaboration with the CDC, and is the primary source of state-based information on health risk behaviors among the adult population (MTDPHHS, 2007). To account for limitations of gathering data through a telephone interview, final data from the BRFSS are weighted, taking into account four factors: the basic probability of selection among subsets of area code/prefix combinations, the number of adults in the respondent's household, the number of telephones in the household, and the number of people in an age-by-sex or age-by-race-by-sex category in the population of the state. The weights for each relevant factor are multiplied together to get a final weight (CDC, 2009). Even after taking into account weighted data, it is possible this data set does not accurately represent the entire AI/AN population in Montana.

Epidemiological Data

Montana's state epidemiologic report only includes cases of HIV/AIDS reported in Montana. There may, in fact, be HIV-positive individuals residing in the state who reported positive elsewhere. Furthermore, sample sizes remain a limitation in states like Montana with low case rates. When data are stratified, numbers may become extremely small. The addition of one case may show a large percentage difference between strata, when there is no significant or practical difference.

CONCLUSIONS

This study was an attempt to examine multiple sources of information regarding HIV/AIDS among AI/ANs in Montana and to use that information to gain further understanding of the epidemic as it exists in AI/AN populations. Four sources of data were reviewed: the Barriers to HIV Testing Questionnaire, CDC standardized HIV C&T intake forms, information on HIV testing from the BRFSS, and state of Montana epidemiologic data. It is worthwhile to remind readers that HIV testing data collected for this assessment focused on urban Indian centers and on testing sites that receive funding from the state public health department. The conclusions drawn from this study should, therefore, be examined in light of the limitations discussed above.

The CDC recently announced a significant decline in the HIV transmission rates nationwide (CDC, 2008). The decline in transmission rates is evident in Montana's AI/AN populations. A review of cases from 1985 to 2008 reveals that the number of individuals newly diagnosed with HIV decreased from ten between 1990 and 1992 to five between 2006 and 2008. Furthermore, state epidemiologic data described in this study reveal few major changes in the character of the HIV/AIDS epidemic over time. Risk behaviors, gender, and age of individuals infected with HIV remain fairly constant.

The decline in incidence and the relatively low number of HIV/AIDS cases among AI/ANs do not appear to be the result of lack of testing. In fact, HIV testing data from state-funded sites and state BRFSS data indicate that not only are AI/ANs in Montana getting tested at greater rates than Whites, but also that testing sites are being utilized by individuals who have increased risk for infection. Data from HIV C&T intake forms completed at state-funded sites revealed that approximately 90% of AI/ANs who were tested at these sites listed at least one risk factor for HIV infection. A substantial proportion of those who were tested reported behaviors corresponding with the highest behavioral risk categories—MSM and IDU.

While we applaud the decreasing transmission rates among AI/AN populations in Montana, we must remain vigilant in our prevention efforts. Unfortunately, there are many barriers to ongoing prevention efforts. Primary among these barriers is the low perception of risk for HIV infection

among AI/ANs, despite strong indicators that many individuals are engaging in behaviors that place them at risk. NASTAD (2008) notes that even health care professionals have a difficult time accepting the importance of HIV/AIDS prevention work when there are few reported cases and many other major health challenges affecting AI/AN populations that require attention. One potential strategy for overcoming this barrier is to integrate HIV prevention education into broader programs that already have culturally appropriate infrastructure in place and where similar behaviors are addressed (e.g., STD and teen pregnancy education and prevention programs). In Montana, where teen pregnancy (MTDPHHS, 2008) and STDs rates are high (MTDPHHS, 2010) and HIV rates are relatively low, young people may find more relevance, and therefore be more receptive, to messages that combine HIV prevention information with STD and pregnancy prevention information.

“Fear of people finding out” has long been a barrier to accessing HIV prevention and testing services. In Montana, this issue has been addressed in several ways. Individuals who are trained to administer HIV tests take their testing services to places where AI/ANs gather socially. Community events both on and off reservations are frequently attended by outreach workers who offer HIV testing in conjunction with preventive services related to other important health issues such as STDs or Hepatitis C. As part of these outreach efforts, an incentive for HIV testing often is offered. The incentive serves to motivate individuals to be tested and also may reduce the stigma of getting an HIV test by offering high-risk individuals an alternative explanation for receiving a test. Receiving a test at a large urban testing center also appears to mediate the “fear of people finding out.” Such testing centers appear to offer more anonymity and inspire confidence that the visit will be kept confidential.

Another significant barrier to HIV prevention among AI/ANs in Montana is the high rate of substance use. In this assessment, examination of risk behaviors reported on HIV C&T forms revealed that nearly one half of individuals receiving an HIV test reported having sex while intoxicated or on drugs. Since behaviors associated with substance use have been linked with the transmission of HIV, it seems important to incorporate HIV/AIDS prevention education into existing substance use prevention and/or treatment programs on and off reservations. Recommendations for integrating prevention programs by pooling resources, targeting individuals whose behaviors place them at highest risk, and increasing the relevance of HIV prevention messages by combining them with messages related to more salient health issues (e.g., teen pregnancy, STDs, substance abuse) are particularly relevant for AI/ANs communities in rural, low-incidence states like Montana where resources are extremely limited and where low perception of risk is an impediment to the promotion of HIV prevention behavioral risk reduction.

We hope that the information gathered in this assessment will add to readers' understanding of the impact of HIV/AIDS on AI/ANs living in Montana. Unfortunately, the picture drawn by this assessment is incomplete. In order to complete the picture, future research should include information about HIV testing and barriers specific to each reservation. Building positive relationships that foster information sharing among tribal programs, urban Indian centers, IHS, the state's communicable disease surveillance program, and researchers should be an important component of future research. Working together, these diverse entities will be able to provide a more in-depth understanding of the impact of HIV/AIDS among all AI/ANs in Montana

K. Ann Sondag
Department of Health and Human Performance
The University of Montana
Missoula, MT 59812
Phone: 406/243-5215
E-mail: Annie.Sondag@mso.umt.edu

REFERENCES

- Bertolli, J., McNaghten, M.C., Campsmith, M., Lee, M.L., Leman, R., Bryan, R.T., et al. (2004). Surveillance systems monitoring HIV/AIDS and HIV risk behaviors among American Indians and Alaska Natives. *AIDS Education and Prevention, 16*(3), 218-237. doi: 10.1521/aeap.16.3.218.35442
- Burks, D.J., Robbins R., & Durtschi J.P. (2010). American Indian gay, bisexual and two-spirit men: A rapid assessment of HIV/AIDS risk factors, barriers to prevention and culturally-sensitive intervention. *Culture, Health and Sexuality, 1*(16), iFirst. doi: 10.1080/13691058.2010.525666
- Centers for Disease Control and Prevention (2008). *HIV Transmission Rates in the United States*. Atlanta: U.S. Department of Health and Human Services. Retrieved from <http://www.cdc.gov/hiv/topics/surveillance/resources/factsheets/transmission.htm>
- Centers for Disease Control and Prevention (2009). *Behavioral Risk Factor Surveillance System: About the BRFSS*. Atlanta: U.S. Department of Health and Human Services. Retrieved from <http://www.cdc.gov/brfss/about.htm>
- Centers for Disease Control and Prevention (2010). Vital signs: HIV testing and diagnosis among adults --- United States, 2001-2009. *Morbidity and Mortality Weekly Report, 59*(47), 1500-1555. Retrieved from http://www.cdc.gov/mmwr/preview/mmwrhtml/mm5947a3.htm?s_cid=mm5947a3_w

- Duran, B., Bulterys, M., Iralu, J., Graham, C., Edwards, A., & Harrison, M. (2000). American Indians with HIV/AIDS: Health and social service needs, barriers to care, and satisfaction with services among a western tribe. *American Indian and Alaska Native Mental Health Research* 9(2), 22-35. doi: 10.5820/aian.0902.2000.22
- Hamill, S., & Dickey, M. (2005). Cultural competence: What is needed in working with Native Americans with HIV/AIDS? *Journal of the Association of Nurses in AIDS Care*, 16(4), 64-69. doi: 10.101b/j.jana.2005.007
- Kaufman, C., Shelby, L., Mosure, D., Marrazzo, J., Wong, D., de Ravello, L., et al. (2007). Within the hidden epidemic: Sexually transmitted diseases and HIV/AIDS among American Indians and Alaska Natives. *Sexually Transmitted Disease*, 34(5), 767-777. doi: 10.1097/01.olq.0000260915.64098.cb
- Mochi, R. (1997). Barriers to HIV counseling and testing for three of Montana's high risk populations. Unpublished master's thesis, University of Montana, Missoula, Montana.
- Montana Department of Public Health and Human Services (2007). *Montana BRFSS Prevalence Data*. Retrieved from <http://74.205.72.25/Data/data.php>
- Montana Department of Public Health and Human Services (2008). *Trends in Teen Pregnancies and Their Outcomes in Montana – 1991 to 2005*. Retrieved from <http://www.dphhs.mt.gov/PHSD/Women-Health/documents/teenpregnancyreport.pdf>
- Montana Department of Public Health and Human Services (2009). *Montana 2009 HIV/STD Annual Report*. Retrieved from http://hivdata.hhs.mt.gov/pdf/HIV_STD_2009_Annual_Report_FINAL.pdf
- Montana Department of Public Health and Human Services (2010). *Annual Report: STDs including HIV/AIDS and Hepatitis C, March 2009*. Retrieved from <http://hivdata.hhs.mt.gov/>
- Montana Office of Public Instruction (2009) *Montana Indians: Their History and Location*. Retrieved from <http://www.opi.mt.gov/pdf/indianed/resources/MTIndiansHistoryLocation.pdf>
- National Alliance of State and Territorial AIDS Directors (March 2008). *Technical Assistance Report: Activities to address HIV/AIDS in Native American communities*. Washington, DC. Retrieved from http://www.nastad.org/Docs/Public/Publication/200843_NA_Report_FINAL_040308.pdf
- Rural HIV/STD Prevention Workgroup (2009). *Tearing Down Fences: HIV/STD Prevention in Rural America*. Bloomington, IN: Rural Center for AIDS/STD Prevention.
- Spielberg, F., Branson, B., Goldbaum, G., Lockhart, D., Kurth, A., Celum, C., et al. (2003). Overcoming barriers to HIV testing: Preferences for new strategies among clients of a needle exchange, a sexually transmitted disease clinic, and sex venues for men who have sex with men. *Journal of Acquired Immune Deficiency Syndromes*, 32(3), 318-328. Retrieved from <http://journals.lww.com/jaids/pages/default.aspx>
- U.S. Census Bureau (2010). *State and County Quick Facts*. Retrieved from <http://quickfacts.census.gov/qfd/states/30000.html>

Vernon, I., & Jumper-Thurman, P. (2005). The changing face of HIV/AIDS among Native populations. *Journal of Psychoactive Drugs*, 37(3), 247-255. Retrived from <http://www.tandf.co.uk/journals/UJPD>

ACKNOWLEDGEMENTS

This project was supported through funding from the HIV/STD Section of the Montana Department of Public Health and Human Services. We would like to thank the section staff for their support, especially Jessie Frazier whose epidemiologic expertise was invaluable. We also would like to thank the clinical staff at participating urban Indian centers and state-funded HIV C&T sites for their assistance in developing and distributing the questionnaire used in this study.