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**A Descriptive Study of Native Americans
Participation in HIV Testing in Montana**

By

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B.A., The University of Montana, Missoula, Montana, 2005

Thesis

presented in partial fulfillment of the requirements
for the degree of

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Health and Human Performance, Health Promotion

The University of Montana
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ABSTRACT

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Health and Human Performance

A Descriptive Study of Native Americans Participation in HIV Testing in Montana

Committee Chair: K. Ann Sondag, Ph.D.

Since reporting first began in Montana in 1985 there have been few, if any, significant changes in regard to HIV/AIDS case rates as well as the demographic characteristics and risk behaviors of Native Americans infected with HIV/AIDS. The fact HIV/AIDS does not appear to have had a disproportionate impact on Montana's American Indian population at the present time is somewhat surprising given other markers of potential HIV risk, such as the increase in both teen pregnancies and other sexually transmitted disease rates like Hepatitis C, suggest an increased level of risk among American Indians when compared to non-Indian populations. Epidemiologic reports, however, indicate that incidence and prevalence of HIV in the population has remained relatively constant.

The purpose of this study was to provide a more accurate picture of Native Americans and their participation in HIV Counseling and Testing (HIV C&T) in Montana. Four data sources used include, 1) The Behavioral Risk Factor Surveillance Survey (BRFSS); 2) Montana state Epidemiological HIV/AIDS records; 3) HIV C&T Intake Forms from state funded testing sites in 2007; and 4) A questionnaire assessing barriers to HIV testing. The four sources were used to collect numbers, demographic characteristics, risk behaviors, and the real and perceived barriers to HIV C&T of Native Americans (NA) being tested for HIV in off-reservation testing sites in Montana.

A synthesis of results from each source revealed the following three conclusions: 1) It appears that NA in Montana are being tested for HIV at about the same rates as Whites. Whites report being tested more in private clinics while NA report testing in public clinics; 2) the epidemic among NA in Montana does not seem to be changing over time, since reporting began in 1985; and 3) there does not appear to be a hidden epidemic among NA living in Montana.

Results from this study will assist state funded HIV C&T sites and Urban Indian Centers in their efforts to target high risk populations and to improve access to HIV C&T for Montana's Native American population.



“Each of us has a role in helping to increase awareness about the impact of HIV and AIDS within Native American communities.

We must all intensify our efforts to advocate, educate, confront, and ultimately eliminate health disparities that exist.”

-Julie Scofield, NASTAD

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“I have seen that in any great undertaking it is not enough for a man or woman to depend simply upon themselves”

~ Forrest Carter, The Education of Little Tree

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CHAPTER I

Introduction to the Study

HIV/AIDS in the United States

Acquired Immune Deficiency Syndrome (AIDS) was first recognized in the United States in 1981. AIDS is a progressed stage of the Human Immunodeficiency Virus (HIV). The transmission of HIV is predominately caused by specific risky health behaviors, including but not limited to, having unprotected sexual contact with an infected person and sharing intravenous drug needles with an infected person. HIV ultimately decreases an individual's immune system making it possible for other opportunistic diseases, which in a healthy immune system would not cause concern, to invade the body, ultimately causing death (Body Health Resources, 2007). As of June 2007, there were approximately one million confirmed cases of individuals who carry the HIV virus, and an estimated 252,000 to 312,000 individuals who are infected but do not know their positive status (United States Department of Health and Human Services (USDHHS), 2008a).

Since the disease was first recognized, all US states have conducted AIDS surveillance using standardized, confidential reporting (USDHHS, 2007). However, it has only been since 1985 states have also conducted HIV surveillance as part of a comprehensive HIV/AIDS reporting program (USDHHS, 2007). Currently, the CDC recognizes HIV testing numbers received from 33 states and five U.S. dependent areas (see appendix A for a list). To be recognized, states must have provided confidential name based reporting since 2001 so data collection stabilizes and data trends can be

monitored. “According to the number of reported AIDS cases, these 33 states represent approximately 63% of the epidemic in the United States” (USDHHS, 2007).

The number of new cases of HIV/AIDS from 2001 to 2005 decreased slightly each year; however, the prevalence of HIV/AIDS increased slightly during the same time period (USDHHS, 2007). At the end of 2005 an estimated 475,200 persons were living with HIV/AIDS in the United States (USDHHS, 2007).

Using data collected and recognized by the CDC from the 33 states, demographic trends emerge among the HIV/AIDS epidemic. The largest number of cases of HIV/AIDS was seen in persons 35 to 39 years, accounting for 16% of all new cases in 2005 (USDHHS, 2007). All races and ethnicities showed slight increases in prevalence rates of people currently living with HIV/AIDS in 2005 (USDHHS, 2007). The estimated number of living HIV/AIDS cases at the end of 2006, according to data collected from 33 states is as follows: Blacks: 232,000; Whites: 166,000; Hispanics: 84,700; Asian/Pacific Islanders: 3,200; and American Indian/Alaska Natives (AI/AN): 2,100 (USDHHS, 2007). In 2006, males accounted for approximately 73% of all HIV/AIDS cases. There was an increased rate of infection from 2001 to 2005 among men who have sex with men (MSM), representing 49% of all new cases of HIV/AIDS in 2005 (USDHHS, 2007).

HIV/AIDS in Montana

The state of Montana, where data from this study was collected, is not included in the 33 states in which CDC recognizes HIV surveillance data. As of June 2008, 870 HIV/AIDS cases have been reported in Montana since the beginning of the epidemic in

1981 (Montana Department of Public Health and Human Services (MTDPHHS), 2008). Of those 870 cumulative cases, 504 are currently living (MTDPHHS, 2008).

The following information was taken from the Montana Public of Health and Human Services Epidemiological Report, June 2008. Males in Montana account for 84% of individuals living with HIV/AIDS, whereas nationally males represent approximately 73% of HIV/AIDS cases. Whites represent 86% of total cases followed by Native Americans at 6%, Blacks at 4% and Hispanics representing 3% of cases. Males and females show different modes of exposure to the virus. MSM males represent 61% of all male HIV/AIDS cases in Montana. MSM and injection drug users (IDU) represent the second largest group at 13%, followed by 9% IDU, 9% non-specific risk, 5% high risk heterosexuals (HRH), and 2% are represented by other risks. HRH women represent 51% of female cases of HIV/AIDS, followed by 25% IDU, 20% unspecified risk, and 4% other risks (MTDPHHS, 2008).

HIV/AIDS among Native Americans

The American Indian and Alaska Native (AI/AN) people account for nearly 2.5 million individuals living in the United States, representing 562 federally recognized tribes and more than 50 state recognized tribes. Hamill and Dickey (2005) report “the AI/AN population is disproportionately affected by many of the social and behavioral factors associated with increased risk of HIV infection” (p. 65). Despite this increased risk, nationally the rate of HIV/AIDS cases in the AI/AN population makes up less than 1% of the total HIV/AIDS cases (Hamill, Dickey, 2005). The national case rates of HIV/AIDS among Native Americans have increased slightly each year since 2003. At a

rate of 8.8 per 100,000 they have the third highest HIV/AIDS rate in the United States (National Alliance of State & Territorial AIDS Directors (NASTAD), 2008). This rate is lower than Blacks and Hispanics who have rates of 67.7 and 25.5 per 100,000, respectively (NASTAD, 2008; USDHHS, 2007a).

Some health professionals estimate the number of AIDS cases among American Indian/Alaska Natives to be much higher than currently reported (Hamill, Dickey, 2005). There are two main explanations for this underreporting of HIV/AIDS. First, as with other minority populations, there is still stigma associated with HIV/AIDS. AI/AN individuals are especially concerned with confidentiality due to the close knit community most Native Americans live in, as well as a severe stigma of homosexuality that continues to exist in their culture. Fear of testing and the underreporting of existing cases of HIV among this community may be high. A second reason for underreporting may be the misclassification of AI/AN as Hispanic, Caucasian, African American, and Asian among health professionals (Hamill, Dickey, 2005). There is an obvious health disparity concerning HIV/AIDS in regards to education, available services, and awareness among the Native American community in rural states (NASTAD, 2008).

Counseling and Testing for HIV

There is a growing movement occurring not only in the public health realm, but among insurance agencies, lawmakers and other public officials to focus on increasing the numbers of individuals who get tested for HIV so they know their status (NASTAD, 2008). There are approximately 16 to 22 million people in the United States alone who get tested for HIV (Branson, Handsfield, Lampe, Janssen, Taylor, Lyss, Clark, 2006).

However, there are approximately 250,000 individuals who are HIV positive but do not know their status (USDHHS, 2008a; Koo, Begier, Henn, Kellerman, 2006; Glynn, Rhodes, 2005). Individuals who know their status are much less likely to transmit the disease to others (Spielberg, Branson, Goldbaum, Lockhart, Kurth, Celum, Rossini, Critchlow, Wood, 2003).

Revised recommendations from the National Center for HIV/AIDS, Viral Hepatitis, STD, and TB Prevention in 2006 call for health care settings to “increase HIV screening of patients, including pregnant women; foster earlier detection of HIV infection, identify and counsel persons with unrecognized HIV infection and link them to clinical and prevention services; and further reduce perinatal transmission of HIV” (Branson, et al., 2006, p. 2). The focus for HIV Counseling and Testing (HIV C&T) currently takes a prevention approach incorporating universal screening. It has been shown to be highly effective. For example, screening blood donors for HIV has nearly eliminated transfusion-associated HIV infection (Branson, et al., 2006).

Testing for HIV has evolved from being done with a blood test that took days to determine the person’s status to today’s diagnostic oral fluid rapid test in which patients know their status immediately. Testing has been streamlined and counseling has become more comprehensive. However, there are countless barriers that inhibit individuals from being tested. There are individual factors; program, policy, or law factors; and counseling and testing factors that must be reviewed before one can consider why an individual might not go to a health facility to be tested for the virus (Spielberg, et al., 2003). Barriers assessed by Spielberg and colleagues (2003) show the

following top five barriers to testing: “Fear of finding out results, not being ready to deal with a positive result, anxiety associated with waiting for results, fear of social discrimination, and concern about named reporting” (p. 322).

Increased concern for confidentiality is one of the primary HIV testing barriers cited by the Native American population. A perceived low or no risk of getting HIV, as well as mistrust of the local health department, lack of knowledge that services are available, inconvenient office hours at testing sites, and lack of confidentiality are also cited as primary barriers to testing among Native Americans both nationwide as well as locally in the state of Montana (Duran, Bulterys, Iralu, Graham, Edwards, Harrison, 2000; Mochi, 1997).

Statement of the Problem

The National Alliance of State & Territorial AIDS Directors (NASTAD) recently issued a report outlining strategies for addressing HIV/AIDS among Native Americans (2008). They state, “each of us has a role in helping to increase awareness about the effect of HIV/AIDS within Native American communities” (2008, p. 2). Unfortunately, in Montana there is a scarcity of information regarding the effect of HIV on Native American communities. Epidemiologic information about NA’s living with HIV and AIDS provides some insight into the epidemic. However, there is a need for more comprehensive information. Specifically, gathering information about the demographic characteristics and risk behaviors of Native Americans who have been tested for HIV, as well as information about barriers to Counseling and Testing may be helpful in defining and describing the effects of HIV/AIDS in Native American communities. Ultimately,

information obtained from this study can be used to increase awareness and target prevention efforts to the Native American populations most at risk.

Purpose of the Study

The purpose of this study was to provide a more accurate picture of Native Americans and their participation in HIV Counseling and Testing in Montana. Specifically, the numbers, the demographic characteristics, and the risk behaviors of Native Americans being tested for HIV in off-reservation testing sites in Montana was described in this study. In addition, this study explored real and perceived barriers to HIV C&T among Native Americans who sought HIV and STD testing at one of four State funded public HIV testing sites and among individuals who sought general health care at one of Montana's five Urban Indian Centers. Results from this study will assist state funded HIV Counseling and Testing sites and Urban Indian Centers in their efforts to target high risk populations and to improve access to HIV counseling and testing for Montana's Native American population.

Research Questions

1. What are the demographic characteristics and risk behaviors of NA living in Montana who are infected with HIV?
2. Approximately how many Native Americans reported being tested at all testing sites in Montana (public and private)?
3. Approximately how many Native Americans were tested in Montana from January 1, 2007 to June 30, 2008 at state funded sites?

4. What are the characteristics of Native Americans who received HIV Counseling and Testing at Montana Department of Public Health & Human Service (MTDPHHS) funded sites and at Urban Indian Centers from January 1, 2007 to June 30, 2008?
 - What are the ages, sex/gender, risk behaviors and county of residence of Native Americans being tested?
5. What are the real and perceived barriers to HIV testing among Native Americans in Montana?

Significance of the Study

The information gathered from this study will be used by the MTDPHHS, local health departments, and local Urban Indian Centers to help increase their awareness of how HIV/AIDS impacts the Montana Native American community. Results from this study will help the state become more knowledgeable about testing numbers and counseling and testing procedures currently in place. This knowledge could potentially help increase the number of Native Americans who get tested for HIV by reducing the barriers to getting tested.

Delimitations and Limitations

Delimitations considered within this study:

1. The study is delimited to Native Americans who currently live in the state of Montana.
2. Data will be collected from self-reported questionnaire responses.
3. Questionnaires will be distributed to MTDPHHS funded HIV Counseling and Testing sites, and Urban Indian Centers.

4. Epidemiological data gathered from MTDPHHS in the years 2007 and 2008 will be assessed.

Limitations affecting this study are discussed in chapter five.

Definitions of Terms

AIDS: Acquired Immune Deficiency Syndrome is a diagnosis made whenever a person is HIV positive and has a CD4+ cell count below 200 per micro liter; OR their CD4+ cells account for fewer than 14 percent of all lymphocytes; OR a person has been diagnosed with one or more of the twenty five different opportunistic diseases usually associated with AIDS (USDHHS, 2007).

AIDS surveillance: AIDS diagnoses that are reported to the Centers for Disease Control from each U.S. State (USDHHS, 2007).

American Indian and Alaska Native (AI/AN): People having origins in any of the original people of North and South America (including Central America), and who maintain tribal affiliation or community attachment (United States Census, 2008).

Descriptive Research: Research that describes the characteristics of an existing phenomenon. Descriptive research is often used to serve as a basis for other research to describe meaningfulness of differences found (Salkind, 2006).

Diagnostic Testing: Performing an HIV test for persons with clinical signs or symptoms consistent with HIV infection (USDHHS, 2008b).

Epidemic: The occurrence in a community or region of a group of illnesses of similar nature, clearly in excess of normal expectancy, and derived from a common or from a propagated source (Gordis, 2004).

Health Risk Behavior: Any personal activity that places an individual at risk for poor health and contributes to a higher probability of morbidity and mortality (USDHHS, 2007b).

HIV: The Human Immunodeficiency Virus is the virus that causes Acquired Immunodeficiency Syndrome (AIDS) by infecting helper T cells and the immune system (USDHHS, 2007b).

HIV/AIDS: Cases of HIV infection, regardless of whether or not they have progressed to AIDS (USDHHS, 2007a).

HIV Prevention Counseling: An interactive process of assessing risk, recognizing specific behaviors that increase the risk for acquiring or transmitting HIV, and developing a plan to take specific steps to reduce risks (USDHHS, 2007b).

HIV Surveillance: HIV diagnoses reported to the CDC from each state that uses confidential, name based HIV reporting systems (USDHHS, 2007a).

IDU: A person who uses a drug (heroin, cocaine, speed) administered with a needle or syringe (Body Health Resources Corporation, 2007).

IHS: Indian Health Services are administered through a system of 12 area offices and 163 IHS and tribally managed service units throughout the United States. Tribal facilities are operated under the authority of the Indian Self-Determination and Education Assistance Act, Titles 1 and V (USDHHS, 2007c).

Incidence: The number of new cases of a disease that occur during a specified period of time in a population at risk for developing the disease (Gordis, 2004).

Informed Consent: A process of communication between patient and provider through which an informed patient can choose whether to undergo HIV testing or decline to do so. Elements of informed consent typically include providing oral or written information regarding HIV, the risks and benefits of testing, the implications of HIV test results, how

test results will be communicated, and the opportunity to ask questions (USDHHS, 2007a).

MSM: Men who report sexual contact with other men (homosexual contact) and men who report sexual contact with both men and women (bisexual contact) (Branson, et al., 2007).

Opt-out Screening: Performing HIV screening after notifying the patient that 1) the test will be performed and 2) the patient may elect to decline or defer testing. Assent is inferred unless the patient declines testing (USDHHS, 2007a).

Prevalence: The number of affected persons present in the population at a specific time divided by the number of persons in the population at that time (Gordis, 2004).

Primary Data: Those data collected by researcher which answers unique questions related to the specific needs assessment (McKenzie, Neiger, Smeltzer, 2005).

Rural: A sparsely developed area.

Secondary Data: Those data already collected by someone else and available for researchers immediate use (McKenzie, Neiger, Smeltzer, 2005).

Surveillance: An ongoing, systematic process of collecting, analyzing, interpreting, disseminating, and evaluating data. Data are used to track disease, and provide information for action to protect the public health (USDHHS, 2007b).

Targeted Testing: Performing an HIV test for subpopulations of persons at higher risk, typically defined on the basis of behavior, clinical, or demographic characteristic (USDHHS, 2007a).

Urban: Relating to cities or intensely developed areas.

CHAPTER II

REVIEW OF LITERATURE

Introduction

The HIV/AIDS epidemic has been one of the defining features of the past quarter of a century. It ranks among the most devastating microbial scourges in human history, one whose full impact has yet to be realized. Since recognition of the human immunodeficiency virus (HIV) in 1981, sixty million people have been infected and nearly half have died. In the United States alone, at the end of 2006 over 1 million individuals had become infected with AIDS (US Department of Health & Human Services (USDHHS), 2007a). Each year an estimated 40,000 new cases of HIV are diagnosed (USDHHS, 2008a). The toll on families, communities and even entire nations has been profound (Fauci, 2008). Several researchers have predicted that between the years of 2005 and 2015 a total of 62.3 million new infections will occur worldwide (Koff, Kahn, Gust, 2007).

Among many minority populations in the United States, specifically Native Americans, there is a lack of information regarding the impact HIV/AIDS has on their community. There are unique issues regarding health departments' interactions with Native Americans in regard to HIV Counseling and Testing. Increasing efforts to build an awareness of the health discrepancies and unique issues and challenges regarding Native Americans have become a priority (National Alliance of State & Territorial AIDS Directors (NASTAD), 2008).

In an effort to increase understanding of the impact of HIV/AIDS on Native Americans, this study provided a more accurate picture of Native Americans and their participation in HIV Counseling and Testing in Montana. This study explored real and perceived barriers to HIV C&T among Native Americans. This chapter will review and discuss current literature pertinent to the study purpose.

The review is divided into two sections: 1) HIV Counseling and Testing; and 2) HIV Counseling and Testing Barriers. Within each section there is a discussion of how the topic relates to Native Americans nationally as well as Native Americans living in the rural state of Montana.

HIV Counseling and Testing

This section reviews HIV Counseling and Testing procedures, along with current proposals of the direction HIV Counseling and Testing should take in the future.

HIV Counseling and Testing Procedures

Between 16 and 22 million persons ages 18 to 64 years are tested annually for HIV (Branson, Handsfield, Lampe, Janssen, Taylor, Lyss, Clark, 2006). In general, people are tested late in their course of HIV infection, and in an acute health care setting. Persons primarily sought HIV testing because of illness, being in a known risk group, or having had a known HIV-positive sex partner” (Wortley, Chu, Diaz, Ward, Doyle, Davidson, Checko, Herr, Conti, Fann, 1995). The National Health Interview Survey conducted by the CDC in 2006 reports that approximately 33% of males and 38% of females nationwide report being tested for HIV within their lifetime (USDHHS, 2007d).

HIV testing has become more accessible, easier, and less invasive in recent years (USDHHS, 2008a). Current HIV testing procedures allow individuals several options for testing. Individuals can receive an HIV test at home, drug treatment facilities, jails and prisons, hospitals, private doctor offices or HMOs, HIV Counseling and Testing sites, and health clinics (USDHHS, 2007e). Compared with earlier testing methods such as blood tests in which an individual waited one to two weeks for results, new testing methods such as diagnostic oral fluid rapid tests, allow individuals to get their results immediately.

There is an increased urgency among health professionals, as well as insurance companies, policy makers and other public officials to increase the number of individuals who are tested for HIV. Knowledge of HIV status is one way to decrease the spread of the virus. Individuals who know their status are much less likely to transmit the disease to others (Spielberg, Branson, Lockhart, Kurth, Celum, Rossini, Critchlow, Wood, 2003). New HIV Counseling and Testing recommendations from the Centers for Disease Control place enormous importance on individuals knowing their HIV status as a means to stop the spread of HIV (Branson, et al., 2006). The main goals of the revised recommendations include, “increasing HIV screening of patients, including pregnant women; foster earlier detection of HIV infection; identify and counsel persons with unrecognized HIV infection and link them to clinical and prevention services; and further reduce perinatal transmission of HIV” (Branson, et al., 2006, p. 2).

The Future of HIV Counseling and Testing

CDC estimates that approximately 250,000 individuals (one quarter of known cases) who are HIV positive do not know their status (USDHHS, 2008a; Koo, Begier, Henn, Kellerman, 2006; Glynn, Rhodes, 2005). Despite the large numbers of people who are unaware of their HIV status, testing for the virus is not routine in all medical settings. In the two populations for which HIV testing is routine it has proven to be an effective prevention. Screening blood donors for HIV has nearly eliminated transfusion-associated HIV infection (Branson, et al., 2006). For nearly five years now, according to the CDC, universal testing of pregnant women has resulted in a 95% decrease in perinatally acquired AIDS cases (USDHHS, 2008a). Despite the great success of universally testing both blood donors and pregnant women, HIV is still not a routine test (Koo, et al., 2006). Excluding HIV from routine testing may contribute to the stigma associated with receiving a test. The simple, inexpensive HIV test currently available can diagnose the infection before symptoms start; possibly extending HIV positive patients lives through the initiation of treatment early on. Universal testing of HIV as well as a streamlined HIV Counseling and Testing system is important for the following reasons:

- Declines in HIV incidence observed in the early 1990s have begun to level off; the prevalence rate in certain populations has even begun to increase.
- Progress in effecting earlier diagnosis has improved only slightly even though the survival rate has steadily been increasing.
- At publicly funded sites, approximately 70% of persons tested received their results and information regarding the test, however, it is unlikely patients

receive HIV prevention counseling and service referrals in conjunction with the test.

(Koo, et al., 2006; Glynn, Rhodes, 2005).

“More timely diagnosis of HIV can improve treatment and care of those infected with HIV, prolong survival, and reduce the spread of HIV” (Koo, et al., 2006).

Unfortunately, approximately 40% of new cases are diagnosed concurrently with HIV and AIDS (Koo, et al., 2006; Kaufmann, Shelby, Mosure, Marrazzo, Wong, DeRavello, Rushing, Warren-Mears, Neel, Jumping Eagle, Tulloch, Romero, Patrick, Cheek, 2007).

This concurrent diagnosis indicates that many individuals do not know their HIV status until long after they have been infected. Most HIV infections are transmitted by people who are unaware of their status showing early diagnosis through universal screening is an important prevention strategy (USDHHS, 2007a; Branson, et al., 2006; Koo, et al., 2006).

Policy makers in the United States have become more aware of the importance of universal testing for HIV and are taking action. New York State is home to 1 in 6 persons living with HIV (Koo, et al., 2006). As recently as June, 2008 the health department in New York City issued a three year initiative seeking to give HIV tests to everyone in the Bronx in the age range 18 to 64. The Bronx has been especially hard hit with the virus. One quarter of all HIV/AIDS cases living in New York City reside in the borough, with a third of the city’s AIDS deaths occurring there each year (Rao, 2008).

Behavior Change associated with HIV Counseling and Testing

Literature regarding the effect of counseling and testing on behavior change has been relatively inconsistent. Counseling is conducted along with an HIV test with the assumption if an individual becomes more aware of high risk behaviors associated with the infection they will initiate safer practices and reduce their risk (Mochi, 1997). A meta-analysis of 27 studies from 1985 to 1997 regarding the effects of HIV Counseling and Testing on sexual risk behavior shows that after receiving HIV Counseling and Testing, “HIV-positive participants reduced their frequency of unprotected intercourse and increased their condom use, relative to HIV-negative and untested participants” (Weinhardt, Carey, Johnson, Bickham, 1999). This analysis demonstrated that HIV Counseling and Testing can be an effective prevention strategy for individuals who are HIV-positive (Weinhardt, et al., 1999). HIV-positive participants reduced their sexual risk behavior leading to a reduced risk of subsequent re-infection and the infection of others. However, this same behavior change was not seen among HIV-negative participants. Several studies report the effect on HIV-negative individuals to modify their sexual risk behavior is low after receiving counseling regarding their negative test result (USDHHS, 2008b; Weinhardt, et al., 1999). The minimal effect on HIV-negative individuals may be due to lack of perceived risk. While people are more likely to change their risky behavior if they believe they are at risk for infection, many individuals minimize their risk for HIV infection (Rao, 2008; Kellerman, Lehman, Lansky, Stevens, Hecht, Bindman, Worley, 2002; Aggleton, O’Reilley, Slutkin, Davies, 1994). In fact, many individuals who are part of a high risk group for contracting the HIV virus consider

themselves to be at low risk. A negative HIV test confirms this in their mind and the risky behavior will not change. Low perception of risk is one of the leading reasons people continue to behave in a risky manner (Aggleton, et al., 1994).

“People in general overestimate the probability of dangerous and particularly dreaded outside threats, such as a nuclear bomb, but underestimate the probability of dangers posed by personal behaviors such as cigarette smoking or alcohol consumption. Thus, it is common for many individuals and groups to regard themselves as being not at risk or at very low risk of HIV infection, denying its personal relevance against the objective evidence” (Aggleton, et al., 1994, p. 344).

Some health professionals believe HIV testing needs to be part of wellness checkups and universal screenings, and streamlined for easy accessibility. The responsibility for testing does not solely lie with an individual to be tested. Many players must be involved if we are to continue to make progress in the eradication of HIV/AIDS in our nation and the world. Individual behavior, along with family interactions, community and workplace relationships and resources, and public policy all contribute to health and influence behavior change (McKenzie, Neiger, Smeltzer, 2005). Behaviors are difficult to change, and simply looking to HIV Counseling and Testing to solve this problem is not logical.

“HIV C&T should be viewed as one part of a comprehensive set of strategies, drawing on programs that have been shown to be effective for primary prevention. These strategies should target not only the individual, as in interpersonal skills training programs, but also communities and social policies. It is only through integrated efforts at these multiple levels the HIV epidemic will be addressed adequately” (Weinhardt, et al., 1999, p. 1404).

HIV Counseling and Testing among Native Americans Nationwide

Relatively low numbers of reported AIDS cases among AI/AN belies the many factors that put them at increased risk for HIV infection. A study done by Duran and Walters in 2004 outlines these risk factors:

- The AI/AN population is disproportionately affected by demographic, economic, and health risk factors.
- Low levels of condom use combined with high levels of sexually transmitted diseases.
- AI/ANs have escalating rates of injection drug use.
- AI/ANs are two to three times more likely than the general U.S. population to engage in excessive drinking, which more often co-occurs with sexually risky behaviors.

(Duran, Walters, 2004)

There are both unique opportunities and challenges present for health departments and other HIV testing sites providing services in Native American communities (NASTAD, 2008). NASTAD strategically addresses the disproportionate impact HIV/AIDS has on racial and ethnic minority communities, such as Native Americans. Native Americans have the third highest AIDS rate in the United States. However, at a rate of 8.8 per 100,000 cases, Native Americans represent significantly fewer cases than Blacks and Hispanics who have the first and second highest rates of 67.7 and 25.5 per 100,000 cases respectively (NASTAD, 2008; USDHHS, 2007a).

According to the US Census conducted in 2000, Native Americans comprise less than 2% of the population (US Census, 2008). An estimated 60% of Native Americans live in urban settings yet frequently travel between urban areas and their home tribal lands for ceremonies, education or employment opportunities (Kaufman, et al., 2007; Walters, Simoni, Harris, 2000). Montana displays this pattern with several urban communities constituting microcosms of national tribal representation (US Census, 2008). “This mass migration of AI/AN from rural to urban settings has led to increases in health problems among this population, however the available research indicates that urban AI/AN individuals are as knowledgeable regarding HIV as the general population” (Walters, Simoni, Harris, 2000; Hall, Wilder, Bodenroeder, Hess, 1990). However, a study conducted by Hall, et al., (1990) found that a relatively high knowledge of safe sex behaviors was not associated with actual safe sex behaviors in this urban Native American population.

Recent studies reveal an obvious health disparity concerning HIV/AIDS education, available services, and awareness among the Native American community in the rural states (NASTAD, 2008; Hamill, Dickey, 2005). In 2000, the Surgeon General, David Satcher, issued a call for action on the HIV/AIDS crisis in American Indian/Alaska Native (AI/AN) communities (Satcher, 2000). In this call he stated many health professionals estimate the number of AIDS cases among AI/AN to be much higher than what statistics are currently reporting and the actual number of HIV cases could be as much as 10 times greater (Satcher, 2000). Misclassification and underreporting of HIV

testing are both possible reasons national statistics regarding this population might be skewed (Hamill, Dickey, 2005).

Duran and Walters, in a study conducted in Indian Country regarding HIV prevention strategies concluded for prevention programs that include HIV Counseling and Testing procedures to be successful they have to integrate indigenous theories and strategies with current Euro-American models of research, implementation, and evaluation (2004). HIV Counseling and Testing sites must appeal to the Native American community to help eradicate this virus within this population.

HIV Counseling and Testing among Native Americans in Montana

Native Americans represent 7% (63) of the total cases (870) of reported HIV/AIDS cases since 1985 in the rural state of Montana. Of those 63 reported cases, there are 33 living as of June 2008. No reported deaths have occurred among the AI/AN population in the last five years (MTDPHHS, 2008).

HIV Counseling and Testing Barriers

Early detection of HIV is important not only for prolonging an individual's life but for the prevention of HIV transmission (Spielberg, et al., 2003). While HIV testing has become easier and more accessible than in the past, many individuals still choose not to get tested. In fact, estimates show 25% of individuals who are HIV positive do not know their status (USDHHS, 2007a; Koo, et al., 2006; Glynn, Rhodes, 2005). This section will review the barriers individuals face when making the decision to receive an HIV test.

Since testing for HIV began, the few studies conducted regarding barriers to test have consistently mentioned the same barriers. The most current study looking at

overcoming barriers to test was completed in 2003. Researchers found that among men who have sex with men (MSM), three main categories could be identified as possible barriers: *Individual Factors, Program, Policy and Law Factors* and *Counseling and Testing Factors*. The top barriers under each category are: 1) Individual factors: afraid to find out results, not ready to deal with positive results, fear of being treated differently if test results positive, worried about a partner getting angry, knowing HIV status would not change anything, and not at risk of being infected; 2) Program, Policy, and Law factors: afraid to have name reported if positive, afraid that getting work or insurance would be difficult if positive result, could not afford treatment, not convenient, not wanting to go to clinic, hard to keep appointment time, not knowing where to get tested, and not being able to afford the test; and 3) Counseling and Testing Factors: too anxious to wait for test results, not wanting to get blood drawn, not wanting to talk with counselor, and did not have time (Spielberg, et al., 2003).

Similar results were found earlier in 2002 by Scott Kellerman and colleagues. High at-risk populations were surveyed three years apart regarding barriers to receiving an HIV test. The number one response for not being tested each year individuals were surveyed was being afraid to find out they might be HIV-positive (Kellerman, Lehman, Lansky, Stevens, Hecht, Bindman, Wortley, 2002). Interestingly, individuals who had received an HIV test were also surveyed and the number one reason for getting an HIV test was to know where they stood (Kellerman, et al., 2002).

A person's stigma regarding HIV can also critically delay both HIV testing and care. In a survey of 828 gay and bisexual men who were unaware of their HIV status,

two-thirds said stigma surrounding HIV positive persons was a reason they did not seek testing (Chesney, Smith, 1999). Statements reflecting this feeling included, “I’m afraid the test results would be used against me” and “I’m afraid how the test results would affect my relationships” (Chesney, Smith, 1999, p. 1163). Not only did stigma affect their decision to test, it affected how they would be tested as well. Persons at risk for HIV are more likely to seek testing when it is offered anonymously (no names are recorded) rather than confidentially (names are kept in confidential records) (Chesney, Smith, 1999). It seems imperative that barriers are broken down at HIV Counseling and Testing sites so more individuals know their status.

HIV Counseling and Testing Barriers among Native Americans Nationwide

It is especially critical to break down barriers to testing among the Native American community due to the increased health disparity among this population.

Several dimensions directly related to testing in this population are important to note:

- AI/ANs experience a faster time course from initial diagnosis of HIV infection to AIDS-defining illness than any other racial group in the United States.
- In 2001, 48% of AI/ANs diagnosed with HIV were subsequently diagnosed with AIDS within 12 months, compared with 40% for the general populations.
- AI/ANs experience one of the lowest survival rates after an AIDS diagnosis is made.

(Kaufmann, et al., 2007)

Available data, however, “does not provide information on whether the rapid progression (and low survival) is due to a late diagnosis of HIV, or an accelerated viral pathogenesis” (Kaufmann, et al., 2007, p. 770).

As with many other minority populations, stigma associated with HIV/AIDS among Native Americans remains a primary reason they are not tested. Native American individuals are especially concerned with confidentiality due to the close knit community in which many of them live. The severe stigma of homosexuality still existing in their culture (Hamill, Dickey, 2005) contributes to the fear of testing among this population.

HIV Counseling and Testing Barriers among Native Americans in Montana

Two studies conducted in the state of Montana reveal similar testing barriers as mentioned nationwide in regard to Native Americans. The first study, conducted ten years ago, assessed barriers to HIV Counseling and Testing among high risk populations in Montana. Among 67 Native Americans surveyed, 56% (38) believed they were at low or no risk; 34.3% (23) usually had safe sex; 25.4% (17) always had safe sex; 25.4% (17) feared others finding out; 23.9% (16) lacked trust in the health department; and 22.4% (15) were unsure of testing locations (Mochi, 1997).

A more recent study conducted in Montana in 2004 revealed barriers to HIV testing as well. Although not Native American specific, many of the same barriers were noted in earlier studies. The more common barriers included: stigma of being tested for HIV; fear of knowing status; fear of lack of confidentiality, especially in small communities; inconvenient hours (no weekends or evenings); lack of transportation;

and fear of entering a large impersonal professional building (Montana Department of Public Health and Human Services (MTDPHHS), 2004)

In a study conducted by the ACLU AIDS Project, over 40 community based AIDS service providers (CBOs) were interviewed nationwide. Researchers found particular problems regarding services in rural areas. They report, in Montana, “it is particularly problematic for Native Americans because Indian Health Services will not pay if someone goes outside its system” (Lange, 2003, p. 6). Fear of disclosure and confidentiality is one of the main barriers among Native Americans. Additional financial worries if deciding to test off their home reservation simply adds to the reasons not to receive a test.

Conclusion

This literature review reveals information regarding the impact of HIV/AIDS among Native American’s in general, and Montana’s Native American’s specifically, is extremely limited. One avenue to broadening our understanding of the impact of the virus among Native peoples is to explore HIV Counseling and Testing behaviors. Specifically, this study sought to definitively describe the demographic characteristics of Native Americans who are tested in Montana, self-reported risk behaviors, locations sought for HIV testing, and the barriers they faced when making the decision to test. The information gathered from this study will be used by the MTDPHHS, local health departments, and local Urban Indian Centers to help increase their awareness of how HIV/AIDS impacts the Montana Native American community

CHAPTER III

METHODOLOGY

The purpose of this study was to provide a more accurate picture of Native Americans and their participation in HIV Counseling and Testing (HIV C&T) in Montana. The numbers being tested, the demographic characteristics, and the risk behaviors of Native Americans being tested for HIV in off-reservation testing sites in Montana were described. In addition, real and perceived barriers to HIV Counseling and Testing among Native Americans were explored. Results from this study will assist state funded HIV Counseling and Testing sites and Urban Indian Centers in their efforts to target high risk groups and to improve access to HIV counseling and testing for Montana's Native American population. Included in this chapter is a description of the methods and procedures used in this study.

Description of Target Population

Native Americans are people "having origins in any of the original people of North and South America (including Central America), and who maintain tribal affiliation or community attachment" (US Census, 2008). There are seven federally recognized reservations representing eleven different tribes in Montana. These include the Blackfeet, Crow, Confederated Salish and Kootenai, Assinibone, Gros Ventre, Sioux, Northern Cheyenne, and Chippewa-Cree tribes. Montana Native Americans both living on the seven reservations and in urban areas represent approximately 6% of the approximate 950,000 individuals living in Montana (US Census, 2008). Nationally, approximately 66% of the Native American population lives in urban areas, with

approximately 540,000 total Native Americans still living on reservations or land trusts (Hamill, Dickey, 2005).

Overlapping populations were examined in this study. The first population consisted of Native Americans who participated in the Behavioral Risk Factor Surveillance Survey (BRFSS) in 2007. The second population consisted of Native Americans who received an HIV test at a state funded site during the time period between January 1, 2007 and December 31, 2007. Data from this population provided information regarding demographic characteristics and risk behaviors of Native Americans in Montana who sought HIV testing. A third population for this study consisted of Native Americans, over the age of 18, who sought health care at one of five Montana Urban Indian Centers between September 1, 2008 and October 31, 2008. Native Americans who sought testing for an STD or HIV at one of four Montana DPHHS funded HIV C&T sites during the same time period was also assessed. Demographic data and information regarding real and perceived barriers to HIV C&T was collected from individuals in these populations who volunteered to complete a short questionnaire.

Study Design

This study utilized a descriptive research design. Descriptive research describes characteristics about the population or phenomenon being studied. Descriptive research answers the questions who, what, where, when and how. For the purpose of this study, frequencies, averages and other statistical calculations were used to describe the extent of the HIV/AIDS epidemic among Montana's Native Americans, the

characteristics of Native Americans who were tested for HIV, and the barriers of seeking an HIV test.

Protection of Human Subjects

The questionnaire and all other applicable research materials were completed in accordance with The University of Montana Institutional Review Board (IRB) (see Appendix B).

PROCEDURES

Selection of Sample

Primary data was gathered from a sample of Native American men and women over the age of 18. Individuals who visited one of four Montana DPHHS funded sites for an STD and/or HIV test, in addition to individuals who sought health care at one of five Urban Indian Centers in Montana were asked by a health care worker at those sites to voluntarily complete a short, anonymous questionnaire. Information from the questionnaire helped answer what real and perceived barriers exist among Native Americans in regards to HIV testing. The four MTDPHHS funded sites included in this sample were chosen based on numbers of Native Americans who sought HIV C&T services in 2007; the top five sites with high testing numbers were chosen. One of the sites, however, declined to participate in the study. All five Urban Indian Centers in Montana participated in the questionnaire distribution.

The five Urban Indian Centers in Montana include The Leo Pocha Clinic in Helena, the Indian Family Health Clinic in Great Falls, the Missoula Indian Center in

Missoula, The Indian Health Board of Billings Clinic in Billings, and the North American Indian Alliance in Butte.

The four MTDPHHS funded sites willing to participate (in descending order of total testing numbers) included Riverstone Health in Billings, Cascade City-County Health Department in Great Falls, Missoula AIDS Council (MAC) in Missoula, and the Butte and Silver Bow City-County Health Department in Butte, Montana.

Secondary data for this study was drawn from state epidemiologic reports, the state BRFSS data from 2007, and existing state funded sites HIV C&T intake forms. Data from secondary sources were made available to the researchers by the STD/HIV Section and the Public Health and Safety Division of MTDPHHS.

Instruments

Primary Data:

Primary data was collected via a short questionnaire (see appendix C). The questionnaire for this study included three sections: 1) demographic questions; 2) questions regarding behaviors that put an individual at risk for HIV infection; and 3) questions about barriers to HIV C&T. Categories and wording for demographic and risk behavior questions were taken directly from the standardized MTDPHHS HIV C&T forms. Questions regarding barriers to HIV C&T 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 HIV/AIDS and STD Section. Adaptations to the questionnaire were made based on feedback provided during the expert review.

Secondary Data:

Secondary data was collected from three existing data sources. First, state epidemiologic data specific to Native Americans was made available to the researchers. HIV/AIDS epidemiologic data is collected by the MTDPHHS on an ongoing basis. The state epidemiologist worked with researchers to examine trends in the incidence and prevalence of HIV/AIDS among Native Americans over a nine year time period (1998 to 2007).

Second, information from the 2007 Montana Behavioral Risk Factor Surveillance Survey (BRFSS) was used. 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 gathered information from U.S. adults about a wide range of behaviors affecting their health. The primary focus of these surveys has been on behaviors that are linked with the leading causes of death, including HIV/AIDS (see appendix D for BRFSS survey questions regarding HIV/AIDS).

Finally, this study utilized information from existing HIV C&T forms. The forms were developed by the Centers for Disease Control (CDC) in 1990 and revised in 2007. Montana health departments' HIV C&T forms are standardized machine-readable forms provided by the CDC. Montana collects test-level data which is submitted directly to a CDC database via scanning software. Counseling and Testing data collected and made

available to the CDC are used to facilitate program monitoring and evaluation at the local, state and national levels (USDHHS, 2008b). The older HIV C&T version was used through 2007, and was the form used by this study. Data taken from the form included: 1) client demographics; 2) HIV testing information including specific test technology, HIV test specimen type, and test results; and 3) client risk factors.

Data Collection

This study utilized four different data collection methods:

1. Existing epidemiological data provided by MTDPHHS was reviewed. Four year trends, including the time period from 1998 to 2007, for HIV/AIDS incidence and prevalence, demographics, and risk behaviors among the Native American community are reported.
2. Data from the 2007 Montana BRFSS provides information regarding HIV testing behaviors, at both private and public HIV testing sites, of a random sampled Native American population currently residing in Montana.
3. Standardized HIV C&T forms completed between January 1, 2007 and December 31, 2007 provide demographic and risk behavior information.
4. A questionnaire was distributed to four MTDPHHS funded sites and five Urban Indian Centers mentioned above (see appendix E for a list of data collection sites). Staff at the MTDPHHS sites asked individuals, over the age of 18, who came in for an STD and/or HIV test to volunteer to complete the questionnaire. Staff at Urban Indian Centers asked all individuals, over the age of 18, who sought health care to volunteer to complete the short questionnaire. At both

the MTDPHHS sites and Urban Indian Centers, individuals who chose to participate either completed the questionnaire at the clinic or finished the questionnaire at a time more convenient, and mailed it to the researchers in a provided self-addressed, pre-paid envelope.

The following chart visually depicts how the four data collection methods were used to answer each of the five research questions.

Chart 1: Data Collection Methods

RESEARCH QUESTIONS:	DATA COLLECTION METHOD:
<p>1. What are the demographic characteristics and risk behaviors of Native Americans living in Montana who are infected with HIV?</p>	<p><u>Secondary Data:</u> Epidemiological data was obtained from MTDPHHS and used to describe the population of NA who are HIV positive.</p>
<p>2. Approximately how many Native Americans reported being tested at all testing sites in Montana (public and private)?</p>	<p><u>Secondary Data:</u> BRFSS data was obtained from the state Director/Epidemiologist of the Public Health & Safety Division of MTDPHHS.</p>
<p>3. Approximately how many Native Americans were tested in Montana from January 1, 2007 thru December 31, 2007 at state funded sites?</p>	<p><u>Secondary Data:</u> Counseling and Testing intake forms were provided by the state HIV/STD Section of MTDPHHS. Forms that indicate Native American as “race” underwent a simple frequency count.</p>
<p>4. What are the characteristics of Native Americans who received HIV Counseling and Testing at Montana Department of Public Health and Human Service (MT DPHHS) funded sites and at Urban Indian Centers from January 1, 2007 thru December 31, 2007?</p> <ul style="list-style-type: none"> ▪ What are the ages, sex/gender, risk behaviors and county of residence of Native Americans being tested? 	<p><u>Secondary Data:</u> Counseling and Testing intake forms were used to extract demographic and risk behavior information on individuals who identified themselves as NA.</p>
<p>5. What are the real and perceived barriers to HIV testing among Native Americans in Montana from September 1, 2008 thru October 31, 2008?</p>	<p><u>Primary Data:</u> A questionnaire was distributed at four Montana state funded HIV C&T sites, as well as at Montana’s five Urban Indian Centers.</p>

Data Analysis

Primary data from the questionnaire was analyzed descriptively. The demographic characteristics, risk behaviors, and barriers to HIV C&T as reported by Native Americans who sought services at specific MTDPPHS funded sites and Urban Indian Centers in Montana were analyzed by actual count and percentage. Charts and graphs are used to represent data whenever appropriate.

Secondary data gathered from standardized intake C&T forms and primary data from the self-report questionnaire was entered into SPSS database for Windows. Data from the C&T forms was analyzed descriptively. Numbers, demographic characteristics and risk behaviors of Native Americans who were tested for HIV at MTDPHHS funded sites between January 1, 2007 and December 31, 2007 were analyzed by actual count and percentage. Epidemiologic and BRFSS data was used to synthesize Counseling and Testing data to provide a more comprehensive picture of the incidence and prevalence of HIV/AIDS among Montana's Native Americans and their HIV testing behaviors.

CHAPTER IV

RESULTS

The purpose of this study was to provide a more accurate picture of Native Americans and their participation in HIV Counseling and Testing in Montana. Specifically numbers, demographic characteristics, and risk behaviors of Native Americans being tested for HIV in off-reservation testing sites in Montana. This study also explored real and perceived barriers to HIV Counseling and Testing among Native Americans. Data was collected from the following sources: 2007 Behavioral Risk Factor Surveillance System (BRFSS); Epidemiological data obtained from the Montana Department of Health and Human Services (MTDPHHS); Counseling and Testing Intake Forms obtained from the HIV/STD Section of MTDPHHS for 2007; and a questionnaire distributed to four Montana State funded health clinics and all five Montana Urban Indian Clinics for the two month period between September 1, 2008 and October 31, 2008. Following are the results from analysis of these sources.

Questionnaire Results

The main purpose of the questionnaire was to assess barriers to HIV counseling and testing. The questionnaire also asked for demographics, information regarding behaviors putting an individual at risk for HIV infection, and questions about barriers to HIV Counseling and Testing. In an attempt to reach as many individuals as possible, two populations had the opportunity to complete the questionnaire. The first population included Native Americans visiting one of four Montana State funded health clinics

specifically for an STD or HIV test. The second population included Native Americans visiting one of five Urban Indian Health Centers for any health concern.

A total of 275 questionnaires were distributed between the nine sites. Of those 275, 161 were completed for a return rate of 59%. Four questionnaires were removed from the analysis because they did not meet the age criteria of being over 18 years of age. A total of 157 questionnaires were used for analysis; with a return rate of valid questionnaires of 57%. The following table depicts distribution numbers, return numbers and rates for valid questionnaires returned from each site.

Table 1: Questionnaire Return Rate

Site	Number	Number Returned	Return Rate
Butte North American Indian Alliance	50	49	98%
Cascade City-County Health Department	25	23	92%
Riverstone Health	25	23	92%
Helena Leo Pocha Clinic	50	28	56%
Great Falls Indian Family Health Clinic	25	12	48%
Missoula Indian Center	25	9	36%
Missoula AIDS Council	25	8	32%
Indian Health Board of Billings Clinic	25	5	20%
Butte Silver-Bow City-County Health Department	25	0	0%
TOTAL	275	157	57%

Basic Demographics

Age:

The respondents (n=156) reported their age as follows:

- Age ranged from 18 to 75

The following table depicts age ranges, frequencies and percents. One respondent did not report age.

Table 2: Questionnaire Respondents Age

Ages	Frequency (n)	Percent (%)
18 to 24	26	16.7
25 to 34	38	24.4
35 to 44	35	22.4
45+	57	36.5
TOTAL	156	100%

Gender:

Females responded to the questionnaire in slightly larger numbers than males.

- 56.7% (n = 89) were female; and
- 43.36% (n = 68) were male.

Sexual Orientation:

The respondents (n=138) reported sexual orientation as follows:

- 90% (n = 124) reported being heterosexual.
- The remaining 10% are distributed as the following:
 - 4.3% (n = 6) bisexual;
 - 2.9% (n = 4) homosexual; and
 - 2.6% (n = 4) were either uncertain of their sexual orientation (n = 2) or listed “other” as their sexual orientation (n = 2).

12% (n = 19) of the total 157 respondents chose not to report their sexual orientation.

Income:

Individuals were asked to check the income category representing their yearly income earnings. Within these income categories, a total of 154 respondents reported their earnings. Three respondents chose not to report their earnings. Over 75% of the

respondents earned \$20,000 or less per year. The following table depicts the income levels of the respondents.

Table 3: Questionnaire Respondents Income

Yearly Income Earnings	Frequency (n)	Percent (%)
Below \$10,000	87	56.5%
\$11,000 to \$20,000	33	21.4%
\$21,000 to \$35,000	26	16.6%
\$36,000 to \$50,000	5	3.2%
\$51,000 to \$75,000	2	1.3%
\$76,000 and above	1	.6%
TOTAL	156	100%

Residence:

All Individuals who reported state of residence (n = 156) lived in Montana, one respondent chose not to report his/her state of residence.

Of the 56 counties in Montana, 15 counties were represented by respondents. Six respondents did not answer this question and were not used for analysis.

Table 4: Montana Counties in which Respondents Reside

County	Frequency (n)	Percent (%)
Beaverhead	1	.06%
Bighorn	7	4.6%
Broadwater	1	.06%
Cascade	17	11.3%
Glacier	3	2%
Hill	5	3.3%
Jefferson	3	2%
Lake	4	2.6%
Lame Deer	2	1.3%
Lewis and Clark	22	14.6%
Missoula	15	9.9%
Park	1	.06%
Rosebud	2	1.3%
Silverbow	47	31.1%
Yellowstone	21	14.0%
TOTAL	151	100%

Distance Traveled to the Clinic:

Of the total respondents (n = 133) who answered this question, the majority, 80% were within a 20 minute drive of the clinic. A total of 24 respondents did not answer this question and were not used for analysis. The following chart depicts respondents reason for their visit as well as time spent traveling to the clinic.

Table 5: Reason for Visit and Time Travelled

Reason for Visit	Distance Traveled to the Clinic		
	≤ 20 minutes	1 to 2 hours	2 to 5 hours
HIV Test	13	6	5
STD Test	1	0	0
General Health Care	93	5	2
TOTAL	107	11	7

Tribal Affiliation:

Of the total respondents (n = 157), the vast majority lived in an urban area off a reservation and were enrolled members of a tribe. One respondent chose not to answer and was not used for analysis.

- 82% (n = 128) live in an urban area off a reservation;
- 15% (n = 24) currently live on a Montana reservation.
- 87% (n = 137) are enrolled members of a tribe;
- 10% (n = 16) are not members; and
- 3% (n = 4) were uncertain whether they were an enrolled member of a tribe.

The following table depicts the reservations and tribes represented by respondents (n = 127).

Table 6: Reservation and Tribes Represented by Questionnaire Respondents

Montana Reservation	Tribes Represented*	Frequency (n)	Percent (%)
Blackfeet	Blackfeet	17	13.3%
Crow	Crow	12	9.4%
Flathead	Salish and Kootenai	15	11.8%
Fort Belknap	Gros Ventre	9	7.0%
Fort Peck	Assiniboine and Sioux	11	8.6%
Northern Cheyenne	Northern Cheyenne	15	11.8%
Rocky Boy	Chippewa – Cree	19	15.0%
	Little Shell	10	7.9%
	Turtle Mountain	5	4.0%

*Tribes with less than 1% response rate (n < 2) are not charted.

They include: Blood Tribe, First Nation, Hidatsa, Navajo (Nation), Lumni Nation Tribe of Washington, Ojibwa, Potawatomi, Sisseton Whapeton Oyate, White Mountain Apache, and descendants and/or distant relatives of tribes.

General Health and HIV Information

Previous HIV Test:

Of 156 respondents:

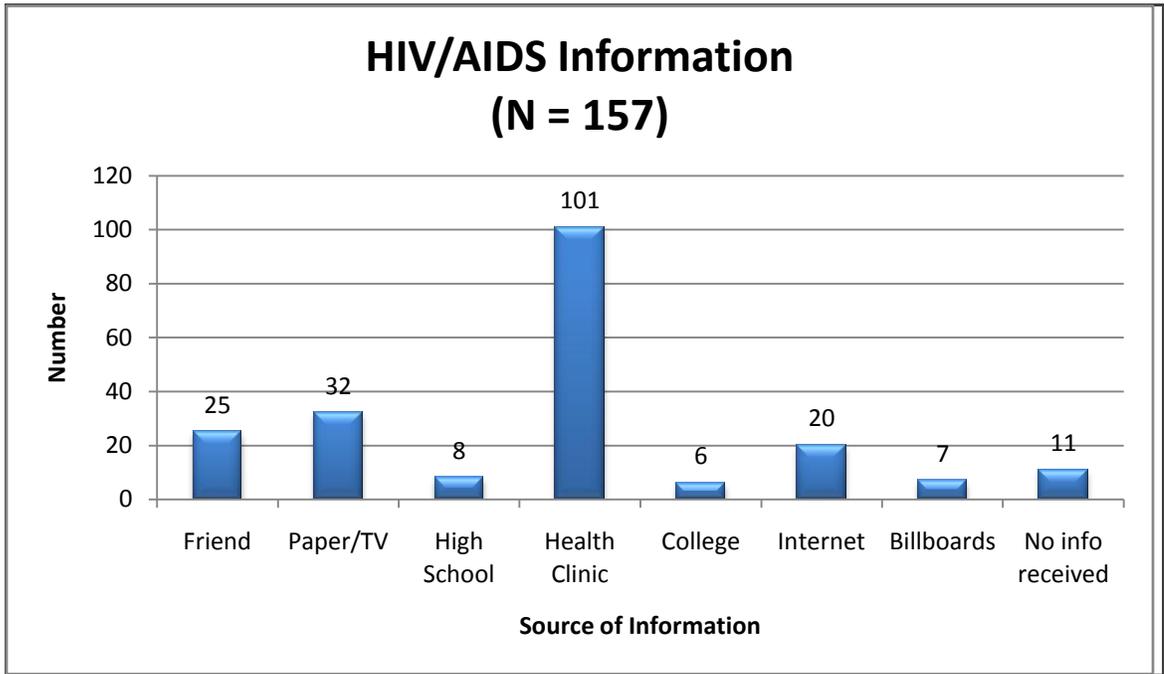
- 60.9% (n = 95) have had an HIV test previously;
- 33.3% (n = 52) had not; and
- 5.8% (n = 9) were uncertain whether or not they have had an HIV test.

Of those respondents receiving a previous HIV test, none of them reported testing positive.

HIV Test Information:

The following chart depicts where individuals reported receiving their HIV/AIDS information. Of 157 respondents, 64% received the majority of their HIV/AIDS health information from a health clinic.

Chart 2: HIV/AIDS Information Received

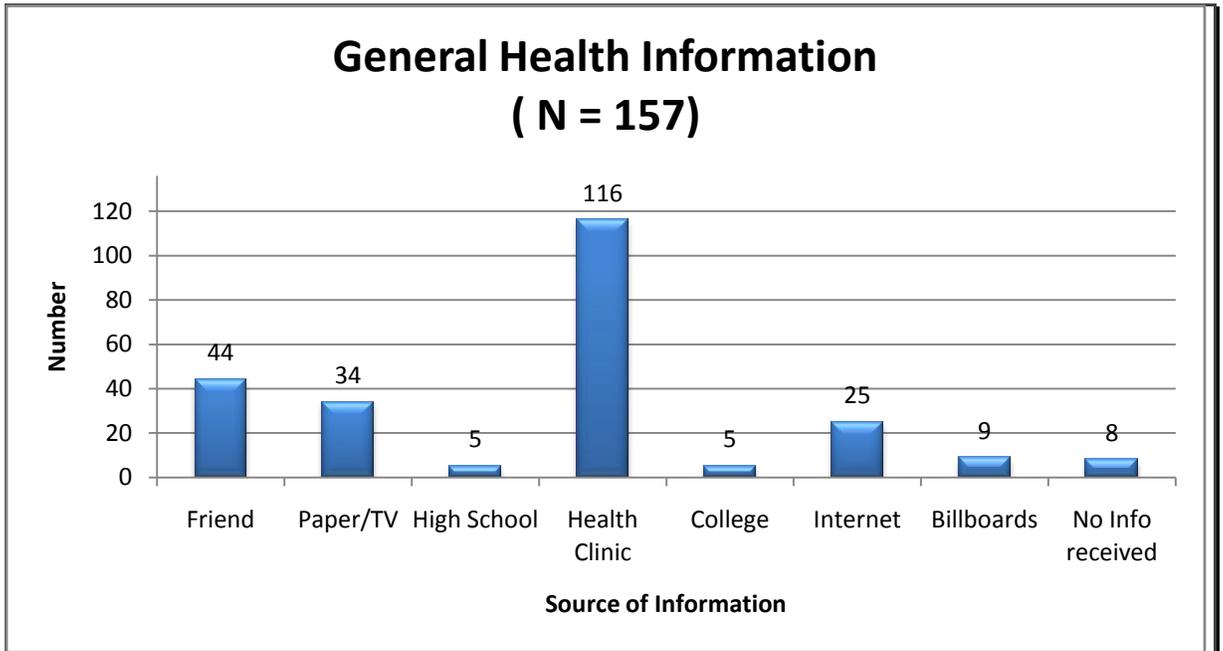


**Total will not equal n; respondents chose all that applied*

General Health Information:

The following chart depicts where individuals reported receiving their general health information, not specific to HIV/AIDS. Again, the majority of individuals (74%) received their general health information from health clinics.

Chart 3: General Health Information Received



*totals will not equal n; respondents chose all that applied.

Motivation to receive an HIV Test:

Individuals visiting the clinic for the purpose of having an HIV test were asked about their motivation for receiving the test. The table below depicts the motivations of 37 people who visited the clinic specifically for an HIV test. Respondents were asked to “check all that apply,” therefore the totals do not equal 100%.

Table 7: Motivation to receive HIV/AIDS test

Motivation Factor	Frequency (n=37)	Percent (%)
My partner has HIV/AIDS	0	0%
I am pregnant	2	.05%
My partner wanted me to test	1	.02%
I tested positive after giving blood	0	0%
I am getting paid to test	6	16.2%
Knowing my status helps me feel safe	17	45.9%
I had unprotected sex	14	37.8%
It is part of my yearly checkup	3	.08%
Moral support for another person testing	0	0

Risk Factors

The questionnaire assessed individuals for factors associated with an elevated risk of contracting the HIV virus. Questions were specifically concerned with individual's sexual partners, condom use, injection drug use, and other risky behaviors such as having sex while intoxicated. The following table details the majority of respondent's factors increasing their risk for HIV/AIDS. Total percentages are based on 157 respondents.

Table 8: Risk Factors for HIV/AIDS

Risk Factor	Males		Females		Total n (%)
	n (total)	Percent (%)	n (total)	Percent (%)	
Have you had vaginal, oral and/or anal sex	47 (60)	78.3%	77 (83)	92.7%	124 (86.7%)
Who do you primarily have sex with					
Men	1 (59)	1%	70 (79)	88.6%	71 (51%)
Women	58	98%	1	1%	59 (42.7)
Both, mostly men	0	0%	6	7.5%	6 (4%)
Both, mostly women	0	0%	2	2%	2 (1%)
Do you wear condoms while engaging in vaginal or anal sex	25 (58)	43%	40	50.6%	65 (47.5%)
Do you wear condoms while engaging in oral sex	36 (57)	63.2%	50 (72)	69.4%	86 (69%)
Have you had sex with someone you know is HIV positive	1 (59)	1.6%	2 (80)	2.5%	3 (2.9%)
Have you used injection drugs in the past 12 months	8 (62)	12.9%	7 (85)	8.2%	15 (10%)
Have you shared drug injection equipment	11 (61)	18%	8 (85)	9.4%	19 (13%)
Have you had sex while intoxicated	40 (68)	58.8%	46 (89)	51.7%	86 (54.8%)
Have you had sex with a transgender	1 (68)	1.4%	0 (89)	0%	1 (.6%)
Have you had sex with an IDU	18 (68)	26.5%	12 (89)	13.5%	30 (19.1%)
Have you had a sexual partner whom is infected with HIV/AIDS	0 (68)	0%	0 (89)	0%	0 (0%)
Have you had sex with an anonymous partner	18 (68)	26.5%	13 (89)	1.1%	31 (19.7%)
Have you traded sex for drugs or money	3 (68)	4%	4 (89)	1.1%	7 (4.5%)
Have you had sex with someone with an unknown HIV status	7 (68)	10.3%	5 (89)	5.6%	12 (7.6%)
None of the above	16 (68)	23.5%	37 (89)	41.6%	53 (33.8%)

Barriers to Testing

The questionnaire's main purpose was to assess the real and perceived barriers to receiving an HIV test among the Native American population here in Montana. The following table displays the barriers noted by 157 respondents.

Table 9: Real and Perceived Barriers to Testing

Barrier to Test	Men (N = 68) frequency (%)	Women (N = 89) frequency (%)
I am not at risk for HIV/AIDS	29 (42.6%)	39 (43.8%)
In a monogamous relationship	14 (20.6%)	14 (15.7%)
Fear of people finding out	11 (16.2%)	10 (11.2%)
I always practice safe sex	10 (14.7%)	10 (11.2%)
I usually practice safe sex	10 (14.7%)	11 (12.4%)
Too scared to get results of test	11 (16.2%)	5 (5.6%)
Too scared to get tested	7 (10.3%)	8 (9.0%)
Fear of discrimination	7 (10.3%)	8 (9.0%)
Not sure where to get tested	6 (8.8%)	10 (11.2%)
Afraid HIV test not confidential	6 (8.8%)	6 (6.7%)
Not important to me at this time	6 (8.8%)	5 (5.6%)
Insurance reasons	3 (4.4%)	6 (6.7%)
Fear of alienation from family	4 (5.8%)	4 (4.5%)
Fear of losing partner	2 (2.9%)	8 (9.0%)
Do not trust Health Department	6 (8.8%)	2 (2.2%)
It is a gay disease	5 (7.3%)	2 (2.2%)
No knowledge of HIV	3 (4.4%)	1 (1.1%)
I don't care	3 (4.4%)	2 (2.2%)
Fear of needles	2 (2.9%)	2 (2.2%)
No cure, why bother	1 (1.5%)	2 (2.2%)
Inconvenient clinic location/hours	1 (1.5%)	2 (2.2%)
Too long to wait for results	2 (2.9%)	3 (3.4%)
Test is too expensive	1 (1.5%)	1 (1.1%)
No AIDS in Montana	1 (1.5%)	0 (0%)
Fear of losing job if positive	0 (0%)	1 (1.1%)
I practice oral sex only	1 (1.5%)	1 (1.1%)

*respondents checked all that applied.

The most significant barrier noted from both male and female respondents (43% and 44% respectively) was not being at risk for HIV/AIDS.

Aside from “not being at risk for HIV” the next top five barriers for men included:

- Being in a monogamous relationship (21%);
- Fear of people finding out (16%);
- Too scared to get results (16%);
- Always practicing safe sex (15%); and

- Usually practicing safe sex (15%).

Aside from “not being at risk for HIV” the next top five barriers for women included:

- Being in a monogamous relationship (16%);
- Usually practicing safe sex (12%);
- Fear of people finding out (11%);
- Always practicing safe sex (11%); and
- Not being sure where to get tested (11%).

Open-Ended Question Results

The questionnaire provided open-ended questions to give respondents a chance to suggest ways in which clinics could make it easier for Native Americans to get tested for HIV/AIDS. From these responses, three themes emerged: 1) Confidentiality needs to be ensured and the clinic needs to have trustworthy workers; 2) Incentives and more cost-effective means to testing need to be provided; and 3) HIV/AIDS testing needs to be promoted on both the reservations in Montana as well as prominent urban areas. The following quotes depict the three themes.

Confidentiality

Confidentiality was the number one suggestion respondents discussed. Most respondents simply wrote the word “confidentiality”. Some, however, expanded on the issue and told why confidentiality surrounding testing was important:

- *“Confidentiality is a huge issue. Any town in MT is a fairly small community, smaller in Indian circles and you are bound to be related 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."

- *"Assure them results are confidential, paper shredder, etc."*
- *"Confidentiality, that's all!"*
- *"There needs to be satellite offices on the rez where folks can go w/o feeling fearful of being watched by "Big Brother" (I.H.S., authorities, etc.)."*
- *"More trust and less judgment. I won't go and get tested by a white person. They are prejudiced against Indians already, so if I was to be positive HIV/AIDS it would be 2X's as bad. The same goes for Hep C."*
- *"There has to be more anonymity involved. I don't think that tribal law and order should be able to see my records."*
- *"More anonymous places like [personal name omitted]. People you can trust".*

Incentives

Along with providing incentives, many respondents remarked about getting the rapid test technology to make testing easier, as well as providing the test during an annual exam to make it more accessible for those without, or limited insurance.

- *"Indians love free incentives! Nobody likes to pay but they love free stuff."*
- *"Funding to buy the testing equipment for the Oral swabs that only take 20 minutes for results"*
- *"Suggest payment options – costs, volunteers, donations"*
- *"Offer it for free or ask during annual exams or physicals"*

- *“Provide gas money”*
- *“[Make it available] for those who have no health insurance, some of us can not do a lot like we would.”*

HIV/AIDS Testing Promotion

One of the most common suggestions provided by respondents was the need to promote HIV testing as to where and when testing was provided, and who needs to be tested. Feedback was also provided as to how clinics and health departments might promote this information.

- *“Have a health fair including HIV testing w/ the quick results and offer it to high school kids.”*
- *“Need to make people more aware of their options!”*
- *“There needs to be more TV ads, magazine ads, etc. for Indian Country.”*
- *“Post notes and Fliers at the Universities 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.”*
- *“Educate community on what it is and finding a Native American Outreach person who is trustworthy.”*
- *“Offer it more when your annual exam comes along and promote it more.”*
- *“I think you need more promotional ads describing risks that are taken by having unprotected sex.”*

HIV Counseling and Testing Intake Form Results

HIV Counseling and Testing Intake Forms were developed by the Centers for Disease Control (CDC) in 1990 to collect counseling and testing data which are used to facilitate program monitoring and evaluation at the local, state and national levels (USDHHS, 2008b). Montana collects test-level HIV data from these forms which are submitted directly to a CDC database via scanning software. Three main sections included on the forms were utilized: 1) client demographics; 2) HIV testing information including specific test technology, HIV test specimen type, as well as test results; and 3) client risk factors.

All HIV Counseling and Testing Intake Forms submitted by testing sites to the state in 2007 were made available to the researchers by the HIV/STD Section of Montana Department of Public Health and Human Services. All forms indicating Native American as “race” were sorted and used to extract demographic and risk behavior information of Native Americans who received an HIV test from state-funded HIV testing sites.

Examination of the intake forms revealed from January 1, 2007 thru December 31, 2007 approximately 992 individuals who received an HIV test indicated Native American as their race. Following are the results from analysis of the 992 forms.

Basic Demographics

Gender:

- 52.6% (n = 521) were male; and
- 47.4% (n = 469) were female.

Two respondents chose not to respond and were not used in analysis.

Race:

- 90% (n = 893) reported race as American Indian/Alaska Native; and
- 10% (n = 98) reported being of mixed race which included American Indian/Alaska Native.

Age:

961 of the total 992 respondents reported age. A total of 31 respondents did not report their age. Of the 961:

- Age ranged from 14 years old to 78 years old.
- The mean age reported was 32 years old; the most frequent reported age was 26 years old.

The following table depicts reported age ranges, frequencies and percentages.

Table 10: HIV C&T Ages

Ages	Frequency (n)	Percent (%)
14 to 19	133	13.8%
20 to 29	367	38.2%
30 to 39	212	22.1%
40 to 49	166	17.3%
50 to 59	71	7.4%
60 to 69	10	1.0%
70 to 79	2	.2%
TOTAL	961	100%

Residence:

The majority (n = 979; 99.1%) of respondents were residents of Montana. There were nine (9) other testers who came from different states:

- Wyoming and Washington each had one (.1%) resident test here in Montana;

- Alaska and California each had two (.2%) residents test in Montana; and
- Three (.3%) individuals who tested here in Montana were from Arizona.

The following table depicts 18 of 56 total Montana counties represented by individuals who received an HIV test at a state-funded health clinic. Of the total 992 tests, 590 respondents chose to answer this question.

Table 11: Montana Counties represented from HIV C&T Forms

County	Frequency (n)	Percent (%)
Beaverhead	3	.5
Bighorn	43	7.3%
Cascade	5	.8%
Custer	14	2.4%
Dawson	2	.3%
Fergus	1	.2%
Gallatin	2	.3%
Garfield	5	.8%
Glacier	169	28.6%
Hill	3	.5%
Jefferson	1	.2%
Lake	209	35.4%
Lewis and Clark	7	.1.2%
Mineral	1	.2%
Missoula	52	8.8%
Roosevelt	3	.5%
Rosebud	4	.7%
Yellowstone	66	11.2%
TOTAL	590	100%

Risk Factors

The HIV Counseling and Testing forms ask individuals to identify behaviors which might increase their risk for contracting HIV/AIDS. Identification of risk factors included an analysis of 992 forms.

There were a total of 521 men and 469 women, for a total of 990 individuals who reported risk factors used for analysis. Two forms were not used for analysis because

gender was not reported. The majority of individuals, both males and females (53%, n = 521), reported having sex with a person of unknown HIV status as the biggest risk factor for HIV/AIDS. Having sex with a person of unknown HIV status and having sex while intoxicated and/or high on drugs were reported the second and third largest risk factor at 53% and 49% of individuals reporting, respectively.

The following table depicts the response rate and percentage for both males and females for each risk factor asked.

Table 12: Risk Factors of Male and Females from HIV C&T Forms

Risk Factors	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 IDU	19%	97	25%	115	21%	212
Injection Drug Use (IDU)	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
Sex with a person who is a known MSM	1%	7	6%	30	4%	37
Sex with a person who is HIV positive	4%	22	2%	10	3%	32
Sex with a partner who is a hemophilia or transfusion/transplant recipient	1%	7	.8%	4	1%	11
Sex (vaginal or anal) with Transgender	.1%	6	.6%	3	.9%	9
Not asked risk factors	0%	0	.2%	1	.1%	1
Refused to report risk factors	0%	0	0%	0	0%	0

Testing Information

Month Testing Occurred:

The following table depicts a count by month of the number of HIV tests received by Native Americans at Montana state-funded HIV testing sites throughout the year 2007. A total of 992 tests were used for analysis. The months of November and December had the most tests conducted with a total of 107 and 105, respectively.

Table 13: Testing Counts by Month

Month	Frequency (n)	Percent (%)
January	72	7.3
February	66	6.7
March	88	8.9
April	103	10.4
May	79	8.0
June	68	6.9
July	103	10.4
August	60	6.0
September	62	6.2
October	79	8.0
November	105	10.6
December	107	10.8
TOTAL	992	100%

Agencies Testing for HIV/AIDS:

There are a total of 18 state funded HIV testing sites throughout the state of Montana. The following table depicts a count of how many HIV/AIDS tests were completed for Native Americans for 17 HIV testing sites in the year 2007. Of the 992 Native American HIV testing forms available for analysis, 756 (76%) forms reported testing site.

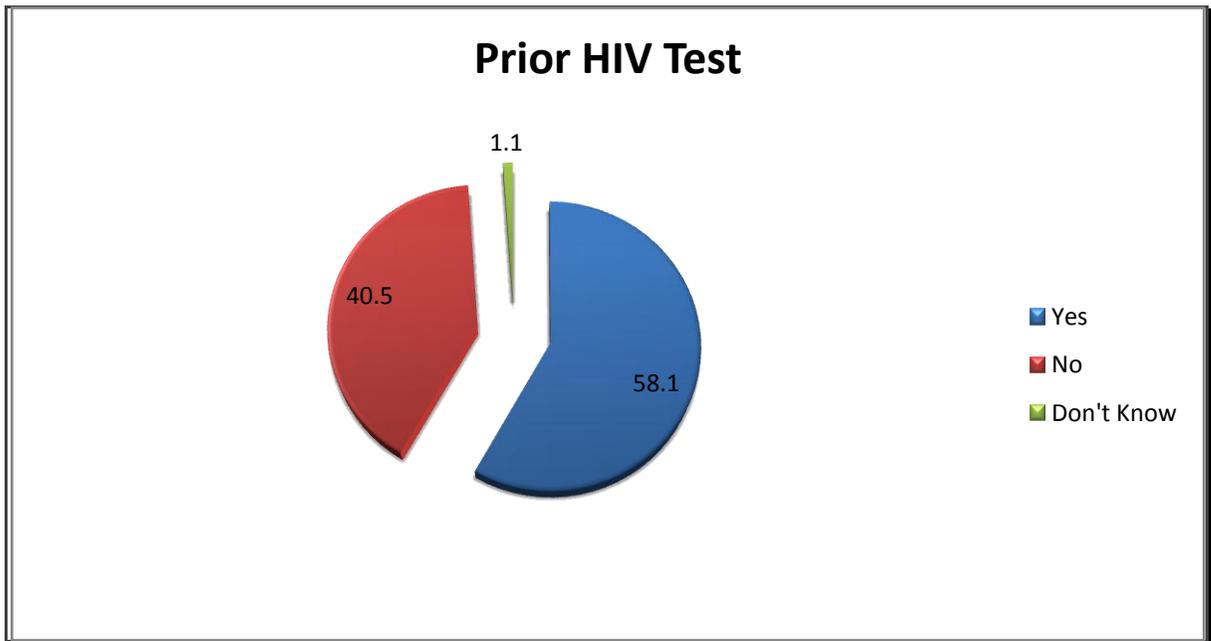
Table 14: HIV Testing Sites Represented on HIV C&T Forms

Agency	Frequency (n)	Percent (%)
Salish Kootenai College	248	32.8%
Riverstone Health	140	18.6%
Cascade City-County Health Department	135	17.9%
Yellowstone AIDS Project	102	13.4%
FDH	40	5.3%
Butte-Silverbow City-County Health Department	28	3.7%
MCDC	20	2.6%
Missoula AIDS Council	9	1%
Missoula Indian Center	7	.9%
Fort Belknap Tribal Health	5	.7%
Hill County Health Department	5	.7%
Bridger Clinic	4	.5%
Flathead City-County Health Department	4	.5%
Central Montana Family Planning	3	.4%
Dawson County Health Department	3	.4%
Lewis and Clark City-County Health Department	2	.3%
Connections	1	.1%
TOTAL	756	100%

Prior HIV/AIDS Test:

The following chart displays prior testing behavior for 984 (99%) of the 992 HIV C&T forms used for analysis. A total of 8 respondents did not respond to this question.

Chart 4: Respondents Prior HIV Testing Habits



- 572 (58.1%) individuals had received a previous HIV test;
- 399 (40.5%) had not received an HIV test previously;
- 11 (1.1%) did not know whether they had received a prior HIV test; and
- 2 (.2%) of individuals were not asked about previous testing habits.

Technology of HIV/AIDS Test:

Of the 992 HIV C&T forms used for analysis, 976 reported which technology was used to perform the HIV test:

- 92% (919) of tests were rapid testing; and
- 5.7% (57) of testing used conventional testing methods.

Incentives for Individuals to Test:

Of the 975 total forms that had checked whether or not an incentive was given to receive the HIV/AIDS test:

- 516 (53%) had received an incentive for testing; and
- 459 (47%) had not received an incentive to test.

The following table depicts state-funded HIV testing sites and the numbers of incentives used for testing and the percentage of total tests completed at each site. To be included in analysis the form had to include both agency and incentive; a total of 742 forms included both requirements.

Table 15: Incentives Provided According to HIV Testing Sites

Agency	Incentive (%)	No Incentive (%)	Total
Salish Kootenai College	239 (98.8%)	3 (1.2)	242
Riverstone Health	21 (15.4%)	116 (84.7%)	137
Cascade City-County Health Department	2 (1.5%)	133 (98.5%)	135
Yellowstone AIDS Project	53 (52.5%)	49 (48.5%)	102
FDH	13 (33.3%)	26 (66.7%)	39
Butte-Silverbow City-County Health Department	0 (0%)	27 (100%)	27
MCDC	4 (23.5%)	13 (76.5%)	17
Missoula AIDS Council	2 (25%)	6 (75%)	8
Missoula Indian Center	0 (0%)	7 (100%)	7
Fort Belknap Tribal Health	5 (100%)	0 (0%)	5
Hill County Health Department	0 (0%)	5 (100%)	5
Bridger Clinic	1 (25%)	3 (75%)	4
Flathead City-County Health Department	0 (0%)	4 (100%)	4
Central Montana Family Planning	0 (0%)	3 (100%)	3
Dawson County Health Department	0 (0%)	2 (100%)	2
Lewis and Clark City-County Health Department	0 (0%)	2 (100%)	2
Missoula City-County Health Department	0 (0%)	2 (100%)	2
Connections	0 (0%)	1 (100%)	1
TOTAL	340	402	742

Epidemiological Data Results

Epidemiological data was provided by the HIV/STD Section of the Montana Department of Public Health and Human Services (MDPHHS). Data was used to describe the population of Native Americans who are currently infected with HIV in the state of Montana, including the demographic characteristics as well as risk behaviors. As of June 30, 2008, a total of 870 cases of Human Immunodeficiency Virus (HIV) and Acquired Immune Deficiency Syndrome (AIDS) have been reported to MDPHHS. Of those reported cases, 63 are cases among American Indian/Alaska Native or mixed race American Indians. Trends in HIV cases were reported from 1985 through June 2008. Following are the results from analysis of this information.

Cumulative Cases since 1983

Basic Demographics

Cumulative reported HIV/AIDS cases, which include cases newly diagnosed in Montana as well as cases diagnosed out of state but currently living in Montana, show 63 Native American cases infected with HIV, with 53 (84%) of cases having progressed to AIDS. The vital status of the reported 63 cases show 33 (52%) alive and 30 (48%) deceased.

Age and Gender:

Of the 63 cumulative HIV/AIDS Native American cases reported in Montana (1983-2007), age and gender distribution is as follows:

Table 16: Age at Diagnosis, Cumulative Cases

Age	Frequency (n)	Percent (%)
Under 5	2	3
15 – 24	13	21
25 – 44	38	60
45 – 64	9	14
Over 64	1	2
TOTAL	63	100%

Gender:

- 71% (n = 45) of cases were male; and
- 29% (n = 18) of cases were female.

Residence:

The following table depicts the 15 of 56 counties represented by individuals who reported positive with HIV/AIDS since 1983.

Table 17: County of Residence at time of Positive Report, Cumulative Cases

County of Residence at time of Report	Frequency (n)
Bighorn	8
Cascade	7
Custer	<5
Dawson	<5
Flathead	<5
Glacier	<5
Hill	<5
Lewis and Clark	<5
Missoula	9
Phillips	<5
Powell	5
Roosevelt	7
Rosebud	<5
Silverbow	<5
Yellowstone	11
Unknown	<5

* Total number will not equal the 63 known cases since cumulative cases depict county of residence at the time of reporting not current residence.

Risk Factors: Mode of Exposure

The following table depicts the mode of exposure for HIV/AIDS for cumulative cases since 1983 among the Native American/Alaska Native or Mixed Native American population in Montana.

Males represent the largest number of cases, with MSM representing the highest percentage of cases.

Table 18: Mode of exposure, Cumulative cases

Mode of Exposure	Male (n = 45)	Female (n = 18)
Men who have sex with Men (MSM)	16	n/a
Injection Drug User (IDU)	11	<5
MSM & IDU	10	n/a
Other/Risk not Specified	<5	10
High Risk Heterosexual (HRH) Sex	7	5
TOTAL	44-48*	15-19*

**If frequencies include totals <5, totals are approximate*

Living Cases since 1983

Basic Demographics

As of June 30, 2008, 33 Native Americans living in Montana were infected with HIV/AIDS. Prevalent HIV/AIDS cases, which include cases newly diagnosed in Montana as well as those cases diagnosed out of state but currently living in Montana, show that of the 33 living cases, (79%) are currently living with AIDS.

Age and Gender:

Of the 33 living cases reported in Montana, age and gender distribution is as follows:

Table 19: Age at Diagnosis, Living Cases

Age	Frequency (n)	Percent (%)
Under 5	<5	*
15 – 24	7	21%
25 – 44	19	58%
45 – 64	6	18%
Over 64	<5	*
TOTAL	33	100%

*If frequency count is <5, percentage can not be calculated.

Gender:

- 67% (n = 22) of cases are male; and
- 33% (n = 11) are female.

Residence:

The following table depicts 11 of 56 counties represented by Native Americans who are currently living with HIV/AIDS in the state of Montana. The counties represent where individuals reported positive, not their current county of residence.

Table 20: County of Residence at time of Report, Living Cases

County of Residence at time of Report	Frequency (n)
Bighorn	5
Cascade	<5
Dawson	<5
Flathead	<5
Glacier	<5
Missoula	8
Powell	<5
Roosevelt	<5
Rosebud	<5
Yellowstone	8
Unknown	<5
Total	33

Risk Factors: Mode of Exposure

The following table depicts the mode of exposure for HIV/AIDS for living cases since 1983 among the Native American/Alaska Native or Mixed Native American population in Montana.

Table 21: Mode of Exposure, Living Cases

Mode of Exposure	Male (n = 22)	Female (n = 11)
Men who have sex with Men (MSM)	10	n/a
Injection Drug User (IDU)	5	<5
High Risk Heterosexual (HRH) Sex	<5	7
MSM & IDU	<5	n/a
Other/Risk not Specified	<5	<5
TOTAL	15-27*	7-15*

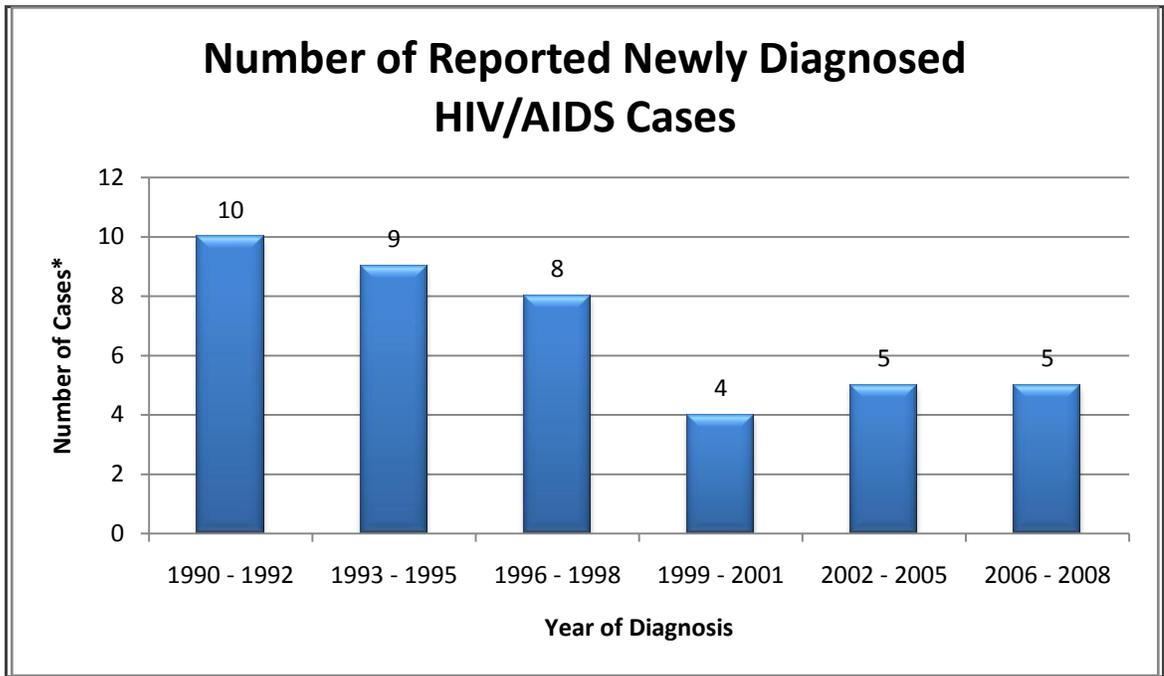
*If frequency is <5 totals are approximate

Trends from 1983 through June 2008

There have been 47 newly diagnosed HIV/AIDS cases among Native Americans since 1985, and 41 since 1990. The rate of newly diagnosed HIV/AIDS cases among Native Americans in Montana has been decreasing as the following charts show.

The following charts depict the Number of reported HIV/AIDS cases by mode of exposure, sex, age, and the number of newly diagnosed HIV cases progressing to AIDS in less than one year.

Chart 5: Number of Reported Newly Diagnosed HIV/AIDS Cases since 1990



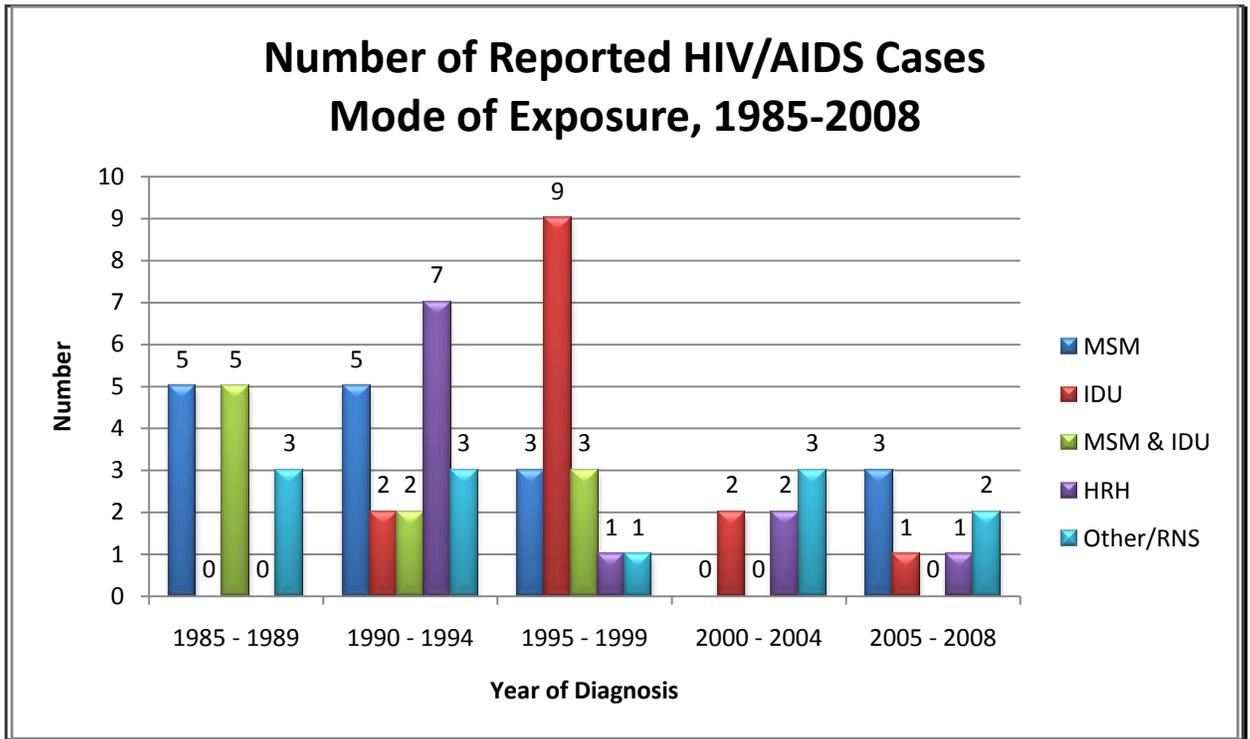
*Rate per 100,000 population

Number of reported HIV/AIDS cases by mode of exposure from 1985 to 2008:

There has been a decline for each three year period for every mode of exposure since 1985 to June 2008 except MSM, in which there was an increase of three positive cases.

- There were zero (0) positive HIV/AIDS reported cases for the years 2000 to 2004; and
- There were three (3) positive HIV/AIDS cases reported in the three year period from 2005 to 2008.

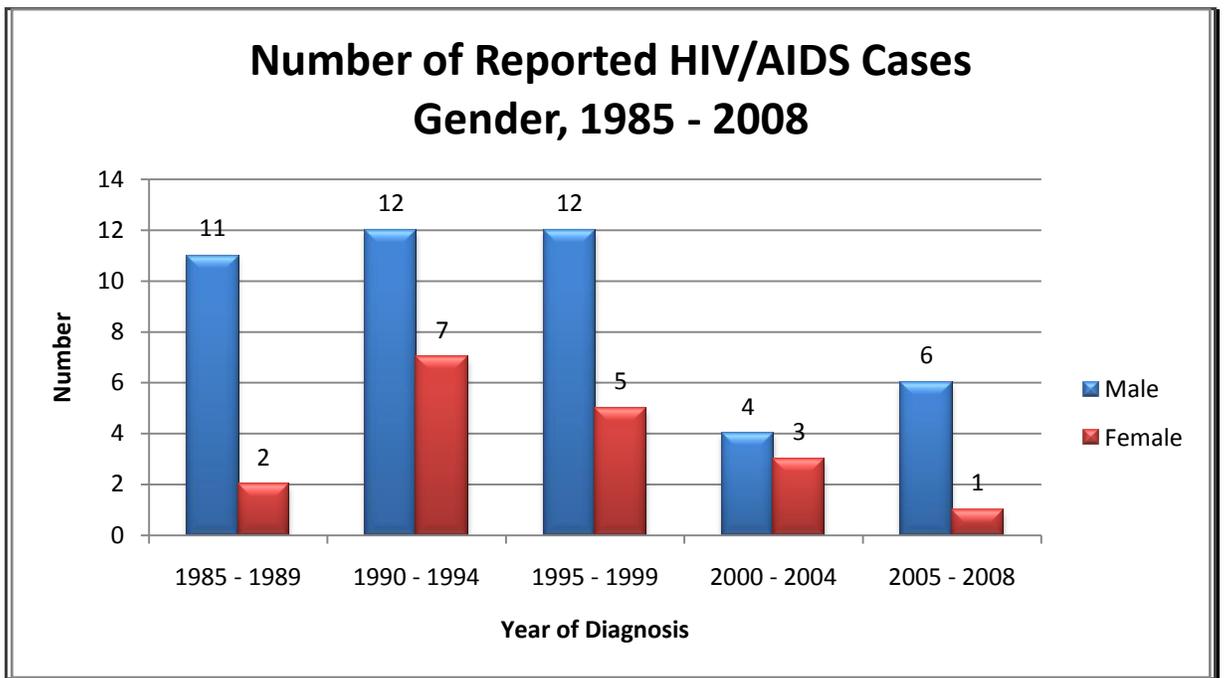
Chart 6: Number of Reported HIV/AIDS Cases by Mode of Exposure since 1985



Number of reported HIV/AIDS cases by sex from 1985 to 2008:

The rate of reported positive HIV/AIDS cases declined in each four year period since 1994 for both males and females until the period from 2004 to 2008, which shows a slight increase in male cases; from 4 reported from 2000 through 2004 to 6 positive reported cases in 2004 to 2008.

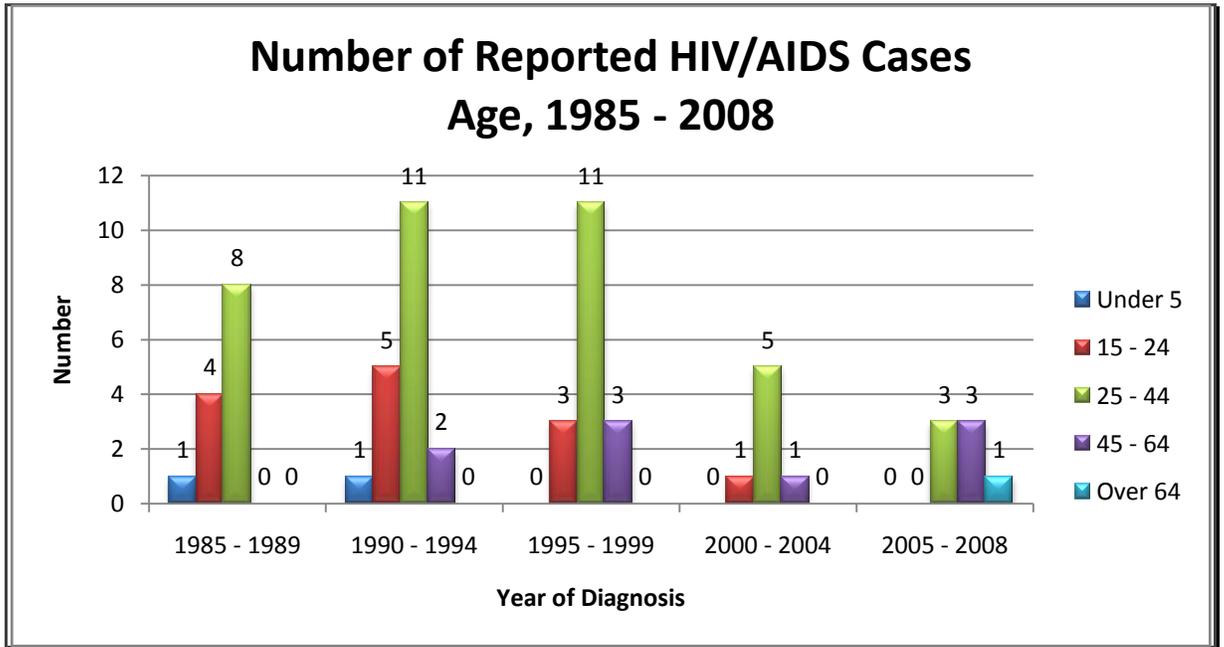
Chart 7: Number of Reported HIV/AIDS Cases by Gender since 1985



Number of reported HIV/AIDS cases by age from 1985 to 2008:

There was a decline in reported cases in each four year period for all age groups until an increase among individuals aged 45 and over in the most recent years from 2004 to 2008. There were 2 more cases reported from the year 2004 thru 2008 and 1 case reported for the first time since reporting began in 1985 with an individual over the age of 64. The number of positive reported cases in individuals under age 5 has been completely eradicated here in Montana since the early 90s.

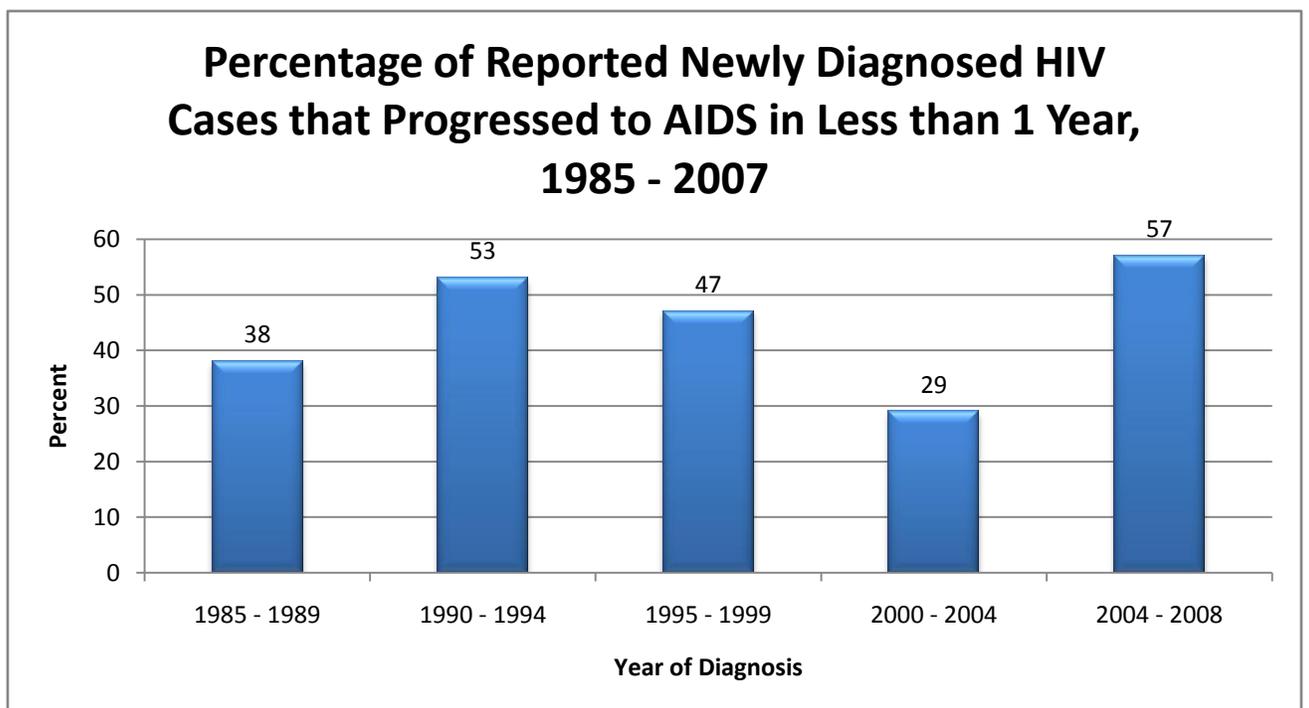
Chart 8: Number of Reported HIV/AIDS Cases by Age since 1985



Percentage of reported Newly Diagnosed HIV cases that progressed to AIDS in less than 1 year from 1985 to 2007:

Newly diagnosed HIV Cases among Native Americans that have progressed to AIDS in less than 1 year has increased since the years 2000 to 2004 by almost 30%.

Chart 9: Percentage of Reported Newly Diagnosed HIV Cases that Progressed to AIDS in less than 1 year



Behavioral Risk Factor Surveillance System Results

The Behavioral Risk Factor Surveillance System (BRFSS) data for the year 2007 was obtained in order to determine the approximate number of Native Americans who reported having been tested at all testing sites, whether public or private, in the state of Montana. The Montana BRFSS uses a disproportionate stratified random sampling design (DSS). Using the DSS design, telephone numbers are classified into strata that are either high density or medium density to yield residential numbers. This ensures high density strata are sampled at the highest rate. BRFSS data are also weighted to account for the probability of selection and post-stratified by age and gender to account for non-coverage and non-response rates.

In 2007, American Indians comprised approximately 6% of the adult Montana population. The MTBRFSS slightly oversampled AI/AN to ensure the weighted frequencies approximate the population proportion. There are a total of three questions within the BRFSS regarding HIV testing. Respondents include individuals aged 18 to 64 years of age. Total respondents for each question are listed separately.

The following tables and charts depict this analyzed information.

Question 1: Have you ever been tested for HIV? Do not count tests you may have had as part of a blood donation. Include testing fluid from your mouth.

- The percentages for both whites and Native Americans are similar; the majority of individuals have not been tested for HIV in the past.

Chart 10: Past Testing Habits, White Population

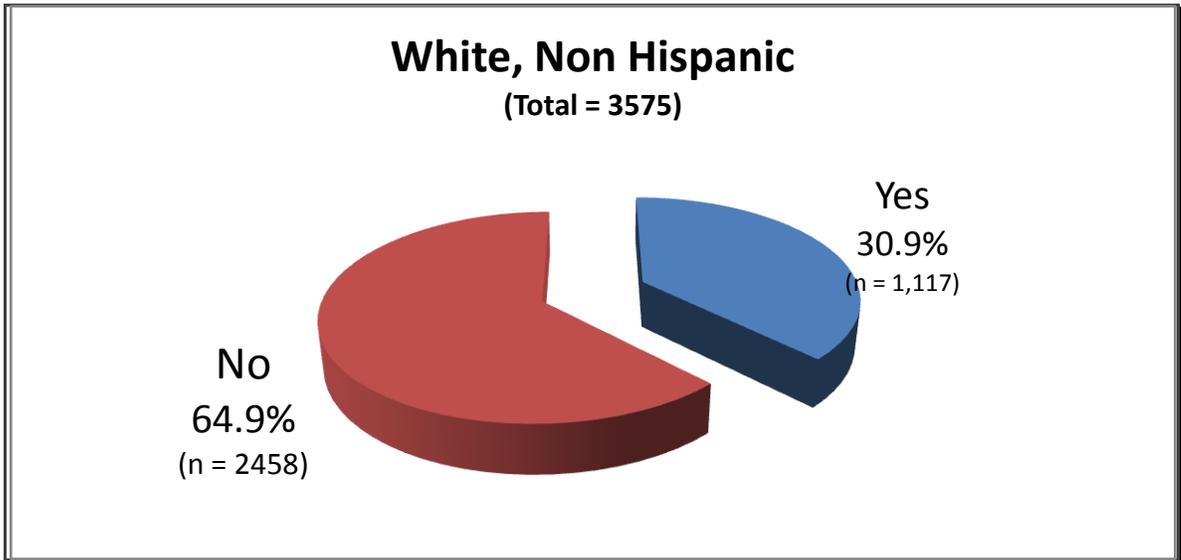
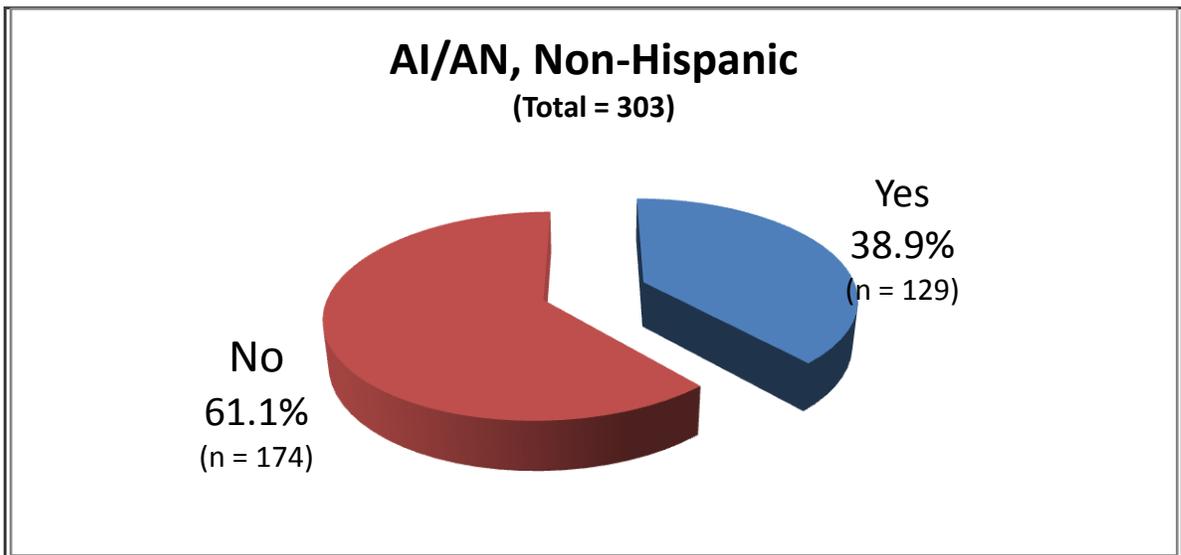


Chart 11: Past Testing Habits, Native American Population



Question 2: Where did you have your last HIV test?

- | | |
|--|---------------------------------------|
| <i>A private doctor or HMO office?</i> | <i>A counseling and testing site?</i> |
| <i>A hospital?</i> | <i>A clinic?</i> |
| <i>A jail or prison?</i> | <i>A drug treatment facility?</i> |
| <i>At home?</i> | <i>Somewhere else?</i> |

- Results are displayed for a total of 1099 White, Non Hispanic respondents and 128 AI/AN. Responses are ordered according to top responses from AI/AN individuals.

Table 22: Location of Previous HIV test, White and Native American Populations

HIV Testing Site	White, Non Hispanic		American Indian or Alaska Native	
	%	n	%	n
Clinic	29%	297	32.4%	49
Hospital	17.1%	203	28.8%	35
Private Doctor or HMO	29.6%	347	18.9%	20
Drug Treatment Facility	1.7%	13	8.7%	10
Somewhere Else	12%	123	4.1%	7
Counseling and Testing Site	4.9%	48	3.9%	3
Jail or Prison	.7%	6	2.2%	3
At Home	5.2%	62	1%	1
Total	100%	1099	100%	128

Question Three: Was it a rapid test where you could get your results within a couple of hours?

- Total respondents include 158 White, Non Hispanic individuals and 29 AI/AN individuals. The majority of respondents in both populations did not receive a rapid HIV test.

Table 23: Previous Test Type, White and Native American Populations

Rapid Test	White, Non Hispanic		American Indian or Alaska Native	
	%	n	%	n
Yes	18.6%	30	19%	8
No	81.4%	128	81%	21
Total	100%	158	100%	29

CHAPTER V

Introduction

The HIV/AIDS epidemic has been one of the defining features of the past quarter of a century. In the United States alone, at the end of the 2006 over one million people have been infected with HIV (USDHHS, 2007a). An increasing number of infections are occurring in minority populations (NASTAD, 2008). Among many minority populations in the U.S. there is a lack of information regarding the impact HIV/AIDS has on their community. This lack of information is particularly evident among Native Americans. Increasing efforts to build awareness regarding the health discrepancies and the unique issues and challenges regarding Native Americans have become a priority (NASTAD, 2008).

Nationwide, the relatively low numbers of reported HIV/AIDS cases among Native Americans belies the many factors that put them at increased risk for infection. Duran and Walters (2004) describe behavioral factors such as low levels of condom use, escalating rates of injection drug use and excessive drinking that put Native Americans at high risk of HIV infection. These behavioral factors, combined with obvious health disparities regarding HIV/AIDS education, available services and awareness among the Native American community in rural states (NASTAD, 2008; Hamill, Dickey, 2005) indicate a likelihood of high rates of infection among Native Americans. Despite the indicators of risk, rates of HIV among Native Americans are not dramatically higher than Whites. At a case rate of 8.8 per 100,000, Native American rates are similar to White

case rates of 8.2 per 100,000 and represent significantly fewer cases than Blacks and Hispanics with case rates of 67.7 and 25.5 respectively (NASTAD, 2008; USDHHS, 2007a).

Surgeon General, David Satcher, in his call for action on the HIV/AIDS crisis in the Native American communities stated many health professionals estimate the number of AIDS cases among Native Americans to be much higher than what statistics are currently reporting, and the actual number of HIV cases could be as much as 10 times greater (Satcher, 2000). Misclassification of race and underreporting of HIV testing were cited as possible reasons national statistics regarding the population might be skewed (Hamill, Dickey, 2005). In light of the high prevalence of risk factors within the population it is reasonable to assume that misclassification and underreporting are plausible explanations for the relatively low number of reported HIV infections among Native Americans. However, in rural states like Montana, with a high population of Native Americans and limited resources for HIV prevention, it is important to base decisions about resource distribution on more than assumptions.

Unfortunately, in Montana there is a paucity of information regarding the effect of HIV on Native American communities. Epidemiologic information about Native Americans living with HIV and AIDS provides some insight into the epidemic. There is, however, a need for more comprehensive information. The purpose of this study, therefore, was to provide a more accurate picture of HIV infection among Native Americans living in Montana and to describe the epidemic in more detail.

Methods

In order to construct a more in-depth picture of the effects of HIV among Native Americans living in Montana several sources of data were examined. First, Behavioral Risk Factor Surveillance System (BRFSS) data for 2007 was obtained. The BRFSS provided information regarding approximate numbers of individuals reporting previous testing behaviors at all HIV testing sites in Montana, both public and private. Second, Montana epidemiological records regarding Native Americans infected with HIV/AIDS were examined. Because of the low number of cases in this population, incidence and prevalence data was grouped into 2 to 4 year periods and 9 to 12 year trends were explored. Third, HIV Counseling and Testing Forms were obtained from the HIV/STD section of the Montana Department of Public Health and Human Services for the year 2007. An approximate total count of Native Americans tested for HIV was obtained, as well as characteristics of Native Americans receiving an HIV test such as age, gender, risk behaviors, and county of residence. Fourth, data related to barriers to testing were obtained from questionnaires distributed at two distinct testing sites.

The two populations assessed at the sites through the questionnaire included Native Americans receiving either an STD and/or HIV test at one of four state funded public HIV testing sites and Native Americans receiving general health care at one of five Urban Indian Centers. Information from the questionnaires was used to describe basic demographics, risk factors for HIV infection, motivations to receiving an HIV test, and barriers to receiving an HIV test. A synthesis of information from all four data sources is

provided. Key findings are discussed and recommendations for future research are offered.

Data Analysis

Secondary data gathered from the standardized Counseling and Testing Intake forms were entered into the SPSS database for Windows. The demographic characteristics, and risk behaviors as reported by Native Americans seeking services at specific MTDPPHS funded sites are reported by actual count and percentage. Primary data from the self-report questionnaire was also entered into the SPSS database for Windows. The demographic characteristics, risk behaviors, and barriers to HIV C&T as reported by Native Americans seeking services at specific MTDPPHS funded sites and Urban Indian Centers in Montana are reported descriptively. Epidemiologic and BRFSS data was used to supplement the HIV C&T data to provide a more comprehensive picture of the incidence and prevalence of HIV/AIDS among Montana's Native Americans and their HIV testing behaviors.

Results

Primary Data

Questionnaire Results

A total of 275 questionnaires were distributed among the nine sites. Of those 275, 157 were completed and valid, for a return rate of 57%. Four questionnaires were removed from the analysis because they did not meet the age criteria of being over 18 years of age.

Demographic characteristics:

Females (n = 89) returned the questionnaire at a slightly larger percentage than males (n = 68). Ages ranged from 18 to 75 years of age, with the largest represented age group being 45 years of age or older (37%). Of the total respondents, 90% reported being heterosexual. All seven tribes were represented by respondents.

Risk Behaviors:

In general, 66% of respondents reported having a least one risk factor placing them at a higher risk for HIV infection. Of the factors placing an individual at the greatest risk for HIV, the largest percentage of respondents (55%) of both males and females reported having sex while intoxicated. The remaining top 4 high risk behaviors included:

- 19% report having sex with an IDU;
- 13% have shared IDU equipment in the last year;
- 10% report being an IDU; and
- Only 1% of males reported being MSM.

Barriers reported:

The questionnaires main purpose was to assess both real and perceived barriers to getting tested for HIV in Montana. Barriers reported among both males and females were similar. The top 5 responses include:

- 43% reported not being at risk for HIV;
- 18% reported being in a monogamous relationship;
- 14% reported usually practicing safe sex;
- 14% reported fearing other individuals would find out results;

- 13% reported always practicing safe sex.

Motivation for testing:

Thirty-seven individuals who visited the public health clinics and completed the Questionnaire assessing barriers reported the purpose of their visit was to receive an HIV test. Those individuals were asked to report their motivation for seeking an HIV test. The three most frequent responses are listed in the table below.

Table 24: Motivation for Testing

Motivation for Testing	Number	Percent
I am getting paid to test	6	16.2%
I had unprotected sex	14	37.8%
Knowing my status helps me to feel safe	17	45.9%

Secondary Data

HIV Counseling and Testing Intake Forms Results

Examination of the intake forms revealed from January 1, 2007 thru December 31, 2007 approximately 992 individuals who received an HIV test indicated Native American as their race.

Demographics:

Males tested at a slightly higher percentage than women, with 53% of males and 47% of females testing at state funded testing sites in 2007. Ages ranged from 14 to 78 years of age. The mean age of testers was 32, while the most frequently reported age was 26. Of all respondents, 58% had previously tested for HIV in the past.

Risk Behaviors:

Only 10% of testers reported not having any risk factor for HIV, 90% of testers had participated in one or more risk behavior placing them at a higher risk for HIV infection. The majority of individuals, both males and females (53%, n = 521), reported having sex with a person of unknown HIV status as the biggest risk factor for HIV/AIDS. Having sex with a person of unknown HIV status and having sex while intoxicated and/or high on drugs were reported the second and third largest risk factor at 53% and 49% of individuals reporting, respectively.

Behavioral Risk Factor Surveillance System Results

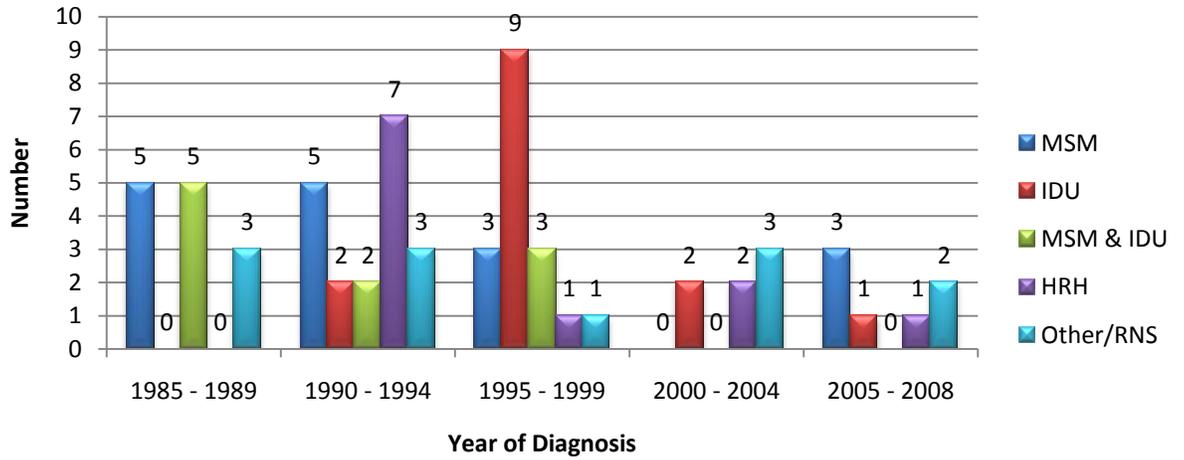
The Behavioral Risk Factor Surveillance System (BRFSS) data for the year 2007 was obtained in order to determine the approximate number of Native Americans who reported having been tested at all testing sites, whether public or private, in the state of Montana. Thirty percent of Whites reported being tested in a private doctor or HMO office, while 32% of Native Americans report being tested in a public clinic.

Epidemiological Data Results

As of June 30, 2008, a total of 870 cases of Human Immunodeficiency Virus (HIV) and Acquired Immune Deficiency Syndrome (AIDS) have been reported to MDPHHS. Of those reported cases, 63 are cases among American Indian/Alaska Native or mixed race American Indians. Of the 63 reported cases, 33 are currently living. The following charts report trends in the cases of HIV/AIDS in Montana since 1983.

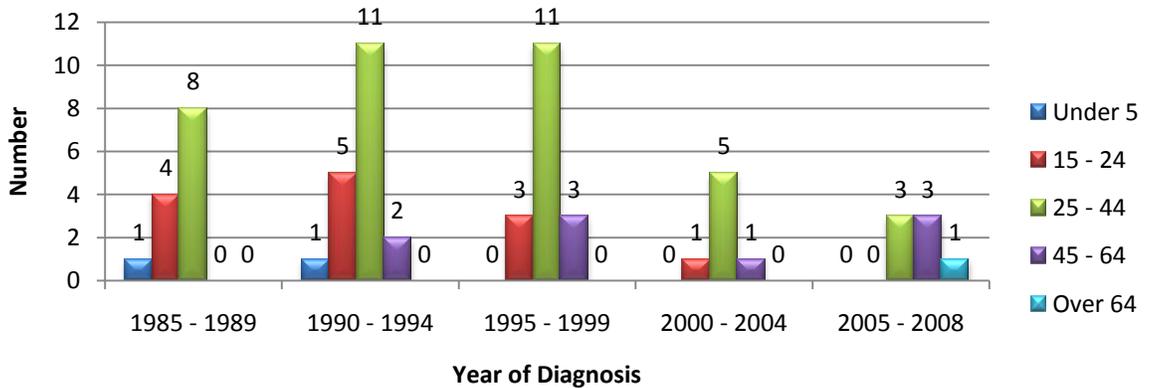
There has been a decline each year for every mode of exposure since 1985 to June 2008 except MSM, in which there was an increase of three positive cases.

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



There was a decline in reported cases each year for all age groups until an increase of 2 cases aged 45 and over in the most recent years from 2004 to 2008. There was 1 case reported for the first time since reporting began in 1985 over the age of 64.

Number of Reported HIV/AIDS Cases Age, 1985 - 2008



Discussion

Prevalence of HIV among Native Americans in Montana

Since reporting first began in Montana in 1985 there have been few, if any, significant changes in regard to HIV/AIDS case rates as well as the demographic characteristics and risk behaviors of Native Americans infected with HIV/AIDS. American Indians represent approximately 6% of our population and represent 7% of the HIV/AIDS cases reported (Epidemiologic Report, 2008/2004). The fact HIV/AIDS does not appear to have had a disproportionate impact on Montana’s American Indian population at the present time is somewhat surprising given other markers of potential HIV risk, such as the increase in both teen pregnancies and other sexually transmitted disease rates like Hepatitis C, suggest an increased level of risk among American Indians when compared to non-Indian populations. Epidemiologic reports, however, indicate that incidence and prevalence of HIV in the population has remained relatively constant. A comparison of cumulative cases (1985 to 2008) to current living cases (2008) reveals only minor changes in the epidemic in the past 27 years.

Table 25: 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%
Montana Counties with most positive reported cases:		
Yellowstone and Missoula		
Mode of Exposure:		
Male – MSM and MSM/IDU	58%	54%
Female – Risk not specified	55%	40%

National case rates of HIV/AIDS among Native Americans have increased slightly each year since 2003 (National Alliance of State & Territorial AIDS Directors (NASTAD), 2008). However, in Montana the number of cases reported among Native Americans has shown a slight decline each year since 1990. Montana's relatively low case rate and the decline in the number of cases since 1990 led many health professionals to speculate that significant underreporting of HIV/AIDS cases is occurring in this population. One plausible reason for underreporting may be because of significant barriers to HIV testing among Native Americans in Montana (Mochi, 1996). Low testing numbers among Native Americans could result in undetected cases of HIV and thus deflated case rates. In order to explore this supposition, HIV Counseling and Testing Forms, the BRFSS Survey and Questionnaire data regarding risk factors and barriers to testing were examined.

HIV Counseling and Testing Among Native Americans in Montana

Examination of HIV C&T intake forms for the year 2007 revealed that of the 5,630 total HIV tests administered at state funded public testing sites 992 individuals indicated Native American as their race. Somewhat surprisingly these numbers indicate approximately 18% of the total tests at these sites were administered to Native Americans. Given that Native Americans represent 6% of the total population in Montana, it would appear they are being tested at public state funded sites at a much greater rate than other races. It is important to note, however, the HIV C&T forms represent tests conducted only at state funded public HIV testing sites. In order to accurately estimate the rate of testing among Native Americans and Whites, it is necessary to account for individuals who are tested in private health care settings as

well. Fortunately, the BRFSS survey (2007) asks respondents about the frequency of testing at all sites – both public and private. Information from the BRFSS indicates Native Americans and Whites are testing at nearly equal rates with 31% of Whites reporting having had an HIV test and 39% of Native Americans. The BRFSS data shows Whites testing primarily at private doctors or HMO's (30%), while Native Americans are primarily tested at public clinics (32%).

A frequently expressed concern among members of Montana's HIV Prevention Community Planning Group is that HIV testing efforts throughout the state are not reaching the populations most at risk for infection. Information taken from the HIV C&T forms may help alleviate concern. Of the 992 total tests recorded in 2007, approximately 10% (n = 107) identified no risk factors for HIV; 90% of individuals tested identified having at least one risk factor. Comparing the most common risk factors for HIV infection in Montana (MSM, IDU, MSM/IDU, and sex with IDU) (MT DPHHS Epidemiological Report, 2008) with those reported by Native Americans who were tested at public testing sites reveals the following:

- 18% (n = 95) of males reported themselves as MSM;
- 19% (n = 185) of both men and women reported being an IDU.
- 21% (n = 212) of individuals reported having sex with a person who is an IDU; and
- 49% (n = 484) of males and females reported having sex while intoxicated or high on drugs.

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

reporting multiple risk factors, including using injection drugs and/or engaging in risky sexual behavior and who are also getting tested for HIV.

HIV Counseling and Testing Barriers among Native Americans in Montana

It is especially critical to break down barriers to HIV testing among individuals in the Native American community because of the disparity in health care in this population. In a study conducted by Kaufmann, et al. (2007) results showed testing is particularly important among Native Americans as this population experiences a faster time course from initial diagnosis of HIV to AIDS than any other racial group in the United States. They also experience one 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 populations (Kaufmann, et al. 2007). One explanation for this phenomenon is that Native Americans delay testing for HIV until they develop symptoms associated with AIDS. Early testing for HIV could improve the survival rate of those infected with the virus. It is important, therefore, to assess the barriers to testing and reduce or eliminate those barriers if possible.

Information about testing barriers specific to Native Americans in Montana was gathered by Mochi in 1997. Questionnaires were distributed by health care workers to 67 Native Americans living on the reservation. In the present study, questionnaires were distributed to 157 individuals by health care workers who were not located on the reservation. Barriers most frequently cited in the 1997 study and the barriers most frequently cited in the present study can be found in the table below.

Table 26: 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% (38)	43.2% (68)
I always practice safe sex	25.4% (17)	13% (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	n/a	18.1% (28)

Interestingly, the number one barrier to testing in 1997 as well as in 2008 was “not being at risk for HIV/AIDS”. This perception may be reasonable given the low incidence of HIV among Native Americans in Montana. The difference in the percent of individuals who marked the barrier “do not trust the health department,” in 1997 compared to 2008 is also of interest. Data reveal approximately a 20% drop in the percent of Native Americans who cited this barrier. This change may be due to a difference in perceptions between Native Americans living on the reservation and those living in more urban areas or it may reflect a more positive relationship between Native Americans and county public health departments in the past 10 years.

While prevention specialists often focus on reducing the 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 a public health clinic for testing, nearly half of them reported “knowing their status helped them to feel safe.” Another two thirds were motivated to test after having unprotected sex, while approximately one fifth were tested because they were offered a monetary incentive. It is critical health professionals are aware of both motivations and barriers to testing when developing interventions

designed to increase the number of Native Americans who are knowledgeable about their HIV status.

Recommendations

Recommendations made after reviewing data from this study include:

1. Combine HIV prevention efforts with efforts to prevent sexually transmitted diseases such as Chlamydia, Gonorrhea, and Hepatitis C as recommended by NASTAD (2007). Given the relatively low case rate for HIV in Montana and the high rates of sexually transmitted diseases in the Native American population this is an important consideration for prevention specialists in Montana.
2. Continue to research possible health disparities present in the Montana Native American population concerning HIV/AIDS. Recent studies revealed a health disparity concerning HIV/AIDS education, available services, and awareness among the Native American community in rural states (NASTAD, 2008; Hamill, Dickey, 2005). This current study revealed the need for further research regarding HIV Counseling and Testing habits on the seven reservations represented in Montana, as well as a need to further break down testing barriers.
3. Review current HIV interventions in the state of Montana which target Native Americans in order to assess whether or not, in light of this new information, they are effective and are being directed at the most pressing health concerns in this population, such as the rise in other sexually transmitted diseases.

4. Review current HIV interventions in the state of Montana in order to assess whether or not they are effective and being directed at the most at-risk behaviors. Prevention programs should focus on high-risk behaviors and populations participating in those behaviors, such as MSM, IDUs, and MSM/IDU, regardless of race.
5. Allocate HIV prevention resources to the education of individuals already living with HIV. Counseling is conducted along with an HIV test with the assumption if an individual becomes more aware of high risk behaviors associated with the infection they will initiate safer practices and reduce their risk (Mochi, R., 1997).
A meta-analysis of 27 studies from 1985 to 1997 regarding the effects of HIV Counseling and Testing on sexual risk behavior shows after receiving HIV Counseling and Testing, “HIV-positive participants reduced their frequency of unprotected intercourse and increased their condom use, relative to HIV-negative and untested participants” (Weinhardt, Carey, Johnson, Bickham, 1999).

Limitations to the Study

Study limitations are numerous within each of the four data collection sources. This section will list limitations of the data and should be noted when reviewing data collected from this study.

Epidemiological Data:

One limitation with state epidemiological reports are the numbers reported only show cases of individuals who were reported positive in Montana. There may, in fact, be

HIV positive individuals residing in the state who reported positive elsewhere.

Furthermore, sample sizes remain a limitation within epidemiological reports. There are not large numbers of Native Americans with HIV/AIDS in the state of Montana. 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.

Behavioral Risk Factor Surveillance System:

The Behavioral Risk Factor Surveillance System (BRFSS) is an ongoing telephone survey conducted by the Montana Department of Health and Human Services (MTDPHHS) in collaboration with the Centers for Disease Control (CDC) to “gauge health risk behaviors and health practices of non-institutionalized adults (18 years and older)” (State Health Access Data Assistance Center (SHADAC), 2006).

To account for limitations of gathering data through a telephone interview, final data from the BRFSS are weighted. The following are factor differences taken into account in weighting BRFSS data:

- 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 a 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. Even after taking into account weighted data, it is possible this data set does not accurately represent the entire Native American population here in Montana.

HIV Counseling and Testing Intake Forms:

The HIV Counseling and Testing Intake Forms were supplied by the HIV/STD section of the Montana Department of Health and Human Services. HIV testers at state-funded sites are required to fill the forms out to comply with the Centers for Disease Control surveillance regulations. Individuals who perform tests at private sites are not required to complete the CDC forms. Thus, data collected from the forms do not represent all Native Americans who received an HIV test in 2007. In addition, the accuracy of the information recorded on the forms is dependent on the clients' ability and willingness to self-report past behaviors.

Barriers to Testing Questionnaire:

Data collected from the questionnaires also was self-reported. Information recorded was dependent upon the participant's memory of previous experiences and willingness to answer questions honestly. Furthermore, distribution of questionnaires was dependent on health clinic workers at four state-funded HIV testing sites and five Urban Indian Clinics. The questionnaire was not available for every Native American and only represents responses of volunteers and cannot be applied to the population as a whole. Data collected does not represent all possible testing sites available in Montana.

Conclusions

This study was an attempt to examine multiple sources of information regarding HIV/AIDS among Native Americans in Montana and to use that information to gain further understanding of the epidemic as it exists in the Native American population. Four distinct sources of data were reviewed: the state of Montana epidemiologic data; CDC standardized C&T intake forms; information regarding HIV testing from the 2007 BRFSS; and a Questionnaire revealing barriers to testing. After reviewing the information from these sources, the following conclusions were drawn about HIV/AIDS among Native Americans in Montana.

1. It appears that Native Americans in Montana are being tested for HIV at about the same rates as Whites. While more Whites reported being tested for HIV in private clinics, more Native Americans reported testing in publically funded clinics which resulted in similar total rates of testing for both groups. Furthermore, data from C&T Intake Forms completed in public clinics revealed that approximately 90% of Native Americans who were tested in publically funded sites listed at least one risk factor for HIV infection. While many of the behaviors cited did not indicate extremely high risk behavior, a substantial proportion of those tested reported MSM and IDU behaviors which would put them in the highest risk populations in Montana.
2. The nature of the epidemic among Montana's Native Americans does not seem to be changing over time. An examination of cases from 1985 to the present reveals individuals most at risk for HIV infection in this population are Men who

have Sex with Men and Injection Drug Users. Men continue to be infected at a much higher rate than women.

3. There does not appear to be a hidden epidemic among Native Americans living in Montana. Given the decline in the number of HIV positive individuals each year since 1998, and the fact there were no new cases reported among the 992 HIV tests completed at state funded sites in 2007, it does not seem reasonable to assume there exists an unusually large number of Native Americans in the state of Montana who are HIV positive and not getting tested.
4. Results from this study do not provide a complete picture of HIV/AIDS among Montana's Native Americans. Results of this study should be considered a starting point for the development of a more accurate picture of the affects of HIV/AIDS among Native Americans who live both on and off reservations in Montana. Information specific to each reservation will provide a more in-depth picture and will allow Native American prevention specialists to target their interventions to those most at risk.

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APPENDIX A:
LIST OF STATES/AREAS USED FOR NATIONAL
SURVEILLANCE DATA

STATES/AREAS USED FOR NATIONAL SURVEILLANCE DATA

The CDC receives reports from all US states and dependent areas of AIDS cases, and these trends are continuously monitored. However, only the following 33 states and 5 dependent areas are used for HIV surveillance. The monitoring of trends in HIV requires the collection of information from states in which the reporting is uniform.

U.S. States

Alabama	Kansas	New Jersey	South Dakota
Alaska	Louisiana	New Mexico	Tennessee
Arizona	Michigan	New York	Texas
Arkansas	Minnesota	North Carolina	Utah
Colorado	Mississippi	North Dakota	Virginia
Idaho	Missouri	Ohio	West Virginia
Indiana	Nebraska	Oklahoma	Wisconsin
Iowa	Nevada	South Carolina	Wyoming

Dependent Areas

American Samoa

Guam

Northern Mariana Islands

Puerto Rico

Virgin Islands, U.S.

APPENDIX B:

UNIVERSITY OF MONTANA

INTERNAL REVIEW BOARD APPROVAL



The University of
Montana

Office of the Vice President
Research and Development
The University of Montana
Missoula MT 59812
Phone (406) 243-6670
Fax (406) 243-6330

Date: June 19, 2008
To: K. Ann Sondag, HHP
From: Judy L. Fredenberg, IRB Chair
RE: IRB proposal approval "A Descriptive Study of Native Americans' Participation in HIV Testing in Montana"

This study has been approved on the date that the "checklist" was signed. If the study requires an Informed Consent Form, please use the "signed and dated" ICF and Assent Forms as "masters" for preparing copies for your study. **Approval continues for one year.** If the study runs more than one year, a continuation form must be approved by **June 18, 2009** or it will need to be resubmitted.

Also, you are required to notify the IRB if there are any significant changes or if unanticipated or adverse events occur during the study. Finally, when you terminate the study, please notify our office in writing so that we can close the file.


Judy L. Fredenberg

[attachment(s)]

APPENDIX C:
DATA COLLECTION QUESTIONNAIRE

Help us Improve HIV Testing Services for Native Americans in Montana



The purpose of this survey is to identify barriers to HIV testing within the Native American community. Your responses will help Public Health Departments and Urban Indian Centers make it easier for Native Americans to get an HIV test.

This survey is completely voluntary and anonymous. Please do not put your name anywhere on this form.

DEMOGRAPHICS:

Please check the box that best describes you.

TODAYS DATE: ___/___ (Month/Day) 2008

AGE: _____

CURRENT GENDER: Male Female
 Transgender (M2F) Transgender (F2M)

RELATIONSHIP STATUS: Married Single In a Committed Relationship

SEXUAL ORIENTATION: Heterosexual Homosexual
 Bisexual Uncertain
 Other (explain) _____

ANNUAL INCOME: below \$10,000 \$11,000 to \$20,000
 \$21,000 to \$35,000 \$36,000 to \$50,000
 \$51,000 to \$75,000 \$76,000 and above

RESIDENCE:

1. What is your current County of residence in Montana?

2. What type of area do you currently live in? Urban Rural

3. Are you an enrolled member of a Montana tribe?
 Yes No Uncertain
If yes, which tribe are you a member of?

4. Where do you currently live?
 On the reservation Off the reservation
 Other (please explain): _____

5. What is the purpose of your visit to the health clinic today?
 HIV/AIDS test Sexually Transmitted Disease (STD) test other reason

6. Where do you get your HIV/AIDS information?
 friend/family member newspaper/TV high school classes
 health care clinic college classes
 have not received any information
 other - please list:

7. Have you had a previous HIV test? yes no uncertain

8. Result of previous HIV test:
 positive negative preliminary positive
 uncertain indeterminate

9. Date of last HIV/AIDS test: ___/___/___ (Month/Year)
 uncertain never been tested

10. My reasons for **NOT** getting tested, or waiting until today to get tested for HIV, include:
PLEASE CHECK ALL THAT APPLY:

- | | |
|--|--|
| <input type="checkbox"/> I am at low or no risk | <input type="checkbox"/> Insurance reasons |
| <input type="checkbox"/> I don't care if I am HIV+ or not | <input type="checkbox"/> Fear of being discriminated against if HIV+ |
| <input type="checkbox"/> No cure, why bother | <input type="checkbox"/> Fear of losing my partner |
| <input type="checkbox"/> Fear of people finding out | <input type="checkbox"/> Too long to wait for results |
| <input type="checkbox"/> Test is too expensive | <input type="checkbox"/> I'm in the window period |
| <input type="checkbox"/> Not sure where to get tested | <input type="checkbox"/> Fear of needles |
| <input type="checkbox"/> There isn't AIDS in Montana | <input type="checkbox"/> Inconvenient location |
| <input type="checkbox"/> Don't trust Health Department | <input type="checkbox"/> No knowledge of HIV |
| <input type="checkbox"/> I usually practice safe sex | <input type="checkbox"/> It's a gay disease |
| <input type="checkbox"/> Fear of losing my job if HIV+ | <input type="checkbox"/> I always practice safe sex |
| <input type="checkbox"/> Fear of alienation from family | <input type="checkbox"/> I practice only oral sex |
| <input type="checkbox"/> I am in a monogamous relationship | <input type="checkbox"/> Too scared to get test done |
| <input type="checkbox"/> Inconvenient testing hours | <input type="checkbox"/> Too scared to find out results of test |
| <input type="checkbox"/> Other reason - please describe: _____ | |

11. Have you ever had vaginal, oral and/or anal sex?
 yes no
If you answered no to this question, please skip to question #16 on the next page.

12. Do you have sex with (please check one)
 men only women only
 both, mostly women both, mostly men

13. How often do you use condoms when engaging in vaginal or anal sex?
 always sometimes never

14. How often do you use condoms when engaging in oral sex?
 always sometimes never
15. Have you ever had vaginal, oral, and/or anal sex with someone you know is HIV+?
 yes no uncertain
16. Have you used injection drugs in the past 12 months?
 yes no uncertain
17. Have you shared drug injection equipment in the past?
 yes no uncertain
18. PLEASE CHECK ALL ANSWERS THAT MOST ACCURATELY DESCRIBE YOU:
 Had sex while intoxicated and/or high on drugs Sexual partner of transgender
 Former injection drug user (last 15 years) Sexual partner of IDU
 Sexual partner has HIV/AIDS Had sex with anonymous partner
 Person who trades sex for drugs or money Sexual partner of unknown HIV status

OPTIONAL QUESTIONS:

19. In your own words, what has prevented you from being tested for HIV previously, or for what reasons did you wait until today to be tested for HIV/AIDS?
20. Can you suggest some ways in which this clinic could make it easier for Native Americans to get tested for HIV/AIDS?

Thank you for taking the time to complete this survey.

This survey is a joint effort between the
Montana Department of Public Health and Human Services and The University of Montana.

APPENDIX D:

BEHAVIORAL RISK FACTOR SURVEILLANCE SURVEY:

Section 18 – HIV/AIDS

2007 Behavioral Risk Factor Surveillance System

Section 18: HIV/AIDS

The following are the questions and responses to Section 18 - HIV/AIDS:

1. Have you ever been tested for HIV? Do not count tests you may have had as part of a blood donation. Include testing fluid from your mouth.
 - a. Yes
 - b. No
 - c. Don't Know / Not sure
 - d. Refused

2. Where did you have your last HIV test? (respondents 18-64 who had ever been tested)
 - a. Private Doctor or HMO office
 - b. Counseling and Testing Site
 - c. Hospital
 - d. Clinic
 - e. Jail or Prison (or other correctional facility)
 - f. Drug Treatment Facility
 - g. At Home
 - h. Somewhere else
 - i. Don't Know/Not sure
 - j. Refused

3. Was it a rapid test where you could get your results within a couple of hours?
 - a. Yes
 - b. No
 - c. Don't Know/Not sure
 - d. Refused

APPENDIX E:
QUESTIONNAIRE DATA COLLECTION SITES

MT DPHHS HIV Testing Sites and Urban Indian Centers

Montana Department of Public Health and Human Services funded HIV C&T Sites

- | | |
|--|--------------|
| 1. Riverstone Health
Billings, Montana | 406.247.3357 |
| 2. Cascade City-County Health Department
Great Falls, Montana | 406.454.6950 |
| 3. Butte City-County Health Department
Butte, Montana | 406.497.5020 |
| 4. Missoula AIDS Council
Missoula, Montana | 406.531.4770 |

Montana Urban Indian Centers

- | | |
|--|--------------|
| 1. Indian Health Board of Billings Clinic
Billings, Montana | 406.245.7318 |
| 2. Indian Family Health Clinic
Great Falls, Montana | 406.268.1510 |
| 3. North American Indian Alliance
Butte, Montana | 406.782.0461 |
| 4. Missoula Indian Center
Missoula, Montana | 406.829.9515 |
| 5. Leo Pocha Clinic
Helena, Montana | 406.442.9244 |