Assessment of the needs of HIV positive people in Montana

Senna Lee Towner

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AN ASSESSMENT OF THE NEEDS OF HIV POSITIVE PEOPLE IN MONTANA

by

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Presented in partial fulfillment of the requirements for the degree of

Master of Science

The University of Montana

July 2005

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THESIS ABSTRACT

Towner, Senna, M.S., July 2005

Health and Human Performance

An Assessment of the Needs of HIV Positive People in Montana

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

The purpose of this study was to collect information about the needs of people living with HIV/AIDS (PLWH/A) residing in Montana. The barriers to receiving HIV/AIDS assistance and treatment were also assessed. A combination of quantitative and qualitative data was used as the basis of methodology. A Montana 2005 Consumer [HIV/AIDS] Questionnaire, developed by the Needs Assessment Work Group and the DPHHS staff, was distributed to PLWH/A throughout the state of Montana. A number of focus group sessions and key informant interviews were conducted for further insight onto PLWH/A needs.

A combination of descriptive statistics was run on questionnaire data. Focus group sessions and key informant interviews were qualitatively analyzed. The most outstanding unmet medical related service needs of PLWH/A were as follows: medical insurance financial assistance, dental care, eye care, physical/occupational therapy, nutritional counseling, and alternative care. The most frequently unmet basic needs for PLWH/A were housing/rent assistance, assistance with paying utility bills, and transportation needs. Unmet support service needs included social/recreational activities, buddy/companion volunteer support, support group/peer counseling, legal services, and referral for services. Frequent barriers to services included lack of insurance coverage, the cost of services, burnout from talking about HIV, the concern that other people may see them when going to get care and will learn about their HIV status, the location of the organization providing services, not knowing who to ask for help, state of mind or mental ability to deal with the treatment, and not having transportation. Risky behaviors PLWH/A engage in are unprotected sex and substance abuse. Comparisons between sub-groups of PLWH/A were examined: IDU PLWH/A experience more unmet needs and barriers to needs. Women's HIV issues, including the unmet need of quality service providers, were revealed. Stigma and discrimination were reoccurring issues affecting the quality of life for PLWH/A. The research literature echoed the results of this study.

The results of this study may assist the Montana Department of Health and Human Services in closing the gaps between the assistance and treatment service needs of PLWH/A in Montana. In summary, this study may help with the prioritization of what little funding is available for PLWH/A in order to design programs which will improve the quality of life for HIV positive individuals in Montana. With limited considerations, the methodology developed for this study can be used for future needs assessments of this population.
**WE ARE THE DECISIVE ELEMENT**

I have come to the frightening conclusion that I am the decisive element. 
It is my personal approach that creates the climate. 
It is my daily mood that makes the weather. 
I possess tremendous power to make life miserable or joyous. 
I can be a tool of torture or an instrument of inspiration. 
I can humiliate or humor, hurt or heal. 
In all situations, it is my response that decides whether a crisis is escalated or de-escalated, and a person is humanized or dehumanized. 
If we treat people as they are, we make them worse. 
If we treat people as they ought to be, we help them become what they are capable of becoming.

- AUTHOR UNKNOWN -
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CHAPTER I

INTRODUCTION TO THE STUDY

Acquired Immunodeficiency Syndrome (AIDS), the disease caused by the Human Immunodeficiency Virus (HIV), is reported as the ninth most common disease in Montana (Department of Health and Human Services [DPHHS], 2004). Individuals living with HIV, regardless of the symptoms they experience, have a significant need for a wide variety of services. They may need medical services (including dental, alternative therapies, drug treatment, nutritional counseling or other alternative therapies); social-support services; psychological counseling services, substance abuse treatment/counseling; rehabilitation services; and/or basic necessity assistance such as food, housing, transportation, and financial services (Health Resources and Services Administration [HRSA] 2005). These services may be relatively easy to access in urban areas, however in rural areas access to services may be more difficult.

Montana, with a population of just over 900,000, fits the description of a rural state. The population is spread over an area comprising 145,552 square miles and includes 56 counties. Of these 56 counties, 45 are designated frontier, 8 rural and only 3 as urban/Metropolitan Statistical Areas (Communicable Disease Bureau, Division of Health Policies & Services and Department of Public Health & Human Services, 2004). People living with HIV or AIDS (PLWH/A) in rural areas often utilize health care facilities that are less adequate than urban health care facilities (CDC, 2004). In addition, access difficulties, such as travel distance and lack of knowledge about testing sites may pose barriers to adequate HIV testing. Barriers to testing, in particular, may contribute to discrepancies in the number of PLWH/A reported in Montana. However, regardless of the epidemiologic
discrepancies, it is apparent that the number of people living with HIV in American rural areas such as Montana is increasing (CDC, 2004). Because of the increasing numbers of PLWH/A residing in rural areas, it is imperative states like Montana pay close attention to meeting the needs of PLWH/A in an effort to decrease any health problems they may have and ultimately improve the quality of their lives.

Persons living with HIV or AIDS in rural areas may experience behavioral, lifestyle and environmental issues that contribute to health problems and eventually result in an overall decrease in quality of life. Health problems for PLWH/A include, but are not limited to, depression, compromised immune systems, HIV re-infection, transmission to uninfected individuals, and medication side-effects, which can have a gamut of health problems associated independent of the HIV infection. HIV Health problems may be exasperated by behaviors such as unsafe sex, failure to seek medical care, failure to take medications, or environmental issues such as inadequate services or inadequate information dissemination (Gielen, McDonnell, Wu, Campo & Faden, 2001). And, while quality of life issues may contribute to health problems for PLWH/A, it is also possible that health problems may contribute to a decreased quality of life for PLWH/A. Quality of life issues include, but are not limited to, poverty, social isolation, stigma, geographical isolation, unemployment, and discrimination (Burgoyne & Renwick, 2004; Crane et. all, 2002; Gielen et. all, 2001; World Health Organization’s Quality of Life HIV Group [WHOQOL-HIV Group], 2003).

Regardless, an analysis of factors contributing to health problems and a decreased quality of life for PLWH/A will assist DPHHS and other organizations contributing to care for PLWH/A in providing services that ultimately will improve both health problems and quality of life for people living with HIV.
Purpose of the Study
The purpose of this study was to collect information about the needs of PLWH/A residing in Montana. The barriers to receiving HIV/AIDS assistance and treatment were also assessed. The Montana Department of Health and Human Services (DPHHS) and Ryan White Title II Consortiums will use information from this study to identify the gaps between the health related needs of PLWH/A and the assistance and services actually being offered.

Research Questions
The research questions examined in this study focus on persons living with HIV/AIDS in the state of Montana. They are as follows:

1. What are the characteristics of PLWH/A in Montana in terms of demographics such as living situation, employment, income, health insurance, and use of assistance and treatment services?
2. What are the assistance, treatment, and care needs of PLWH/A in Montana?
   a. What are their medical needs in terms of dental, alternative therapy and drug treatment needs?
   b. What are their counseling and other social support needs?
   c. What are their basic needs in terms of finances, housing, transportation, food and employment?
3. What resources and assistance, treatment, and care services are being used by PLWH/A in Montana?
4. What are the barriers to receiving HIV prevention assistance, treatment, and/or services?
   a. What are the structural barriers?
b. What are the organizational barriers?

c. What are the individual barriers, such as knowledge, physical or mental well-being, community etc.? Do we want this? What are the identified gaps between needs and services?

**Statement of the Problem**

Progress in HIV treatment and medical assistance means the needs of PLWH/A are ever-changing. It is important, therefore, to identify the current needs of PLWH/A in Montana, the barriers to meeting the needs, and the gaps between needs and services. Information from this study will offer a framework for the Department of Public Health and Human Services (DPHHS) and Ryan White CARE staff to improve the quality of HIV assistance, treatment and care services to persons living with HIV and/or AIDS in Montana. The ultimate goal is to provide the necessary care and treatment to persons living with HIV/AIDS that will ultimately improve the quality of their lives.

**Delimitations**

The delimitations of the study are as follows:

1. The study is delimitated to HIV positive people living in Montana.
2. Data was collected via questionnaires, focus groups and face-to-face and online key informant interviews.
3. Data was restricted to participants’ self reports on questionnaires and in focus groups and interviews.
4. The participants for this study were limited to volunteers.
Limitations

The limitations for this study are as follows:

1. Information gathered for the study via questionnaire was limited to the voluntary action of participants completing the questionnaire.

2. Information gathered for the study via interviews and focus groups was limited to what the participants were willing and able to share.

3. Data gathered for this study was limited to the honesty and accuracy of the participants when filling out the questionnaires and participating in the focus groups and interviews.

4. Data gathered for this study was limited to those individuals who were recruited by Ryan White case managers, indigenous leaders/gatekeepers, the University of Montana and DPHHS needs assessment team and key informants.

Definition of Terms

Acquired Immunodeficiency Syndrome (AIDS): An HIV infected person receives a diagnosis of AIDS after developing one of the Center of Disease Control (CDC) defined AIDS indicator illnesses or on the basis of certain blood tests (helper T-Cell [CD4 Cell] count) (CDC, Divisions of HIV/AIDS Prevention, 2004).

Assessment of unmet need and service gaps: A process of collecting information about the needs of persons living with HIV or AIDS (PLWH/A), identifying current resources available to meet those needs, and determining what gaps in care exist (Ryan White CARE Needs Assessment guide, 2004: VI-9).

Gap analysis: Comparing needs, assistance and treatment programs available with needs, assistance and treatment programs needed but unavailable (HRSA, 2005).
Human Immunodeficiency Virus (HIV) positive persons: For the purpose of this study HIV positive persons will be defined as those people living with any of several retroviruses that infect and destroy helper T cells of the immune system causing the marked reduction in their numbers that is diagnostic of AIDS (Acquired Immunodeficiency Virus) (CDC, Division of HIV/AIDS Prevention, 2004).

Montana Targeted Outreach Program: A street and community outreach project working to stop the spread of HIV and Hepatitis C (HCV) throughout Montana. The program targets injecting drug users (IDU), men who have sex with men (MSM), and MSM who are IDU and/or use other drugs (MSM/IDU). MTAP works in collaboration with eight local community based organizations and tribal agencies throughout Montana to service HIV and HCV prevention information, disseminate health education/risk reduction materials, offer rapid HIV counseling and testing, and conduct agency referrals. MTAP is funded through a cooperative agreement with the Centers for Disease Control and Prevention (CDC).

Need: The difference between the present situation and a more desirable one (Gilmore & Campbell, 2005: 6).

Needs Assessment: For the purpose of this study, a needs assessment is the process of collecting information about the needs of people living with HIV (both those receiving care and those not in care), identifying current resources available to meet those needs, and determining the gaps in care that exist (HRSA, 2005).

Perceived needs: These are the needs envisioned and reported by the participants in a needs assessment process. People are the primary sources of information (Gilmore & Campbell, 2005).
Primary Medical Care: For the purpose of this study, primary medical care refers to remedial evaluation and clinical care that is consistent with Public Health Service guidelines for HIV/AIDS health care. Specifically, primary medical care includes, but is not limited to the following assistance treatment and services:

- Oral health care
- Outpatient mental health care
- Outpatient substance abuse treatment
- Nutritional services, and
- Specialty medical care referrals
- CD4 cell monitoring, viral load testing, antiretroviral therapy, prophylaxis and treatment of opportunistic infections, malignancies, and other related conditions (HRSA, 2005).

Ryan White CARE Act: A federal program awarding funding to states with the aim of improving the quality of life for people living with HIV. This Act includes a number of programs, some of which are called ‘Titles’. This research project will deal with the Montana’s Title II care program. Title II specifically aims at improving the quality, availability and organization of care for people with HIV statewide.

Ryan White Consortiums/HIV Consortium: A regional or statewide planning entity established by many State grantees under Title II of the CARE Act to plan and sometimes administer Title II services. An association of health care and support service providers that develop and deliver services for PLWH under Title II of the CARE Act. The consortium includes case managers. Case managers offer client-centered service that links clients with health care and psycho-social services to insure timely, coordinated access to medically appropriate
levels of health and support services and continuity of care (Ryan White Needs Assessment Guidance, 2004).
People diagnosed with HIV are living for many years with the disease as a result of new and improved treatment options. With extended life expectancy, quality of life has become a central issue in the health management for PLWH (Gielen, McDonnell, O’Campo & Faden, 2001). Burgoyne & Renwick, two researchers who examined the effects of social support on quality of life over a four-year period for PLWH, state “quality of life [to be] identified as a key component of overall health among [PLWH]” (2004:1354). Quality of life is a broad term. Possible issues contributing to life satisfaction for PLWH/A include: social role functioning (including social stigma and discrimination); self esteem; spiritual fulfillment; a sense of control over one’s environment; a sense of security in the present and future (including employment and personal finances); a sense of social integration, enjoyment, appreciation and pleasure; physical conditioning; and mental health and status (Aggleton & Parker 2003 and Crane, Quirk & Straten, 2002). These are just some of the quality of life issues that may be directly related to the general health of PLWH/A.
Although the number of AIDS related deaths has declined in the last century, HIV and AIDS continues to pose significant quality of life challenges particularly in areas most closely related to health, economic, and social status (Takahashi, Wiebe & Rodriquez, 2001). For example, individuals who have a low-income or are without private medical insurance may have difficulty accessing treatment due to such barriers as expense, transportation and/or knowledge (HRSA, 2005). Over the years of HIV diagnoses, stigma is continually argued as the outstanding issue linked to the quality of life for PLWH/A (Holloway et al, 2004). The attitudes, beliefs and policies related to stigma are persistently widespread in the United States and around the world. Whether or not stigma is actually the largest barrier, it is undoubtedly a problem inhibiting responses to HIV at the individual, community and societal levels (2004).

People living with HIV/AIDS (PLWH/A) in rural and urban United States are targets of stigma and have been since the first cases were diagnosed in 1981. Since then, discrimination in the workplace, in social settings, and even in attempts to secure safe housing have created dire circumstances for PLWH/A. People diagnosed with HIV are often shunned by family members, neighbors, and even medical providers (HRSA, 2005).

Stigma has many definitions, but Erving Goffman’s is one of the more cited. Goffman developed a framework for the study of stigma and described it as “an undesirable or discriminating attribute that an individual possesses, thus reducing that individual’s status in the eyes of society” (HRSA, 2004:7). Although his contribution to the study of stigma is nearly a half a century old, his framework still offers valuable insight into HIV/AIDS-related
stigma. Goffman focused on the public's attitude toward a person who possesses an attribute that falls short of societal expectations. The person with the attribute is "reduced in our minds from a whole and usual person to a tainted, discounted one."

People living with HIV/AIDS are misunderstood and made to feel negatively stained by their diagnosis with slurs such as:

1. Perceived as responsible for having the disease.
2. Viewed as living with a disease that is fatal or degenerative.
3. Viewed as living with a disease that is contagious or likely to infect others.
4. Are living with a disease that produces physical changes that are visible to others and unpleasant to look at (Holloway et al, 2004).

These conditions add to what Brimlow and associates so clearly summarize as, "...unfavorable attitudes, beliefs, and policies directed toward people perceived to have HIV/AIDS as well as toward their significant others and loved ones, close associates, social groups, and communities" (2003).

The HIV/AIDS Bureau: Health Resources and Services Administration discuss a study done by researchers of the International Center for Research on Women (ICRW) which explores emerging themes attached to HIV/AIDS stigma in both urban and rural areas (2004). Themes which are most applicable to Montana include:

1. Knowledge and fear interact in unexpected ways that allow stigma and discrimination to persist.
2. There is dissonance between people's stated intentions not to stigmatize and their stigmatizing actions - indicating a lack of awareness of their own stigmatizing and of their discriminatory attitudes, actions, and language.
3. Public disclosure of positive HIV serostatus is advocated, but it is acknowledged as difficult and unusual.
4. Care and support for [PLWH/A] are widespread but coexist with stigma.
5. Poverty and stigma create a double burden for the poor, who have few resources with which to cope with the effects of stigma.
6. Sex, morality, shame, blame, and guilt are closely related to HIV/AIDS-related stigma.
7. Women face more and often harsher stigma than men do, and they have fewer resources to cope with stigma.
8. Young people are blamed for HIV because they are perceived to frequently engage in "inappropriate" sexual behavior (Nublace and MacQuarrie, 2003).

Themes like these display basic stigmas against age, gender, sexual orientation, ethnicity, class and addiction are linked to HIV/AIDS-related stigma. The issue is compounded when HIV/AIDS-related stigma coincides with one or more other stigmas, particularly those associated with homosexuality, bisexuality, and injection drug use (IDU) (Brimlow, Cook & Seaton, 2003). For this reason, the implementation of interventions to expurgate HIV/AIDS-related stigma should bring awareness and mitigation, not elimination, through systems that match the complexity of the issue (HRSA, 2004).

Montana clearly has communities experiencing HIV/AIDS-related stigma. In 2004, Montana's Governor's Advisory Council on AIDS conducted a survey exploring HIV/AIDS-related concerns that should be considered important public policy issues. A survey conducted in seven of Montana's health regions collected responses from 120 individuals, 35 first place votes designated stigma/discrimination the number one quality of life concern faced by PLWH/A. The other nineteen votes were balanced between concerns tied to medical care, other financial issues, drugs/alcohol abuse, housing, employment and depression. This 2004 statewide study corresponds with national HIV/AIDS-related quality of life issues. It is apparent the complex issue of HIV/AIDS-related stigma needs to be addressed in Montana. As more people are living longer lives with HIV infection, there is a concomitant need for quality of life issues to be addressed. In addressing these issues, varying PLWH/A services and service provision strategies need to be assessed to see how well they accommodate.
In addition, as biomedical breakthroughs and rapid expansion in drug therapies continue to improve the lives of PLWH/A, quality of life barriers, such as stigma, continue to exist in the assistance and treatment care delivery system (Eng, Mullan & Salmon, 1992). These barriers can be overcome through interventions that enable individuals to create and adopt non-stigmatizing principles, values and behaviors. Up-to-date HIV/AIDS assessment research can assist in an intervention plan addressing the quality of life for PLWH/A.

**Epidemiological Analysis**

*Global and National HIV Cases*

Acquired Immunodeficiency Syndrome (AIDS) was first diagnosed over 20 years ago. Since then the disease remains a critical health issue for the United States and across the Globe. The UNAIDS Global Summary of the AIDS epidemic (2004) reports between 35.9 and 44.3 million people living with HIV or AIDS worldwide. In 2004, approximately 4.9 million new infections were reported and approximately 3.1 million people died of AIDS related deaths. Although the United States has better access to progressive HIV treatment care than much of the rest of the world, it still suffers from the pandemic. There are an estimated 800,000 to 950,000 people currently living with HIV in the United States, with approximately 360,000 people living with AIDS. This includes 180,000 to 280,000 who do not know they are infected (Byers, Sweeney, et al., 2000 & Kaiser Family Foundation, 2003). Since 1981, when AIDS was first diagnosed, through 2003, a total of 929,985 persons had been reported to the CDC as having AIDS in the United States. Many of these people are still reported to be alive. However, through 2003 approximately 524,060 deaths of persons with AIDS were reported.

The CDC estimates 20,000 people die of AIDS related illnesses every year. This number is half the annual approximation of those diagnosed with the disease. For example,
the CDC recorded 43,171 new cases of HIV or AIDS in 2003 and an estimated 18,017 people died of AIDS related deaths this same year (CDC, 2003 & Damrow & Murphy, 2004). Although this rate is relatively stable, there has been some variation in the last ten years.

Advances in HIV treatments during the mid-to-late 1990's led to small declines in estimated AIDS cases and AIDS related deaths. In 1997 there were 49,999 AIDS cases reported and 22,067 AIDS related deaths. In 1998 there were 43,183 AIDS cases reported and 18,214 AIDS related deaths reported. This shows a 13% decline in AIDS cases reported and a 17% decline in AIDS related deaths from 1998 to 1999. In 1999 there were 41,849 AIDS cases reported and 16,765 AIDS related deaths. This shows a mere 3% decline in AIDS cases reported and an 8% decline in AIDS related deaths from 1998 to 1999. Although the 1998 to 1999 decline rate for AIDS related deaths still continued to slow with some significance, the rate of decline for AIDS cases left little hope for a continuing annual decline. From 1999 until 2003---2003 being the latest surveillance data---AIDS case rates were relatively stable (CDC, 2003). This displays much work still needs to done in terms of HIV prevention and services (Holtgrave, Pinkerton and Merson, 2002). However, advancements in treatment therapies do correlate with declining AIDS related death rates.

People are living longer with the HIV/AIDS. In 1998, 274,624 people were living with HIV/AIDS, in 2000, there were 322,865 living with the disease, and in 2003, there were 405,926 people living with HIV or AIDS. This growing population represents an increasing need for continued HIV prevention services for HIV-infected individuals and for treatment and care services (CDC, 2003; HRSA, 2005; and Levi 2000).
**Demographics of HIV**

The CDC's AIDS Update Report (2003) links the male sex to higher proportions of HIV infections in the United States: Through 2003, males accounted for 749,887 HIV cases reported, while females accounted for 170,679 HIV cases, and 9,419 cases were reported for children under the age of 13. In 2003, an estimated 31,614 were reported to be diagnosed with HIV, 11,498 females and 59 children under the age of 13. Although men appear in larger numbers, the female HIV rate is on the rise. Women's HIV incidence more than tripled between 1986 and 2001. Currently, women comprise about 21% of the total number of those estimated to be living with HIV in United States. Approximately 43,000 new female AIDS cases were reported in 2001 (Kaiser Family Foundation, 2003).

In addition to the increasing rate of female HIV incidence, women also suffer higher rates of yearly AIDS related deaths and lower rates of decline for AIDS case rates. From 1993 to 2001, male AIDS case rates dropped by 64% but only 34% for women. The number of AIDS related deaths declined by 70% among men and a mere 39% among women (Kaiser Family Foundation, 2003). Specifically, African-American women are on the rise for contracting HIV infection (UNAIDS, 2005). African American women comprised an estimated 64% of new HIV infections among women in 2001. This is shocking when African American women represent only 12% of the female population overall. In 2001, the case rate for African American women was 47.8, which was almost 20 times higher than the rate for white women at a case rate of 2.4 (Kaiser Family Foundation, 2003). Regardless, women are on the rise for HIV infection regardless of their race or ethnicity.

UNAIDS (2005) and Kaiser Family Foundation (2003) claim one of the reasons for the disproportionate male/female HIV rates to be unequal access to health care. It is believed that "Many women with HIV/AIDS encounter barriers to treatment and do not
receive optimal levels of care” (Kaiser Family Foundation, 2003:2). Males with HIV/AIDS in care have twice the likelihood of females of having private insurance (36% compared to 14%). In addition, 21% of women in care are without insurance, while only 19% of men are uninsured. On this same note, the Kaiser Family Foundation states women living with HIV or AIDS in the care system are more likely than their male counterparts (61% compared to 39%) to be covered by Medicaid— the largest source of public financing for HIV. This is not because females have easier access to health care but because they are more likely to be low-income and qualify for Medicaid care as a pregnant woman or parent of a dependent child (2003).

Overall, HIV/AIDS in the United States is becoming more likely to be experienced by women. Women at risk for HIV need access to information and prevention education. Of those women diagnosed with HIV, many still face even more sizable barriers to receiving HIV related services than men even with great advances in HIV treatment, care and services. As women contribute to the HIV pandemic at greater rates, it is important to consider the changing needs for PLWH/A, as women may have different needs than men. These needs may relate to family responsibilities and or unequal access to care (Kaiser Family Foundation, 2003).

\textit{Montana HIV Cases}

Since 1985, the Department of Public Health and Human Services (DPHHS) has reported 622 cases of Human Immunodeficiency Virus (HIV) in Montana. Of those 622 people, approximately 506 meet the Centers for Disease Control and Prevention case definition of AIDS. Of the 622 cases, 450 were Montana residents at the time of their diagnosis. The remaining 172 were diagnosed while residing in another state and later returned to or moved
to Montana. Since 1985, there have been 266 AIDS related deaths recorded in Montana (Damrow & Murphy, T, 2004).

In 2004, Montana reported seven AIDS cases and ten cases of HIV infection (non-AIDS), a total of 17 HIV/AIDS cases (Damrow, 2004). This compares to the yearly average of 10-20 cases per year. The Communicable Disease Bureau et al. (2004) used the CDC’s 2003 data for comparing Montana’s 2003 AIDS case rate to the rest of the nation: Montana’s case rate of an estimated 1.4 AIDS cases per 100,000 people is comparable to states similar in population size, but is significantly lower than the national estimated average of 15.1 cases per 100,000.

Although Montana’s HIV rate is lower than the national average, Montana still compares to the rest of the nation in that more people are living with the disease. In fact, in 2000 there were just 431 AIDS cases in Montana; four years later we see over 200 more cases of PLWH/A. Although much of this increase is due to variability in reporting, it is still apparent HIV numbers are increasing in Montana. Montana matches the HIV trends of most rural areas in America. The disease is infiltrating smaller communities in the United States, where it has been largely ignored in the past (CDC, 2004).

**HIV/AIDS on the Rise in Rural America**

Since the 1980’s, AIDS has been associated with urban American gay white men and injection drug users. However, the last 20 years has brought changes in the populations and geographic areas affected by HIV/AIDS. The disease spread from metropolitan epicenters to women, youth, people of color, and to vulnerable populations in rural communities and states. By 1999, people residing in rural areas (areas with less than 50,000 people) accounted for six percent of the cumulative reported AIDS cases and seven percent of newly reported AIDS cases. By December, 1999, almost 21,000 adults and adolescents were living with
AIDS in non-metropolitan areas of the United States (CDC, 2003). Because HIV is becoming more prevalent in rural communities and states, HIV care capacity in these areas needs to build through existing resources and partnerships and by continuously reviewing and updating HIV service plans (McKinney, 2000).

PLWH/A living in rural areas face issues such as poverty, finding physicians who accept Medicaid patients, stigma, isolation, discrimination and travel distance from doctors and clinics (CDC, 2004). With these issues at the forefront, HIV prevention specialists who met at the Northeast Conference on Rural HIV Service Delivery in 2000 concluded with the following recommendations: They suggested rural areas train and/or recruit primary care physicians and practitioners to recognize the signs and symptoms of HIV infection. They recommend small communities plan strategies for possible changes in HIV care that may result from changing healthcare policies. The conference suggested rural communities strengthen linkages to urban-based specialists through telemedicine, telephone consultations, and visits by specialists to rural sights. They also recommended non-metropolitan areas work at funding and training professionals to provide higher levels of mental and physical support to cater to the increasing numbers of PLWH/A (McKinney, 2000). These recommendations are put forth to assist rural communities assess their HIV service resources and the barriers PLWH/A experience in accessing those resources.

**Health Problems of PLWH/A in Montana**

There has been little local epidemiological research conducted on the health issues of PLWH/A. From the most recent Needs Assessment of Montanans living with HIV/AIDS published in 2001 the three top needs, derived from an analysis of survey data, were in no specific order, “the need for alternative therapies, dental care and mental health counseling” (Hachunbruch, 2001). Although these issues of health care are pertinent in 2005, there is
value in looking at the current spectrum of health issues. There is no easy way to curtail the
infinite list of health problems documented, however most of the major health issues fit into
one of these five categories:

1. Reinfection and Superinfection
2. Anti-HIV medication side effects
3. Aging
4. Opportunistic infections
5. Mental Issues (i.e. Depression)

**Reinfection and Superinfection**

Reinfection is a labor-intensive health issue to research, thus limited in its findings.
However the lack of data does not discount it as an emerging and major concern. Dr. Joel
Blankson, an infectious disease physician claims reinfection to “not only affect how
physicians counsel patients; it also has major implications for vaccine development”
(Blankson, 2004).

Until approximately 1994 the assumption was that two HIV positive individuals
could engage in behaviors like unprotected sex and needle sharing without putting one
another at additional risk (Avert.org, 2005). This has since been reconsidered as people
coinfected\(^1\) with two or more strains are now being documented. A PLWH may have more
than one strain of HIV because of the viruses’ efficient ability to mutate itself. There are
two types of HIV: HIV-1 and HIV-2; both types are transmitted through vaginal fluid,
semen, blood, and from mother to child and are both linked to the precursor of AIDS.
However, science claims the HIV-2 strain to be less easily transmitted and there is usually a
longer period between infection and illness. West Africa has the highest number of

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\(^1\) The term coinfection is used interchangeably with reinfection. However, when referencing HIV/AIDS
coinfection also refers to the HIV virus existing concurrently with another virus, most often Hepatitis B (HBV)
because HBV and HIV share routes of transmission. HIV-HBV coinfection has emerged as a significant and
widespread problem among individuals at risk. Research claims 9 percent of HIV positive people in western
countries are HBV surface antigen positive (HIV and Hepatitis.com, 2005).
documented HIV-2 cases. In the rest of the world, including the United States, HIV-1 is the most predominant strain (Avert.org, 2005).

The HIV-1 strain is classified into three groups. Within these three groups there are various subgroup strains. Intermittently, subtypes can meet in the cell of an infected person and mix their genetic material together to create a new hybrid virus. The classification of HIV strains becomes extensive due to the complexity of the virus. It is important to note the general extensiveness of these strains in order to adapt medications avoid the reinfection related resistance (Avert.org, 2005).

In addition to reinfection, there is also a growing concern surrounding superinfection. Superinfection is a distinguished strain second infection of an HIV infecting a host several months after the first strain occur rather than simultaneously. A person’s immune response to the first virus is sometimes not enough to prevent the infection of the second strain, especially with a virus belonging to a different subtype. As of 2005, research does not yet identify superinfection as an emerging concern like reinfection, as it appears to take place only in special circumstances.

In summary, research shows PLWH/A can be infected with a second strain or subtype of the HIV virus that may be resistant to medications able to treat the first strain. The second strain or reinfection may increase the carrier’s viral load and/or reduce his or her CD-4 count to push the person into AIDS diagnosis and possibly speed the dying process (Blankson, 2004). It is unknown whether or not anyone in Montana has a dual infection of HIV but it is a future health problem as ferocious as HIV itself.
Side effects of medications

Highly Active Antiretroviral Therapy (HAART), the variety of over fifteen medication used to treat the HIV virus, were introduced to PLWH/A in 1996 (HRSA, 2005; AIDS Action Council, 2001). HAART recreated the HIV diagnosis; making it an outpatient chronic disease rather than a death sentence. The therapy works by targeting an enzyme in human DNA which aims at stopping human cells from producing new, mature healthy HIV virus. Nucleoside Reverse Transcriptase Inhibitors (NRTIs) are the first class HAART used by PLWH/A to suppress replication of retroviruses (HRSA, 2005). A visual representation of their operation is as follows:

![Illustration from the Merck Manual of Medical Information, 2005](image)

Since the introduction of HAART PLWH/A are living longer lives with improved quality of life. However, an improved quality of life does not mean a lack of medical complications such as side effects. Rather, there are a plethora of problems associated with HAART.

Lipodystrophy and lipodeposition are the most common ailments referring to the issue of body composition; losing of fat and depositing fat respectively (HIVpositive.com, 2001). Lipodystrophy and lipodeposition can be viewed below (Nature.com, 2005):
Currently, in the United States, the prevalence of lipodystrophy is an estimated 25%-50% of HIV-infected patients receiving combined antiretroviral therapy.

In addition to lipodystrophy, medication side effects vary considerably. According to HRSA, “The side effects that people get depend on the medications they take, and their own bodies. Not everyone gets every side effect – and some people have relatively few or no side effects” (2005). Side effects may include:

- feeling very tired
- headaches
- appetite loss
- skin rashes
- diarrhea
- fever
- bone problems
- kidney stones
- gas and bloating
- heart disease
- pancreatitis (an inflammation of the pancreas gland)
- liver problems
- insulin resistance and diabetes
- body fat distortions (having too much or too little fat on different parts of your body)
- nausea (feeling sick to your stomach)

Dr. Brian A. Boyle, assistant professor of medicine at Weill Medical College of Cornell University states, “To say overall which side effects patient are going have with antiretroviral is relatively difficult because it’s going to depend on individual medications, how the
medications were put together and depending on the individual patients, patients have
different side effects depending on the medications they're on” (HIVpositive.com, 2001).
The consequences of HIV treatment are diverse and complicated. Therefore, when
assessing the 80-90% of the population that has side effects considerations have to be made
to assure the best approach for each kind.

Aging

The health issue of aging relates to HIV treatment side effects. According to AIDS.org,
“Changes caused by aging can resemble or worsen treatment side effects. For example, older
age is a major risk factor for heart disease and for increasing fat in the abdomen” (2004). As
health problems resulting from the natural aging process begin to impact PLWH/A
choosing medications appropriate for each individual becomes more difficult. Additionally,
it is tricky to separate the effects of natural aging from the effects of medication,
compounding the issues of side-effects even more (HRSA, 2005). Lastly, as medications
improve for the general PLWH/A population, those infected with the virus are living longer.
As a result, long-term consequences of taking medications for more than a decade are
brought to light. Aging is not a concern to ignore, as over 11% of the PLWH/A population
is over 50 years old (AIDS Action Council, 2001). In Montana, this percent is approximately
eight, with 7% over 49 at the time of diagnosis (Damrow, 2004).

Dental Health

One of the first health issues a person diagnosed with HIV experience are oral lesions. Oral
lesions often act as predictors of disease progression and/or severe immune suppression,
making them a dangerous manifestation. There are several types of lesions, including, but
not limited to, aphthous ulcers, necrotizing ulcerative periodontitis, intraoral Kaposi's
sarcoma, long-standing herpes simplex virus infections, oral hairy leukoplakia, and
candidiasis. HIV antiretroviral medications can suppress lesions, but a recurrence may promote a T-cell count to drop, or an HIV relapse (HRSA, 2001).

**Opportunistic Infections**

People living with HIV and AIDS are likely to be infected with malignancies that take advantage of the opportunity offered by a weakened immune system (avert.org, 2005). The weakened immune system creates an “opportunity” for infections to occur and cause health problems, or “opportunistic infections” (OIs) (HRSA, 2005). Opportunistic infections include, but are not limited to: human papillomavirus (HPV), cervical cancer, urinary track infections, tuberculosis, hepatitis C, candidiasis (thrush), histoplasmosis, and genital ulcers (HRSA, 2004).

**Behavioral Analysis**

Although homosexuality carries a heavy stigma in this culture and is often assumed to be related to HIV, HIV incidence rates have been on the rise for the last ten years for women and the general heterosexual population worldwide and in the United States (BBC News, 2004). The Joint United Nations Program on HIV/AIDS (UNAIDS) 2004 Report on the Global Epidemic states an estimated one third of new HIV infections recorded in North America are being attributed to heterosexual contact. The report claims approximately one quarter of newly acquired HIV infections can be linked to injecting drug use (IDU) in North America, while men who have sex with men (MSM) account for about 42% of HIV transmissions in North America. Heterosexual female HIV infection is not necessarily on the rise because of high-risk behavior, instead the infection is often contracted by unprotected sex with long-time partners who also have sex with men or use injecting drugs and do not inform their female partners (UNAIDS, 2005).
The CDC (2003) analyzed data from 11 states and found that 34% of HIV-positive African-American men stated having sex with both women and men, but very few African-American women reported knowledge of their partners having sex with men. The logic behind this secrecy is complex, however the CDC’s study suggests “the overlapping risk behavior [is] rooted mainly in the stigma that remains attached to homosexuality” (CDC 2003:2). This stigma relates to the current leading cause of death for African American women ages 25-34 being AIDS related.

Educational Analysis

Barriers to Service Needs

The varying characteristics of rural environments need to be considered when assessing HIV services and service provision strategies. In 2000, the Northeast Conference on Rural HIV Service Delivery established four primary barriers to the access and use of assistance and treatment services. These barriers can be transferred to rural areas in the western part of the nation and are as follows:

(1). Low population density: Low population density often limits the number of health and social services that can be offered locally. This increases travel distance to obtain medical and/or service care; reduces public transportation options; and inhibits efforts to organize HIV planning and advocacy groups.

(2). Low prevalence of HIV/AIDS: Even with the infiltration of PLWH/A into rural areas, metropolitan areas have a greater prevalence of PLWH/A. With a relatively low prevalence rate, states and communities are discouraged from supporting HIV initiatives; service providers have a difficult time achieving economies of scale; and HIV management experience becomes limited for rural clinicians and service providers.
(3). **Rugged topography and climate:** The quality of roads and/or seasonal changes may create burden with time and/or inconvenience for those traveling to services.

(4). **Limited health care infrastructure:** Rural communities often do not have the healthcare options of urban communities; this may restrict service options and limit service provider choices.

These unique barriers to service that PLWH/A can face when living in rural areas, can help predict some of the needs of person’s living with HIV in rural areas (Mueller, Slifkin, Shambaugh-Miller & Randolph, 2004).

**Needs of PLWH/A in Rural Areas**

Gilmore and Campbell describe a need as “… the difference between the present situation and a more desirable one” (2005:6). Unmet needs refer to assistance, treatment, or care services of those individuals not currently in care as well as those in care which are only partially met or not being met (HRSA, 2004). An unmet need exists if a person’s functional performance is not up to standard and if support available is not able to meet the person’s need. Person’s living with HIV or AIDS have a variety of needs in terms of assistance, treatment and care and many of these needs are unmet. These needs can include, but are not limited to, medical services (including dental, drug treatment, nutritional counseling or other alternative therapies); social and/or psychological support services; basic necessity services such as food, housing, transportation, and financial services (HRSA, 2005). Some of these needs are discussed below:

**Medical Service Needs**

The HIV/AIDS Bureau of HRSA explains “Responding to AIDS is about more than responding to an infectious disease. It is about dealing with the perception that antiretroviral therapy has stopped AIDS. And it is about dealing with poor access to health information
and health care—both of which have fueled the epidemic since its inception” (2004:4). Although antiretroviral therapy has contributed to more PLWH/A, it has not decreased the rate of AIDS case rates and it has only offered minor contributions to the decline in AIDS related death rates. In addition, the American health care system capacity is limited. It does not reach many people who are threatened with the numerous health problems associated with HIV, which include, but are not limited to, hepatitis C, poor nutrition, diabetes, alcoholism, drug dependencies, mental illness and/or opportunistic infection such as tuberculosis (CDC & HRSA, 2004). Often the demographics and poverty level of PLWH/A influences their ability to access health care. In 2002, at least one of every two PLWH/A lived below the Federal Poverty Level; fewer than 1 in 10 had any private health insurance; and only 27.9 percent were enrolled in Medicaid (HRSA, 2005). These rates show serious concern for medical services reaching PLWH/A.

AIDS incidence and mortality have rates are seriously affected by underserved and un/underinsured people (CDC, 2003). Without health care access, PLWA die. Although medical enhancements, like once-daily dosing, offer hope in treatment that can help break down barriers to extremely demanding—and sometimes debilitating—antiretroviral regimens, there is indication that many people do not have private or public health insurance or the personal resources to pay for new medical treatments. If people are without medical coverage of some sort, these new treatments may be entirely unavailable (HRSA, 2004). In Montana, the same Governor’s AIDS Council 2004 Survey that had 35 votes for stigma/isolation being the number one concern for PLWH/A, 69 of the 120 respondents voted medical care as the number one concern affecting the quality of life for PLWH/A. It is evident medical care is a concern for PLWH/A across the nation, not excluding Montana.
**Dental care.** A primary medical care concern for PLWH/A in rural areas, including Montana, is dental care. Montana is also noted for its dental crisis, which emulates a crisis evident in rural communities across the nation. This calamity is divided into two categories, first there is a shortage of dentists in Montana. In 2000, ten of the 56 counties had no dentists at all. In 2000, two-thirds of Montana dentists were over the age of 45, leading this same report to predict many Montana dentists to retire within five years, or by this year, 2005 (Rural Health News, 2001). The second issue is the number of people, including many PLWH/A, who do not have dental insurance or who receive Medicaid, and many dentists do not accept Medicaid patients, as they are not often reimbursed (HRSA, 2001). Dental care is a major medical concern for PLWH/A living in rural areas across the country, including Montana.

**Social and/or Psychological Support Service Needs**

Many psychological disorders are associated with HIV/AIDS. In the United States and Europe, severe mental illness occurs in 20 to 50 percent of PLWH/A. Illnesses include, but are not limited to, AIDS-related dementia; depression including anxiety, panic disorder, posttraumatic stress disorder; impulsivity or personality disorder, and/or drug related disorders and psychoses. In addition, there is a frequent overlap between substance abuse and mental illness (HRSA, 2004). With the high rate of mental illness, there is obvious need for psychological support.

Recent longitudinal research conducted by Burgoyne and Renwick (2004) found counseling services, specifically social support groups, to be a salient indicator for quality of life for PLWH/A. Specifically, the study examined 41 adult outpatients living with HIV/AIDS in Canada. Over the study's four-year period of time, there was an associated reduction in mean viral load and the mean number of opportunistic infections was
progressively significantly reduced. Both of these patterns follow similar studies done on the
effects of social support and quality of life for PLWH/A (Burgoyne & Renwick, 2004). The
study’s findings suggest sufficient evidence for underscoring the importance of interventions
aimed at maximizing social support for PLWH/A.

Social support is marked as especially important for women living with HIV/AIDS
(Gielen et al., 2001 and Kaiser Family Foundation, 2003). This is in part due to the fact the
women living with the disease are more likely than men to have children under the age of 18
living in their homes (76% of women compared to 34% of men). Without social (and
financial) support, having dependents living at home may complicate their ability to manage
their own illness. Social support is said to improve quality of life for individuals and their
families (Kaiser Family Foundation, 2003).

**Basic Service Needs**

Approximately one-third to one-half of persons living with HIV/AIDS in the United States
are either homeless or in imminent danger of losing their homes. This is due to
compounding factors such as PLWH/A may require housing that provides emergency,
transitional, or long-term affordable solutions which may be difficult to obtain because of
increased medical costs, financial limitations that parallel the inability to keep employment
due to AIDS related illnesses, and waiting lists for affordable housing (U.S. Department of
Housing and Urban Development [HUD], 2004). Adding to the housing problem is the
issue of PLWH being able to maintain a much healthier status due to progressive medical
treatments. This healthier status means they frequently do not qualify for disability
determination. However, even thought they are healthier, they may not be able to work full
time meaning they continue to need low-income housing (Montana Department of
Commerce [MDC], 2000). However, HUD (2004) claims low-income housing is decreasing
across the nation, disregarding the ongoing concern of homeless PLWH/A. Montana is no exception to this trend.

In Montana, affordable housing continues to decrease (MDC, 2000). Rural areas like Montana pose exceptional issues because of travel distance to health care facilities. It is imperative PLWH/A reside in housing close in proximity, or have access to transportation to sufficient health care centers as to receive the extensive and specific treatment they will require for the remainder of their lives (MDC, 2000). Without appropriate housing, the barriers to service needs are compounded for PLWH/A.

Conclusion

The national annual case rate for HIV has been relatively stable for the last half-century. However, advancements in HIV treatments have contributed to more people living with the disease. In addition to more PLWH/A, there has been a recent shift in the demographics of PLWH/A. Men living in metropolitan areas are no longer the highest risk population; the disease now threatens women and children and is sweeping across rural communities.

People diagnosed with HIV/AIDS suffer from a number of health related problems, which can contribute to a decreased quality of life. It is crucial the national health care system and public health departments adapt their treatment and assistance services to meet the needs of the ever-changing population of affected by HIV as to contribute to better health and an increased quality of life. The United States has the capacity to adapt to new HIV treatment realities. Rural Montana also can keep up-to-date with these realities. As a rural community we can ensure efficient and productive services that offer the most good. This can be done by first assessing the needs of Montana HIV residents.
CHAPTER III

METHODOLOGY

Nationwide availability of new and effective treatment therapies for HIV means more people are living with the disease. This progress also means an increase of people living with HIV or AIDS (PLWH/A) in rural areas like Montana. For this reason it is important HIV prevention specialists identify interventions to increase the quality of life for people living with HIV. It is also important to identify interventions that will reduce the risk of transmission from HIV positive individuals to individuals who are negative. With this in mind, Montana’s’ HIV Needs Assessment Work Group in collaboration with staff from The University of Montana Department of Health and Human Performance, designed this study for the purpose of collecting information about the needs of PLWH/A in Montana.

Researchers gathered information from both HIV positive people receiving, and those not receiving HIV related services and/or treatment. The extent to which services are accessible, available and appropriate for those living with HIV in Montana were identified as well as barriers to accessing those services. Finally, this study assessed unmet needs related to services and/or treatment for PLWH/A. The results of this study will be used by the Montana Department of Health and Human Services (DPHHS) and Ryan White Title II Consortiums to update the current needs of HIV positive people and to develop appropriate health treatment and assistance programs for this population.

Description of Target Population

The human subject population assessed in this study were HIV positive male and females over the age of 18 living in Montana. HIV positive people included those diagnosed with any of several retroviruses that infect and destroy helper T cells (CD4) of the immune
system causing the marked reduction in their numbers. HIV is diagnostic of AIDS (Acquired Immunodeficiency Virus) (CDC, 2004). For the purpose of this study HIV positive includes those individuals diagnosed with HIV and/or AIDS.

Protection of Human Subjects

The human subject application material and consent forms were completed in accordance with the University of Montana Institutional Review Board (IRB) (see Appendix A).

Procedures

Instrumentation, Nature of Selected Sample, and Data Collection

Data was collected using three distinct methods; questionnaire, focus group and interview. The instrumentation, sample and data collection techniques for each method are described below.

Questionnaire

Instrumentation. A questionnaire, Montana 2005 Consumer Questionnaire, was developed by the Needs Assessment Work Group and the DPHHS staff (Appendix B). The questionnaire was modeled after the Ryan White Foundation HIV positive needs assessment questionnaire guidance (HRSA, 2005), and other established needs assessment questionnaires used throughout the nation. This instrument gathers information in the following areas: demographics of target population, HIV/AIDS status, behaviors since becoming HIV positive, assistance and/or treatment service use, and barriers to assistance and/or treatment services. The questionnaire was reviewed and revised by an expert panel consisting of staff from the Ryan White Program, The University of Montana faculty, and HIV indigenous leaders/gatekeepers. Following the review and revisions, the questionnaire was pilot tested by members of the target population.
**Nature of selected sample.** The questionnaire was distributed to PLWH/A who are 18 years of age or older and live in Montana April 15 through May 31, 2005. Both Ryan White and non-Ryan white clients were targeted throughout the seven Ryan White consortia, which aim to serve the needs of the Montana governor’s five health planning regions. These regions include Billings with 86 HIV/AIDS clients, Kalispell with 16 clients, Helena with 16 clients, Missoula with 91 clients, Butte with 14 clients, Great Falls with 28 clients, and Bozeman with 12 clients. In total, Ryan White clients comprise 263 of the estimated 351 individuals living with HIV/AIDS in Montana as of December 31, 2004.

**Data collection.** Questionnaire packets were prepared and included a cover letter written by a indigenous leader consultant explaining the purpose and importance of completing the questionnaire (Appendix C), a modified consent form containing information typical of consent forms (Appendix D), a self-addressed stamped envelope and a questionnaire that was color coded according to one of seven Ryan White consortia. Researchers described the purpose of the project and the procedures involved in the distribution of the questionnaire packets to individuals who agreed to assist with the project:

Specifically, questionnaire participants were recruited using three different methods. First, the seven Ryan White Title II case managers throughout Montana’s five planning regions were asked to offer the questionnaire to clients coming into their offices. Case managers from each consortia were also asked to mail the questionnaires to clients who did not make an office visit during the data collection period.

Second, 15 Montana Targeted Outreach Project (MTAP) outreach workers were asked to distribute questionnaires. Of the 15 asked, six agreed to distribute questionnaires. Outreach workers, in the course of their usual prevention activities, offered questionnaires to
individuals who had shared their HIV positive status with them but did not have a Ryan White case manager. Outreach workers are located throughout Montana.

Third, infectious disease practitioners were contacted and asked if they had HIV/AIDS patients who did not have a Ryan White case manager and who would be interested in filling out the questionnaire. The Needs Assessment Team asked practitioners to request their recruited HIV clients not to fill out the questionnaire twice via another recruitment process. A requested number of questionnaire packets were delivered to practitioners offices and disseminated by the infectious disease doctor.

Fourth, the snowball technique was used to assure that individuals who are not in contact with MTAP outreach workers or an infectious disease doctor, and who are not receiving Ryan White care were included in the sample. The snowball technique is appropriate for rural states like Montana where access to high-risk groups is a challenge. For this project, the technique involved the recruitment of four individuals (indigenous leaders and/or gatekeepers) who are recognized for their leadership, participation and involvement with the target population. The indigenous leaders/gatekeepers were paid as consultants on this project and were asked to distribute questionnaires among their clients, friends and other acquaintances. The individuals contacted by the indigenous leaders/gatekeepers also were asked if they would be willing to distribute questionnaires to other HIV positive individuals in the target population with whom they are acquainted and who were willing to participate.

Each questionnaire participant was asked to read the cover letter and modified consent form. Ryan White clients who filled out the questionnaire were able to complete the questionnaire in their case manager’s office or take it with them and return it to the researchers in the self-addressed stamped envelope included in the questionnaire packet.
Individuals who received the questionnaire from an outreach worker, an HIV/AIDS practitioner, or from an indigenous leader/gatekeeper were also able to fill out the questionnaire in the presence of the outreach worker, practitioner, or indigenous leader/gatekeeper or take the questionnaire packet with them and return it to the researchers in the self-addressed stamped envelope.

**Focus Groups**

**Instrumentation.** The focus group questions for this study were developed based on a literature review, the Ryan White Foundation HIV needs assessment focus group guidance (HRSA, 2005), the PRECEDE-PROCEED Model for health program planning (Green & Kreuter, 1999), and past rural and urban HIV needs assessment focus group questions. The focus group interview schedule included a group of predetermined questions that aim at the following issues: quality of life issues, health problems, behaviors and environmental factors related to health problems, barriers to accessing services and any other thoughts related to the needs of PLWH/A (Appendix E). The focus group questions were evaluated and revised by the expert review panel before focus groups took place with the target population.

**Nature of selected samples.** Participants in all focus groups consisted of PLWH/A who are 18 years of age or older and live in Montana. Both Ryan White and non-Ryan White clients were involved in the group interviews. One focus group consisted of HIV positive women, a second group consisted of HIV positive men, and the third and fourth groups were a mix of men and women who are HIV positive. The focus groups were conducted in separate locations throughout the state. One focus group took place in Missoula, one in Butte, one in Great Falls and one in Billings.

Volunteer participants were recruited by the four indigenous leader/gatekeeper consultants on the project. Indigenous leaders/gatekeepers who are currently facilitating
support groups solicited volunteer participants from their groups. Individuals known to the
indigenous leaders/gatekeepers who are not currently in a support group were also invited to
volunteer.

Data collection. Each of the four focus groups consisted of 6 to 12 individuals. The
individuals were "...used to obtain information about the feelings, opinions, perception,
insights, beliefs, misconceptions, attitudes, and receptivity" of the needs of PLWH/A
residing in Montana (McKenzie, Neiger & Smeltzer, 2005:76). Those individuals who
participated in a group were recruited by invitation. When individuals were asked to
participate in the focus group they received general information about the session, however
they did not receive details about the session. McKenzie et al. explain avoiding specific
description as a "...precaution [that] helps ensure that responses will be spontaneous yet
accurate (2005:76)."

All arrangements for the focus groups were made by the indigenous
leaders/gatekeepers. At the beginning of each focus group the facilitators explained the
purpose and importance of the meeting and distributed the modified consent form
(Appendix F). Participants were then be given a copy of the set of predetermined questions.
A researcher or a gatekeeper assisted the facilitator by taking notes in the focus groups.
Focus group sessions were audio recorded to assure accurate records of responses. The
focus groups took place in a location that was convenient, private and conducive to
maintaining participants' confidentiality. Volunteers received a free lunch or dinner and
$25.00 for their participation.

Key Informant Interviews

Instrumentation. Interview questions for this study were developed based on a literature
review, the Ryan White Foundation HIV needs assessment interview question guidance
(HRSA, 2005), the PRECEDE-PROCEED Model for program planning (Green & Kreuter, 1999), and past rural and urban HIV needs assessment interview questions. The interview schedule included questions that aim at the following issues: quality of life issues, health problems, behaviors and environmental factors related to health problems, barriers to obtaining needed services, and any other thoughts related to the needs of PLWH/A (Appendix G). The questions were evaluated and revised by the expert review panel prior to finalizing the interview schedule.

**Nature of selected samples.** Five key informant interviews were conducted. Three interviews were conducted in person and audio recorded. Two interviews were conducted via e-mail. Interviewees were sent the interview questions and an informed consent and were asked to reply to the questions in writing. Three key informants were male and two were female.

Informant interviews were conducted with professionals providing psychological, social and/or basic support to PLWH/A in Montana. Indigenous leaders/gatekeepers recommended individuals who they believed would be able to provide the best information regarding the needs of PLWH/A in Montana. The interviews were held in a place convenient for each Montana professional throughout the state.

**Data Collection.** Researchers, based upon recommendations by the indigenous leaders/gatekeepers, contacted professionals who provide services to PLWH/A. The professionals were asked to participate in an interview regarding their perceptions of the needs of PLWH/A. Arrangements were made to conduct the interviews in a convenient and private place with the individuals who are selected and agree to be interviewed. Prior to beginning the interview, interviewees were given a verbal explanation of the project and
asked to read an informed consent (Appendix H). Interviews lasted from 30 minutes to one hour and were tape recorded for accuracy.

Data Analysis

Data collected for this study came from a questionnaire, four focus groups, and six key informant interviews. The identities of individuals who completed the questionnaire were anonymous. The identities of individuals who participate in the focus groups and interviews were confidential. No names or other identifying information was reported as part of the data analysis. All data was reported as group data. Quantitative and qualitative analyses were completed.

Questionnaire Analysis

Questionnaire responses were statistically analyzed using the SPSS computer program. Questionnaire analysis included descriptive statistics to report the perceived needs among PLWH/A in Montana. Frequencies were reported by actual count and sample sizes. Frequencies will also be illustrated through charts, graphs, and tables when appropriate.

Focus Group and Interview Analysis

Focus group and interview data were qualitatively analyzed. Immediately following the sessions, the researcher reviewed the notes and the tapes to make sure they made sense, to identify any areas of ambiguity or uncertainty, and to review the overall quality of the information received from participants. Observational data (such as where the focus group/interview occurred, number of participants, participants’ reactions to interviews and/or focus group, and any additional information needed to make sense of the focus groups and/or interviews) was also noted. A contact summary sheet (Appendix I) was used in this process. The tapes were transcribed verbatim and the notes from the focus groups and interviews were compared with the transcripts to check for accuracy. Researchers
worked collaboratively with contracted workers to identify themes and draw conclusions.

The transcripts were read repeatedly in order to identify quotes following patterns, perceptions, the general impression, and concerns identified by participants. Researchers created categories from the patterns, and classified the transcript data under the appropriate identified categories. The categories were then clustered into themes. Quotes from the participants were used to support and illustrate the themes. Significant information, unusual and informative findings were also reported.
CHAPTER IV

RESULTS

The purpose of this study was to conduct an assessment regarding the needs of people living with HIV/AIDS residing in Montana. The barriers to receiving HIV/AIDS assistance and treatment were also assessed. The assessment included data collection from the following sources: Montana 2005 HIV/AIDS Consumer Questionnaire, Face-to-Face and Online Key Informant Interviews, and Focus Groups. Following are the results from analysis from these sources.

Questionnaires Results

There are an estimated 351 people living in Montana with HIV/AIDS. In an attempt to reach as many of those individuals as possible, 269 questionnaires were distributed throughout Montana via Ryan White consortia within the five health regions, six MTAP outreach workers, and five Montana service providers. Of the 269 questionnaires, 168 were completed for a return rate of 62%. (Two questionnaires were returned too late for analysis). Below questionnaire distribution numbers, return numbers, and return rates are presented:

<table>
<thead>
<tr>
<th>RYAN WHITE</th>
<th>NUMBER</th>
<th>NUMBER RETURNED</th>
<th>RETURN RATE</th>
</tr>
</thead>
<tbody>
<tr>
<td>Billings</td>
<td>70</td>
<td>40</td>
<td>57%</td>
</tr>
<tr>
<td>Kalispell</td>
<td>15</td>
<td>15</td>
<td>100%</td>
</tr>
<tr>
<td>Helena</td>
<td>14</td>
<td>10</td>
<td>71%</td>
</tr>
<tr>
<td>Missoula</td>
<td>70</td>
<td>37</td>
<td>53%</td>
</tr>
<tr>
<td>Butte</td>
<td>15</td>
<td>12</td>
<td>80%</td>
</tr>
<tr>
<td>Great Falls</td>
<td>28</td>
<td>21</td>
<td>75%</td>
</tr>
<tr>
<td>Bozeman</td>
<td>12</td>
<td>4</td>
<td>42%</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>MTAP OUTREACH</th>
<th>NUMBER</th>
<th>NUMBER RETURNED</th>
<th>RETURN RATE</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>24</td>
<td>16</td>
<td>67%</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>SERVICE PROVIDER</th>
<th>NUMBER</th>
<th>NUMBER RETURNED</th>
<th>RETURN RATE</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>21</td>
<td>11</td>
<td>57%</td>
</tr>
</tbody>
</table>

| TOTAL           | 269    | 168             | 62%         |
Basic Demographics

Age and Gender

The respondents (n= 166) reported age and gender as follows:

- Average age is 41
- Age ranged from 22 to 81 years old
- 21% (n=35) were female; 77% (n=128) were male
- 1% (n=1) of respondents are transgender (male to female)
- 1% (n=2) of respondents did not report gender

Ethnicity

The ethnicity of respondents was relatively proportionate to the ethnicity of PLWH/A living in Montana. A comparison of the ethnicity of the known HIV positive population in Montana (DPHHS, December 31, 2004), and the ethnicity of the participants in the Montana needs assessment project is provided in Table 1 below. (n=166)

<table>
<thead>
<tr>
<th>Ethnicity</th>
<th>HIV+ People in Living in Montana</th>
<th>HIV+ Project Participants</th>
</tr>
</thead>
<tbody>
<tr>
<td>White</td>
<td>85%</td>
<td>87%</td>
</tr>
<tr>
<td>Native American</td>
<td>6%</td>
<td>10%</td>
</tr>
<tr>
<td>African American</td>
<td>4%</td>
<td>1%</td>
</tr>
<tr>
<td>Hispanic</td>
<td>3%</td>
<td>1%</td>
</tr>
</tbody>
</table>

> Italian was listed as the “other” category.

Sexual Orientation

The respondents (n=163) were asked to identify with a sexual orientation. Sixty percent identified themselves as gay. This percent corresponds with the percent of HIV/AIDS cases in Montana among MSM (62%), although it is important to note that not all men who have sex with other men identify as gay (DPHHS, December 31, 2004). Chart 1 describes results.
Chart 1: Sexual Orientation

- heterosexual 32% (n=62)
- gay 60% (n=99)
- bisexual 6% (n=9)
- other 2% (n=3)

➢ "Other" comments included: Me, myself & a little of it all, non-sexual and human.

**Employment Status**

Table 2 explains the employment status of questionnaire respondents.

<table>
<thead>
<tr>
<th>Employment Status</th>
<th>Percent (%)</th>
<th>Frequency (n)</th>
</tr>
</thead>
<tbody>
<tr>
<td>On Disability</td>
<td>31%</td>
<td>n=51</td>
</tr>
<tr>
<td>Employed Full Time</td>
<td>24%</td>
<td>n=39</td>
</tr>
<tr>
<td>Not Employed</td>
<td>17%</td>
<td>n=29</td>
</tr>
<tr>
<td>Employed Part Time</td>
<td>12%</td>
<td>n=12</td>
</tr>
<tr>
<td>Self-Employed</td>
<td>6%</td>
<td>n=10</td>
</tr>
<tr>
<td>Other</td>
<td>10%</td>
<td>n=17</td>
</tr>
</tbody>
</table>

"Other" comments included:
- Filing for disability
- Not employed & on disability
- Employed part-time with disability
- Student
- Retired
- Retired & self-employed
- Minister
- I would love to work
- Work injury

**Income**

The respondents (n=151) reported the following:

- The maximum monthly income was $3000 per month; the minimum monthly income was $0.00.
- The mean income was $816.
- The median income was $752.
- 49 people reported living on $700 or less per month.
- 102 people reported living on $715 or more.
- The greatest frequency of people (n=12) reported making $1000 per month.
Living Arrangements

The questionnaire respondents were asked to report their living arrangements (n=164).

Over half of the respondents were living in their own house or apartment at the time of the survey. See Table 3 for reported results.

Table 3. Living Arrangements

<table>
<thead>
<tr>
<th>Living Arrangements</th>
<th>Percent (%)</th>
<th>Frequency (n)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Your own house or apartment</td>
<td>63%</td>
<td>n=104</td>
</tr>
<tr>
<td>In a friend or relative's house/apartment</td>
<td>28%</td>
<td>n=46</td>
</tr>
<tr>
<td>Jail or prison</td>
<td>4%</td>
<td>n=6</td>
</tr>
<tr>
<td>Living in public housing</td>
<td>3%</td>
<td>n=5</td>
</tr>
<tr>
<td>Live on the streets or in a shelter</td>
<td>1%</td>
<td>n=1</td>
</tr>
<tr>
<td>Pre-release center</td>
<td>1%</td>
<td>n=1</td>
</tr>
<tr>
<td>Drug/alcohol treatment center</td>
<td>1%</td>
<td>n=2</td>
</tr>
<tr>
<td>Hospice or nursing facility</td>
<td>--</td>
<td>--</td>
</tr>
<tr>
<td>Other</td>
<td>4%</td>
<td>n=6</td>
</tr>
</tbody>
</table>

* Percentages do not add up to 100. Respondents checked all that applied.

> *"Other" comments included: Rent and in my partner's house.*

Number of Dependent Children in Household

Of the 166 respondents, 11% (n=19) reported having one or more dependent children. See Table 4 for reported number of dependent children.

Table 4. Dependent Children

<table>
<thead>
<tr>
<th>Number of Children</th>
<th>Percent (%)</th>
<th>Frequency (n)</th>
</tr>
</thead>
<tbody>
<tr>
<td>0</td>
<td>86%</td>
<td>n=43</td>
</tr>
<tr>
<td>1</td>
<td>6%</td>
<td>n=10</td>
</tr>
<tr>
<td>2</td>
<td>4%</td>
<td>n=7</td>
</tr>
<tr>
<td>3</td>
<td>2%</td>
<td>n=3</td>
</tr>
</tbody>
</table>

Health Insurance and/or Other Assistance

Of the 163 respondents, 83% (n=137) reported having health insurance or other assistance and 16% (n=26) reported not having health insurance or other assistance. See Graph 1 for the kind of insurance or other assistance used by respondents.
Graph 1. Health Insurance/Assistance Type

* I.H.S stands for Indian Health Services or Tribal Health
* Percentages do not add up to 100. Respondents checked all that applied.

**“Other” comments included: Insurance through my husband’s work and twelve months pre-existing then no Ryan White.

HIV/AIDS Status

Perceptions of Overall Health Status

The respondents (n=164) were asked to rate their overall health based on a five point Likert Scale ranging from very good to very poor. Over half of the respondents (57%) reported being in very good or good health, while approximately 42% reported being in fair, poor or very poor health. See Table 5 for responses.

Table 5. Overall Health

<table>
<thead>
<tr>
<th>Overall Health</th>
<th>Percent (%)</th>
<th>Frequency (n)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Very Good</td>
<td>16%</td>
<td>n=26</td>
</tr>
<tr>
<td>Good</td>
<td>42%</td>
<td>n=69</td>
</tr>
<tr>
<td>Fair</td>
<td>32%</td>
<td>n=53</td>
</tr>
<tr>
<td>Poor</td>
<td>8%</td>
<td>n=14</td>
</tr>
<tr>
<td>Very Poor</td>
<td>1%</td>
<td>n=2</td>
</tr>
</tbody>
</table>
HIV Mode of Transmission

The respondents (n=163) were asked to report on how they believed they became infected with HIV. See Table 6 for results.

Table 6. Mode of Transmission

<table>
<thead>
<tr>
<th>Transmission</th>
<th>Percent (%)</th>
<th>Frequency (n)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sex with a man</td>
<td>72%</td>
<td>n=120</td>
</tr>
<tr>
<td>Sex with a woman</td>
<td>5%</td>
<td>n=9</td>
</tr>
<tr>
<td>Injecting drug use</td>
<td>5%</td>
<td>n=8</td>
</tr>
<tr>
<td>Don't know</td>
<td>5%</td>
<td>n=9</td>
</tr>
<tr>
<td>Sex with an injection drug user</td>
<td>4%</td>
<td>n=6</td>
</tr>
<tr>
<td>Blood transfusion</td>
<td>2%</td>
<td>n=3</td>
</tr>
<tr>
<td>Other</td>
<td>4%</td>
<td>n=7</td>
</tr>
</tbody>
</table>

"Other" comments included:

- Partner in the 1980s.
- Air Force – multiple use of needles when vaccinated.
- From my job as an R.N. - needles prick- have been covered in blood.
- At work as a nurse

Number of Years Living with HIV/AIDS

The questionnaire respondents (n=164) reported living with HIV/AIDS an average of ten years, with a minimum of less than one year and a maximum of 31 years.

AIDS Diagnosis

The respondents (n=164) were asked to report if they were diagnosed with AIDS at the time of their HIV diagnosis. See Table 7 for concurrent AIDS Diagnosis.

Table 7. Concurrent HIV and AIDS Diagnosis

<table>
<thead>
<tr>
<th>AIDS Diagnosis</th>
<th>Percent (%)</th>
<th>Frequency (n)</th>
</tr>
</thead>
<tbody>
<tr>
<td>No</td>
<td>77%</td>
<td>n=126</td>
</tr>
<tr>
<td>Yes</td>
<td>19%</td>
<td>n=32</td>
</tr>
<tr>
<td>Can't Remember</td>
<td>4%</td>
<td>n=6</td>
</tr>
</tbody>
</table>

Respondents (n=165) were also asked to report if they were currently diagnosed with AIDS. Approximately half of the respondents (49%) reported that they were not currently diagnosed with AIDS. This data implies that there is a slight under-representation of
individuals with AIDS in this study, because according to the DPHHS December 31, 2004, of the 351 PLWH/A in Montana, 68% meet the CDC AIDS definition, the remaining 32% are non-AIDS, but living with HIV. See Table 8 for results.

**Table 8. AIDS Diagnosis**

<table>
<thead>
<tr>
<th>AIDS Diagnosis</th>
<th>Percent (%)</th>
<th>Frequency (n)</th>
</tr>
</thead>
<tbody>
<tr>
<td>No</td>
<td>50%</td>
<td>n=82</td>
</tr>
<tr>
<td>Yes</td>
<td>46%</td>
<td>n=77</td>
</tr>
<tr>
<td>Don’t Know</td>
<td>4%</td>
<td>n=6</td>
</tr>
</tbody>
</table>

**CD4 Count and Viral Load**

Respondents were asked if they knew their current CD4 count and/or viral load (n=164) and if they had had their CD4 count or viral load tested in the last 12 months (n=164). Nearly all of the participants (94%) had their viral load tested in the last 12 months. Tables 4 and 5, respectively, describe results.

**Table 9. Current CD4 and/or Viral Load**

<table>
<thead>
<tr>
<th>Knowledge of CD4/Viral Load</th>
<th>Percent</th>
<th>Frequency (n)</th>
</tr>
</thead>
<tbody>
<tr>
<td>No</td>
<td>16%</td>
<td>n=27</td>
</tr>
<tr>
<td>Yes</td>
<td>82%</td>
<td>n=136</td>
</tr>
</tbody>
</table>

**Table 10. Twelve Month CD4/Viral Load**

<table>
<thead>
<tr>
<th>Tested CD4 or Viral Load in last 12 Months</th>
<th>Percentage (%)</th>
<th>Frequency (n)</th>
</tr>
</thead>
<tbody>
<tr>
<td>No</td>
<td>5%</td>
<td>n=8</td>
</tr>
<tr>
<td>Yes</td>
<td>94%</td>
<td>n=156</td>
</tr>
</tbody>
</table>

**HIV/AIDS Case Manager**

Respondents (n=164) were asked if they had ever had a case manager. The results showed:
- 81% (n=134) reported having a Ryan White or other unspecified case manager,
- 6% (n=10) reported no longer having a case manager,
- 12% (n=20) reported *never* having a case manager and
- 1% (n=2) did not respond to this question.

Respondents (n=30) who answered “no longer” or “never” having a case manager were asked to explain why they did not have one. See Table 11 for results.
Table 11. Reasons for Not Having a Case Manager

<table>
<thead>
<tr>
<th>Why Not</th>
<th>Percentage (%)</th>
<th>Frequency (n)</th>
</tr>
</thead>
<tbody>
<tr>
<td>I don’t know how a case manager could help me</td>
<td>33%</td>
<td>n=10</td>
</tr>
<tr>
<td>I’m worried people will find out I have HIV or AIDS</td>
<td>27%</td>
<td>n=8</td>
</tr>
<tr>
<td>I didn’t know one was available</td>
<td>20%</td>
<td>n=6</td>
</tr>
<tr>
<td>Confidentiality</td>
<td>17%</td>
<td>n=5</td>
</tr>
<tr>
<td>I don’t need services</td>
<td>13%</td>
<td>n=4</td>
</tr>
<tr>
<td>I can get services myself</td>
<td>13%</td>
<td>n=4</td>
</tr>
<tr>
<td>I live too far away</td>
<td>10%</td>
<td>n=3</td>
</tr>
<tr>
<td>A different service provider helped me get services</td>
<td>3%</td>
<td>n=1</td>
</tr>
<tr>
<td>They don’t speak my language</td>
<td>--</td>
<td>--</td>
</tr>
<tr>
<td>They don’t understand my culture</td>
<td>3%</td>
<td>n=1</td>
</tr>
<tr>
<td>Use alternative therapy/standard medicine too harsh</td>
<td>--</td>
<td>--</td>
</tr>
<tr>
<td>Other</td>
<td>17%</td>
<td>n=5</td>
</tr>
</tbody>
</table>

* Percentages do not add up to 100. Respondents checked all that applied.

➤ Only one “other” comment was included, stating “Most workers assume you’re gay.”

**Behaviors since Becoming HIV Positive**

**Sexual Activity**

The respondents (n=165) were asked to report their sexual activity since becoming HIV positive. Of the 109 participants who reported being sexually active, almost one-half reported that they did not always use condoms.

See Chart 2 for results.
Participants (n=57) who responded “never” or “sometimes” were asked to identify the situations where they did NOT use them. See Table 12 for results.

**Table 12. Situations when Condoms are NOT Used**

<table>
<thead>
<tr>
<th>Situation</th>
<th>Percentage (%)</th>
<th>Frequency (n)</th>
</tr>
</thead>
<tbody>
<tr>
<td>With my regular partner who is HIV positive.</td>
<td>26%</td>
<td>n=15</td>
</tr>
<tr>
<td>When my sex partner refuses to use condoms.</td>
<td>19%</td>
<td>n=11</td>
</tr>
<tr>
<td>With any sex partner who is HIV positive.</td>
<td>16%</td>
<td>n=9</td>
</tr>
<tr>
<td>When I feel uncomfortable bringing up condoms.</td>
<td>14%</td>
<td>n=8</td>
</tr>
<tr>
<td>When my viral load is undetectable.</td>
<td>2%</td>
<td>n=1</td>
</tr>
<tr>
<td>Other</td>
<td>21%</td>
<td>n=12</td>
</tr>
</tbody>
</table>

* Percentages do not add up to 100. Respondents checked all that apply.

“Other” comments included:
- With someone special who has HIV.
- I don’t have unsafe sex anymore because other strains.
- When drugs or alcohol are involved.
- I’m married to an HIV negative man and he loves me.
- My husband refuses to use all the time.
- One nighters.
- Because my sex partner refuses.
- Drugs.
- We want to have a baby.
- When I have some other type of problem, such as a kidney infection.

**HIV Disclosure**

Respondents (n=164) were asked if they disclosed their HIV status to sexual partners. Of the 124 individuals who reported being sexually active, 85% reported always disclosing their status. See Chart 3 for results.
Respondents (n=158) were asked if they ask the status of sexual partners. While 85% of the respondents reported they always reveal their HIV status to sex partners, only about one-half always ask their sex partners about their HIV status. See Chart 4 for results.

![Chart 4. Ask Partner to Disclose](image)

**Sexually Transmitted Diseases**

Respondents (n=164) were asked if they had tested positive for sexually transmitted diseases (STDs) besides HIV/AIDS in the last two years. 84% (n=140) of the respondents reported not testing positive for STDs in the past two years; 15% (n=24) reported testing positive for STDs the last two years.

Respondents (n=24) who tested positive reported the STDs for which they tested positive. See Table 13 for responses.

**Table 13. STDs**

<table>
<thead>
<tr>
<th>STD</th>
<th>Percentage (%)</th>
<th>Frequency (n)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Herpes</td>
<td>29%</td>
<td>n=7</td>
</tr>
<tr>
<td>Genital warts</td>
<td>25%</td>
<td>n=6</td>
</tr>
<tr>
<td>Gonorrhea</td>
<td>13%</td>
<td>n=3</td>
</tr>
<tr>
<td>Chlamydia</td>
<td>8%</td>
<td>n=2</td>
</tr>
<tr>
<td>Syphilis</td>
<td>--</td>
<td>--</td>
</tr>
<tr>
<td>Other</td>
<td>4%</td>
<td>n=1</td>
</tr>
</tbody>
</table>

* Percentages do not add up to 14.5%; Three respondents testing positive for STDs in the last two years did not answer this question. Respondents also checked all that applied.

➢ "Other" STDs included Hepatitis C.
**Medical Illnesses**

Respondents (n=164) were asked if they had any other medical illness besides HIV/AIDS. 59% (n=98) responded “yes” for other medical illnesses and 40% (n=66) reported “no”.

Participants (n=98) who responded “yes” were asked to identify their medical illness. See Table 14 for results.

<table>
<thead>
<tr>
<th>Type of Medical Illness</th>
<th>Percent (%)</th>
<th>Frequency (n)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hepatitis B/C</td>
<td>41%</td>
<td>n=40</td>
</tr>
<tr>
<td>Mental Illness</td>
<td>36%</td>
<td>n=35</td>
</tr>
<tr>
<td>Opportunistic Infection</td>
<td>24%</td>
<td>n=23</td>
</tr>
<tr>
<td>Drug Dependency</td>
<td>20%</td>
<td>n=20</td>
</tr>
<tr>
<td>Alcoholism</td>
<td>18%</td>
<td>n=18</td>
</tr>
<tr>
<td>Heart Disease</td>
<td>1%</td>
<td>n=8</td>
</tr>
<tr>
<td>Other</td>
<td>39%</td>
<td>n=39</td>
</tr>
</tbody>
</table>

* Percentages do not add up to 100. Respondents checked all that applied.

“Other” responses included:
- Abnormal pap smear
- Arthritis
- Artificial leg
- Asthma
- Back problems
- Blood disease/bad back
- Cervical dysplasia
- Deaf
- Degenerative Disc Disease,
  Chronic pain management,
  Pancreatitis, Migraine Headaches
- Eye problems- have also had stage II melanoma skin care
- High blood pressure
- High cholesterol (2 respondents)
- ITP, Ischemic Thrombocytopenia Purpura (bleeder)
- MS
- Neuropathy (3 respondents)
- Recovering junky
- Shingles

**Substance Use**

Respondents (n=164) were asked if they had used any substances in the past year.

- 40% (n=67) said they had not used substances
- 58% (n=97) responded they had.

Respondents (n=97) were asked which substances they have used in the past year. Alcohol and marijuana were the most frequently used substances (39% of respondents reported using both), while meth/crystal is used by nearly 17% of the respondents. See Graph 2 for results.
"Other" responses included:

- Morphine
- Shrooms
- X,G, K (2 respondents)

Respondents (n=165) were asked to report if they had injected drugs in the past year. Of the respondents:

- 6% (n=10) reported injecting drugs in the past year.
- 93% (n=155) reported not injecting drugs in the past year.

Respondents (n=165) were asked to report if they had shared needles while injecting drugs in the past year. Of the respondents:

- 1% (n=1) reported sharing needles.
- 99% reported not sharing needles in the past year.

Respondents (n=163) were asked if they believed their substance use to be a problem. Of the respondents:

- 11% (n=19) believed their drug use to be a problem.
- 5% (n=8) were unsure if their substance use was a problem.
- 82% (n=136) did not believe substance use to be a problem.
**Emotional Concerns**

Respondents (n=164) were asked if they had emotional concerns which had caused them problems in the last six months.

- 72% (n=120) said they did have emotional concerns.
- 27% (n=44) said they did not have emotional concerns.

Respondents (n=118) were asked to report which emotional concerns have caused them problems in the last six months. See Table 15 for results.

<table>
<thead>
<tr>
<th>Emotional Issues</th>
<th>Percent (%)</th>
<th>Frequency (n)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Depression</td>
<td>84%</td>
<td>n=101</td>
</tr>
<tr>
<td>Anxiety/Fear</td>
<td>77%</td>
<td>n=92</td>
</tr>
<tr>
<td>Loneliness/Isolation</td>
<td>60%</td>
<td>n=71</td>
</tr>
<tr>
<td>Stress</td>
<td>51%</td>
<td>n=61</td>
</tr>
<tr>
<td>Anger/Resentment</td>
<td>38%</td>
<td>n=45</td>
</tr>
<tr>
<td>Suicidal Tendencies</td>
<td>28%</td>
<td>n=33</td>
</tr>
<tr>
<td>Guilt</td>
<td>24%</td>
<td>n=29</td>
</tr>
<tr>
<td>Other</td>
<td>1%</td>
<td>n=10</td>
</tr>
</tbody>
</table>

* Percentages do not add up to 100. Two participants that reported having emotional issues did not specify their issues. Respondents checked all that applied.

**Emotional issues listed under “other” were:**

- Can't stay focused
- Fear at AIDS and dieting
- Money
- No money for outside activities - just stay home
- Nightmares
- Major sexual side effect - not really into it anymore
- I have no current suicidal tendencies though I plan to “check out” when this disease incapacitates me. I have isolated myself, though I am content being a recluse now. I don't intend burdening anyone, including medical staff, with my problem when it's unmanageable.

The respondents were asked if they received any treatment for emotional or stress related problems, such as depression. Of the respondents:

- 46% (n=77) reported receiving treatment.
- 54% (n=89) reported not receiving treatment.

Respondents (n=73) were asked which emotional treatments they were using. See Table 16 for results.
Table 16. Emotional Treatments

<table>
<thead>
<tr>
<th>Treatment</th>
<th>Percentage (%)</th>
<th>Frequency (n)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Prescription medicine</td>
<td>83%</td>
<td>n=61</td>
</tr>
<tr>
<td>Counseling</td>
<td>38%</td>
<td>n=28</td>
</tr>
<tr>
<td>Medical marijuana</td>
<td>11%</td>
<td>n=8</td>
</tr>
<tr>
<td>Alternative therapies</td>
<td>5%</td>
<td>n=4</td>
</tr>
<tr>
<td>Other</td>
<td>5%</td>
<td>n=4</td>
</tr>
</tbody>
</table>

* Percentages do not add up to 100. Four participants that responded “yes” to using treatment did not specify their treatment. Respondents checked all that applied.

“I tell people how I’m feeling” was listed under the “other” category.

The respondents (n=164) were asked if becoming HIV positive had caused problems in close relationships. Results showed:

- 56% (n=93) reported having relationship problems.
- 43% (n=71) reported not having relationship problems.

The respondents (n=89) were asked to report the problems being HIV positive has caused in their close relationships. See Graph 3 for reported results.

“Other” comments included:

- Afraid to make friends- fear of rejection
- Establishing new relationships
- Family
- Fear of infecting others
- Friends dumped me/ no money/ sick/ no friends
- Hated by ex-wife
- Have none
- I have given up all close relationships
- In the past
- Lack of partner
- Limited amount of partners
- Loss of friends
- Pulling away by others as I progress
- Pushing every one out of my life

* Percentages do not add up to 100. Four participants that responded “yes” to having problems did not specify. Respondents checked all that applied.
Uncomfortable meeting people
Who can I talk to? Friends not infected

The respondents (n=165) were asked to report the type of counseling they preferred. See Graph 4 for reported responses.

* Percentages do not add up to 100. Respondents checked all that applied.

‘Other’ types of counseling preferred included:
- My friends stopping over
- Any that helps
- Guided meditation
- Spouse
- Heterosexual group counseling

Treatment and Assistance Needs

Medical Needs

Participants were asked to respond to a list of medical assistance and treatment opportunities. For each opportunity listed, they were asked to put an “X” in one of the three boxes, ‘Need and use, Don’t need, Need, can’t get.’ See Table 17 for responses to Medical Care and Related Needs.
Table 17. Medical Care and Related Needs

<table>
<thead>
<tr>
<th>Assistance/Treatment</th>
<th># of Respondents</th>
<th>Need and use</th>
<th>Don't need</th>
<th>Need, can't get</th>
</tr>
</thead>
<tbody>
<tr>
<td>Treatment adherence support (help taking your HIV meds correctly)</td>
<td>n=160</td>
<td>25%</td>
<td>67%</td>
<td>4%</td>
</tr>
<tr>
<td></td>
<td>n=42</td>
<td></td>
<td>n=111</td>
<td></td>
</tr>
<tr>
<td>Physical or Occupational Therapy</td>
<td>n=163</td>
<td>13%</td>
<td>71%</td>
<td>15%</td>
</tr>
<tr>
<td></td>
<td>n=22</td>
<td></td>
<td>n=117</td>
<td></td>
</tr>
<tr>
<td>Nutritional counseling</td>
<td>n=160</td>
<td>15%</td>
<td>72%</td>
<td>10%</td>
</tr>
<tr>
<td></td>
<td>n=24</td>
<td></td>
<td>n=120</td>
<td></td>
</tr>
<tr>
<td>Medical Equipment (wheelchair, etc.)</td>
<td>n=161</td>
<td>5%</td>
<td>90%</td>
<td>2%</td>
</tr>
<tr>
<td></td>
<td>n=8</td>
<td></td>
<td>n=150</td>
<td></td>
</tr>
<tr>
<td>Financial assistance with medications</td>
<td>n=163</td>
<td>64%</td>
<td>21%</td>
<td>2%</td>
</tr>
<tr>
<td></td>
<td>n=106</td>
<td></td>
<td>n=35</td>
<td></td>
</tr>
<tr>
<td>Medical care (doctor, nurse, clinic, etc.)</td>
<td>n=163</td>
<td>75%</td>
<td>16%</td>
<td>8%</td>
</tr>
<tr>
<td></td>
<td>n=124</td>
<td></td>
<td>n=26</td>
<td></td>
</tr>
<tr>
<td>Help paying for medical insurance</td>
<td>n=159</td>
<td>31%</td>
<td>37%</td>
<td>28%</td>
</tr>
<tr>
<td></td>
<td>n=51</td>
<td></td>
<td>n=62</td>
<td></td>
</tr>
<tr>
<td>Eye care</td>
<td>n=160</td>
<td>49%</td>
<td>30%</td>
<td>18%</td>
</tr>
<tr>
<td></td>
<td>n=81</td>
<td></td>
<td>n=50</td>
<td></td>
</tr>
<tr>
<td>Dental Care</td>
<td>n=159</td>
<td>54%</td>
<td>19%</td>
<td>24%</td>
</tr>
<tr>
<td></td>
<td>n=87</td>
<td></td>
<td>n=32</td>
<td></td>
</tr>
<tr>
<td>Other</td>
<td>n=19</td>
<td>1%</td>
<td>2%</td>
<td>8%</td>
</tr>
<tr>
<td></td>
<td>n=2</td>
<td></td>
<td>n=3</td>
<td></td>
</tr>
</tbody>
</table>

Responses to “Why I can’t get it” were as follows:

**Treatment Adherence Support:**
- Don’t know how to get
- Don’t know anyone who can help with this
- I can’t find decent doctor
- I would like occupational therapy to move into a related but less type of work.
- I would love to be able to go to gym or health spa to help keep muscles toned
- In prison
- Will need when released from prison
- Don’t know whom to ask
- Not sure
- I need exercise class, no money
- Medicare/Medicaid doesn’t pay for long term

**Physical or Occupational Therapy:**
- Can’t afford (n=4)
- Don’t know where to go (n=2)
- Does this exist here?
- Too far away (n=2)
- Rural Montana
- Not disabled according to MT
- Takes too much gas
- Not offered
- Don’t know if there is a service available. I also have children
- Don’t know if available
- I would like occupational therapy to move into a related but less type of work.
- I would love to be able to go to gym or health spa to help keep muscles toned
- In prison
- Will need when released from prison
- Don’t know whom to ask
- Not sure
- I need exercise class, no money
- Medicare/Medicaid doesn’t pay for long term

**Nutritional Counseling:**
- Asked for/never received
- Too far away
- Not offered
- Don’t know if there is a service available- cannot afford it. I also have children
- Not available
- Not sure if available
- In prison
- Will need when released from prison (n=2)
- Will need later
- Time and convenience lacking

**Medical Equipment:**
- Need help with bathroom modification maybe something to hold n to so I don’t fall

**Financial Assistance with Medications:**
- According to the powers that be I make too much $
- Don’t know where to go
- Make too much income
- I don’t know if I need to
- Got dropped by Ryan White after can’t afford, I went on disability
- Co-pays

**Medical Care:**
- Got dropped by Ryan White after can’t afford, I went on disability
- Afraid can’t afford COBRA
- Don’t know where to go
- The nearest is in Great Falls- I live in Basin

**Help Paying for Medical Insurance:**
- Only have Medicare
- Cannot afford it, make too much money for Medicaid
- Insurance only pays so much. I have an outstanding clinic bill.
- Can’t afford
- AIDS
- Need but don’t know how I can pay for service
- Medical insurance? What is that?
- Medicaid payment takes approximately 47% of my social security and can’t seem to find anyone to help me
- Afraid can’t afford COBRA
- Don’t know anything about it
- Already have HIV no one will insure me
- Does this exist here?
- Cannot afford to pay the high payments.

**Eye Care:**
- Medicaid only pays every 2 yrs
- Cannot afford it, make too much money for Medicaid
- Have to pay insurance upfront/can’t afford

- Who here knows anything about HIV care
- Don’t know where to go to get it & I cannot afford it

- Earn too much
- Not offered to me that I know of
- Didn’t know about help
- Hate meetings and paperwork
- Will need when released from prison (n=3)
- Will need later (n=2)
- Too much money
- Can’t afford spend down for Medicaid

- Hate doctors and hospitals
- Will need when released from prison (n=2)
- Will need later (n=2)
- $ issues

- Earn too much
- Need supplement to Medicare
- Not offered
- Do not have medical insurance
- Don’t know where to go
- Preexisting $
- No one will insure HIV people
- Can’t get it
- Lost job, pre-existing condition
- Don’t know where
- Hate paperwork
- Will need when released from Prison (n=3)
- Will need later (n=2)
- Can’t afford
- No insurance on my own.
- Not available
- Can’t get medical coverage.
- Medicaid takes cost of living raise
- Not health insurance
- Need major medical- too expensive

- Need but don’t know how I can pay for service
- Earn too much
- Not offered
- No one wants to take Medicare
- Can't afford (n=4)  
- Haven't needed it yet, but my in the future- If I would need major eye care I would need help  
- Will need when released from prison

**Dental Care:**
- Very spendy.  
- It just hurts! I'm scared.  
- No programs here for that.  
- Sometimes cost is too high  
- No Medicare or card  
- Cannot afford it, make too much money for Medicaid  
- Ryan While has paid for part but need a lot more done, can't afford  
- It's hard to find someone to take Medicaid  
- According to the powers that be- I make too much $  
- Have to find dentist to work with HIV in my area  
- Need but don't know how I can pay for service  
- Live too far, many trips, gas  
- Don't know where to go (n=2).  
- No one wants to take Medicare  
- Has assistance but ran out of funds  
- Earn too much

**Other:**
- I fall down a lot.  
- Work- can't get a job  
- Mental health- no decent mental health familiar with HIV  
- Physical/social support- not available  
- No one has ever said to me “I am/will be your case manager”. I see some wonderful people at Deering Clinic and anyone of them may already be my case manager- they are all very attentive. Great support- loving people.  
- Chiropractor  
- All- I live over 100 miles round trip to anything available to me  
- Hospital care with no insurance  
- I fall down a lot  
- Work- I can't get a job  
- Mental health- no decent mental health familiar with HIV  
- Physical/social support- not available.  
- Massage (n=3)- muscle aches, stiffness, etc./ would like/ Ryan White can't pay  
- Medical marijuana  
- Gym membership-preventative care is important- can someone help me with cost?  
- Chair lift- have difficulty with stairs though I have a WC lift outside, I need a chair or some kind of lift inside.

(n=4)  
- Will need later (n=2)  
- Unsure of needs- how important is care?  
- Don't know where to get the help (n=3)  
- Don't know how to get help  
- Cannot afford (n=3)  
- Only available when case manager has money  
- Haven’t needed it yet, but my in the future- If I would need major dental care I would need help  
- My teeth are bad  
- Will need when released from prison (n=4)  
- Will need later (n=2)  
- Limited care/caps/crowns, etc…  
- Looking for a dentist that takes Medicaid/not strong enough yet.  
- Won't pay for what needs to be done  
- No dental insurance  
- Can't afford  
- Dentists don't work on people with HIV or AIDS. I have full coverage but all the dentists I find don't help or find ways of getting rid of me. Please help with the dentists. It's frustrating and my teeth are bad. (Kalispell)  
- No money- fear of pain
Non-western therapies. Respondents (n=114) were asked what role alternative therapy plays in their life. Responses are as follows:

<table>
<thead>
<tr>
<th>If you are currently using naturopathy, herbal medicine, acupuncture or other non-Western therapies, do you consider this to be your primary form of medical care?</th>
</tr>
</thead>
<tbody>
<tr>
<td>NO: 59% (n=98)</td>
</tr>
<tr>
<td>YES: 10% (n=16)</td>
</tr>
<tr>
<td>NO RESPONSE: 31% (n=52)</td>
</tr>
</tbody>
</table>

If “YES”, please specify which therapies are most important to you:

- Herbals that support organs, acupuncture leg and organ pain. Reiki for mental health.
- Liver cleansing/kidney cleansing, bowel cleansing & Superfood (nutritional therapy) everyday.
- Acupuncture/supplement, etc.
- Coral calcium
- I use acupuncture
- Herbal medicines

Although some respondents did not use naturopathy, herbal medicine, acupuncture or other non-Western therapies as their primary form of medical care, non-Western therapies complimented their traditional forms of medicine. Comments were as follows:

- Both primary forms- I would like marijuana for medicinal purpose: To help me with my appetite. I almost have none at times throughout the month
- Not primary however, I have done acupuncture & massage in past- can’t afford it now
- Not primary- but optional
- I was using acupuncture, massage, jen sin, yoga, but my case manager told me money was no longer available. Most of these treatments seemed to help along with my medical treatment I would very much have liked to continue
- Would like to use herbs & acupuncture but cannot afford
- I do use herbs and naturopathy whenever I can afford it.
- Not primary, but I do use all of the above also
- I smoke pot to keep my weight up.
- Not primary but I do use massage and pay myself.
- Not primary but I am using acupuncture.
- Not primary but I now have a neurologist
- Not primary but I use alternative therapy: Massage therapy/only if grant money is available.
Basic Assistance Needs

Participants were asked to respond to a list of basic assistance and treatment opportunities.

For each opportunity listed, they were asked to put an "X" in one of the three boxes, 'Need and use, Don't need, Need, can't get.' See Table 18 for responses to Basic Assistance Needs.

Table 18. Basic Assistance Needs.

<table>
<thead>
<tr>
<th>Basic Assistance</th>
<th># of respondents</th>
<th>Need and use</th>
<th>Don't need</th>
<th>Need, can't get</th>
</tr>
</thead>
<tbody>
<tr>
<td>Assistance with paying utility bills</td>
<td>n=163</td>
<td>36%</td>
<td>42%</td>
<td>18%</td>
</tr>
<tr>
<td>Housing or rent assistance</td>
<td>n=160</td>
<td>34%</td>
<td>43%</td>
<td>19%</td>
</tr>
<tr>
<td>Home delivered meals/groceries</td>
<td>n=159</td>
<td>8%</td>
<td>83%</td>
<td>5%</td>
</tr>
<tr>
<td>Clothing</td>
<td>n=158</td>
<td>2%</td>
<td>83%</td>
<td>10%</td>
</tr>
<tr>
<td>Transportation</td>
<td>n=160</td>
<td>11%</td>
<td>69%</td>
<td>16%</td>
</tr>
<tr>
<td>Practical support (help with shopping, cooking, cleaning, laundry, chores, moving, pets, etc.)</td>
<td>n=157</td>
<td>7%</td>
<td>80%</td>
<td>8%</td>
</tr>
<tr>
<td>Other</td>
<td>n=22</td>
<td>2%</td>
<td>4%</td>
<td>7%</td>
</tr>
</tbody>
</table>

Responses to “Why I can’t get it” were as follows:

Assistance with paying utility bills:
- How do I find out?
- Does this exist here?
- Don’t know where to get.
- Telephone too much money.
- Funds not available
- I could use help with propane bill.
- No money available to us in Great Falls to help get it once a year.
- Earn too much
- Don’t know how to ask can you let me know?
- No case manager

Housing or Rent Assistance:
- Make too much income
- There’s a list

- Will need when released from prison (n=3)
- I’m in prison
- Will need later.
- Don’t know where to go
- Utilities are not included in rental cost
- No agency helps pay utilities and rent especially if utilities are not in your name
- Medicaid takes too much money out of disability
- Help with utility bills/ Nov-Feb would really help. They were outrageous, but I was too embarrassed to ask for more help
- How do I get help?
- Does this exist here?
- Don’t know where to get
• No income
• Earn too much
• I can only get it for 5 months
• Rent too high to fall under guidelines
• Don’t meet criteria
• Criteria of my home doesn’t meet guidelines.
• Don’t know how to ask- can you let me know?

Home Delivered Meals/ Groceries:
• Not available
• Don’t know how to go about this

Clothing:
• I need help- how do I find out?
• Lack of funds
• Too many bills
• Didn’t know there was help.

Transportation:
• Bus passes/gas vouchers taken away.
• I live too far away
• When I have a part time job or medical appointments – actually I need my license
• Don’t drive and am dependent on friends’ schedules; sometimes they are not available
• Car problems keep me financially broke
• Don’t know where to get
• Not available
• Can’t afford

Practical Support:
• Toilet paper, pet food, shampoo, tooth paste, shaving supplies, more food items: I can’t afford these items.
• Not available
• Help getting laundry, groceries, garbage to & from car, due to stairs.
• Don’t know who to contact or ask. Having

• Owe money to HUD
• No case manager
• Will need when released from prison (n=3)
• In prison
• Will need later
• YAP doesn’t like me.
• Don’t know where to go
• Make too much money

Getting it. Who to contact?
• Available?
• Don’t know how to get help with this.

• Will need when released from prison (n=3)
• In prison
• Will need later
• Cannot get
• Don’t know where to get help

• Car broke-using lover’s car.
• Sometimes need help with car payment
• Will need when released from Prison (n=3)
• In prison
• Can’t afford car insurance.
• Will need later.
• Could use help with repairs
• No money for car insurance/can’t afford to drive
• Care insurance is required by state
• Need help with gas

a real struggle keeping myself fed, house clean, etc.
• In prison
• Will need when out of prison
• Will need later.
• I’m not sure how
• Have not attempted to acquire assistance- only need occasionally
• Sometimes I need physical assistance due to neuropathy-
when friend is not available I’m SOL.

Other:

➢ FUN/PLAY: No money to even fish or use gas money for anything but paying gas to people who take me to medical appointments. I can’t make the retreats this year as there is no way for me to get there. No one from my area is going due to the long drive, lack of transportation and money as a holder of a MS in Health Administration I know how important attitude, laughter, and fun are for keeping healthy. I believe, although to some this is a luxury, to PLWH it is an integral part of living.

➢ Vehicle support- refunding to help with auto responses

➢ Moving from one apartment to another- moving 3 times in past 5 years & I am disabled- cannot get anyone to help pay for moves.

➢ Help with paper and cleaning things- don’t know if there is help but paper products and laundry soup, shampoos and cleaning soaps are difficult to obtain.

➢ Job- I can do a job

➢ Steroids and medical marijuana- doctor will not consent

➢ Care for pet- when in hospital my pet goes in kennel which is expensive

➢ Housecleaning- only get help with meal preparation not enough time for major housecleaning.

➢ Food and gas cards are usually a god-sent. By the end of the month I usually have little or no food to prepare.

Counseling and Social Support Needs

Participants were asked to respond to a list of medical assistance and treatment opportunities. For each opportunity listed, they were asked to put an “X” in one of the three boxes, “Need and use, Don’t need, Need, can’t get.” See Table 19 for responses to Counseling and Social Support Assistance.
Table 19. Counseling and Social Support Needs

<table>
<thead>
<tr>
<th>Service</th>
<th># of respondents</th>
<th>Need and use</th>
<th>Don’t need</th>
<th>Need, Can’t get</th>
</tr>
</thead>
<tbody>
<tr>
<td>Case management services</td>
<td>n=161</td>
<td>72%</td>
<td>16%</td>
<td>8%</td>
</tr>
<tr>
<td></td>
<td>n=120</td>
<td></td>
<td>n=27</td>
<td>n=14</td>
</tr>
<tr>
<td>Information and referral for services</td>
<td>n=162</td>
<td>57%</td>
<td>31%</td>
<td>10%</td>
</tr>
<tr>
<td></td>
<td>n=95</td>
<td></td>
<td>n=51</td>
<td>n=16</td>
</tr>
<tr>
<td>Child care</td>
<td>n=162</td>
<td>2%</td>
<td>93%</td>
<td>3%</td>
</tr>
<tr>
<td></td>
<td>N=3</td>
<td></td>
<td>n=154</td>
<td>n=5</td>
</tr>
<tr>
<td>Legal services</td>
<td>n=159</td>
<td>8%</td>
<td>69%</td>
<td>19%</td>
</tr>
<tr>
<td></td>
<td>n=13</td>
<td></td>
<td>n=114</td>
<td>n=32</td>
</tr>
<tr>
<td>Adoption/ Foster care for children</td>
<td>n=162</td>
<td>--</td>
<td>96%</td>
<td>2%</td>
</tr>
<tr>
<td></td>
<td>n=159</td>
<td></td>
<td>n=159</td>
<td>n=3</td>
</tr>
<tr>
<td>Social/ Recreation Activities</td>
<td>n=162</td>
<td>13%</td>
<td>58%</td>
<td>27%</td>
</tr>
<tr>
<td></td>
<td>n=21</td>
<td></td>
<td>n=96</td>
<td>n=45</td>
</tr>
<tr>
<td>Buddy/ Companion volunteer support</td>
<td>n=163</td>
<td>11%</td>
<td>61%</td>
<td>27%</td>
</tr>
<tr>
<td></td>
<td>n=18</td>
<td></td>
<td>n=101</td>
<td>n=44</td>
</tr>
<tr>
<td>Support groups/ peer counseling</td>
<td>n=163</td>
<td>21%</td>
<td>52%</td>
<td>24%</td>
</tr>
<tr>
<td></td>
<td>n=34</td>
<td></td>
<td>n=86</td>
<td>n=40</td>
</tr>
<tr>
<td>Spiritual support</td>
<td>n=157</td>
<td>26%</td>
<td>60%</td>
<td>9%</td>
</tr>
<tr>
<td></td>
<td>n=43</td>
<td></td>
<td>n=99</td>
<td>n=15</td>
</tr>
<tr>
<td>Other</td>
<td>n=12</td>
<td>1%</td>
<td>2%</td>
<td>4%</td>
</tr>
</tbody>
</table>

Responses to “Why I can’t get it” were as follows:

*Case Management Services:*
- That person doesn’t act like they want to help me
- Need to see a case manager
- Don’t know if case management could help me
- Earn too much
- Live too far out of town
- Recently moved
- Will need when released from prison (n=2)
- In prison
- Will need later
- I don’t know

*Information and Referral for Services:*
- Don’t know who to call/contact (n=2)
- Don’t know if information/referrals could help me
- Don’t know where to get information
- Not sure what’s out there
- Available?
- Will need when released from prison (n=3)
- In prison
- Will need later
- Limited knowledge of services
- No one will watch them-aggressive kids
- social security- nightmare

*Child Care:*
- How does that work?

*Legal Services:*
- May need- don’t know where to go.
- Don’t have money
DESPARATELY NEED!! No one seems to know where I should go—legal aid, etc.

Credit bad- people on my ASS!

Can’t get a job- discrimination?

Not available

Need for will and etc.

Don’t know who to call

I could use some help with a will (n=3)

Financial burden

Adoption/Foster Care for Children:

Money, I would love to adopt.

Social/Recreation Activities:

Not into drama or queens 😐

Not available for straight men

Can’t afford to do much myself and YAP stopped with social support

Not available (n=2)

I just stay home

Transportation

Rural area MT- Sheridan

Distance/cost/energy

Cannot afford

Not available (n=2)

Due to distance

Don’t know how/where to get it

Does this exist here?

None available in small town

Too far/ at night/ can’t afford

Don’t know where to get

Buddy/Companion Volunteer Support:

Everyone too busy.

Not offered

Not available (n=4)

Small town/low population

Don’t know where to get

Too far/ at night/ can’t afford

There are not any support groups that I am aware of

Montana legal services only helps Indians (n=2)

Don’t know how.

Available?

Will need when released from prison (n=2)

In prison

Don’t know where to look

Don’t’ know where to turn.

Can’t afford and question if available

Doesn’t seem available

State services are difficult to contact

There are not any support groups that I am aware of

I am isolated

Seems AIDS CBOs don’t want to follow through

Too infrequent/ too far

Don’t know how.

Would love to go to a gym to try and keep muscles toned but can’t afford.

Not sure if available

Will need when released from prison (n=3)

In prison

Will need later

Scared to go to support

Can’t afford and no HIV support system

Lack of resources

Don’t know of any recreation

Conscious on doing it.

I am isolated

Would be nice, besides family

Don’t know how to ask

Don’t know how.

Will need when released from prison (n=3)

In prison

Will need later

Didn’t know I could

Fear of discrimination/stereotype

Not too available in Missoula
Support Groups / Peer Counseling:
- Death of this sort of
- Transportation and evening hours of groups are too late at night
- Not available (n=4)
- People are not confidential - it’s not support if everyone finds out you are positive and all the details go with it.
- Small town/low population
- Distance/energy
- Live in small town
- Too far/ at night/ can’t afford
- Don’t know where to get

Spiritual Support:
- None available
- Transportation
- No accepting church in my area

Other:
- I’m quite sure that these areas that I don’t have a need for there are others that do.
- Support group - not available
- Being heterosexual - not much support
- Psychological

Open-Ended Questions related to Assistance & Treatment Needs

Respondents (n=166) were asked to answer two open-ended questions referencing the need and availability of assistance and treatments. The number of participants who responded and their responses to each question are as follows:

Question #1: Are there other forms of help that we have not mentioned that you would like to have access to, or are currently using?

The respondents who replied to this question reported the following:

Medical Care and Related Needs:
- Massage, acupuncture, homeopathy, natural remedies monetary help for herbs and vitamins (n=7)
- Financial assistance with medications (n=3)
- Financial assistance with x-rays (n=1)
- Help paying Medicaid (n=1)
- Free HIV/AIDS testing for immediate family (n=1)
• Help with prescription benefits (n=1)
• Help balancing finances from work and SSI for medical help. (Unable to work and still be accepted for SSI). (n=1)
• Would like assistance paying remaining doctor bills that are remaining after Medicare pays its share (n=1)
• Over the counter drugs: Gloves, sharp containers for lancets (n=1)
• Help with unpaid medical expenses (n=1)
• Help with all my small medical bills (n=1)
• Prescription drugs assistance (non-HIV) (n=1)
• Assistance with finding a doctor who will prescribe something for chronic pain related to neuropathy for someone who has a history of drug addiction but has been clean for eight years (n=1)
• Helena needs an HIV specialist (n=1)

Basic Needs Assistance:
• Assistance with gym membership and/or fitness and exercise programs (n=2)
• Financial assistance with home repairs, auto repairs, car insurance (n=1)
• Help with pet care and house work help after surgeries (n=1)
• Help with paperwork for housing assistance (n=1)
• Financial assistance with higher education (n=1)
• Educational classes that teach crafts/trade (n=1)
• Affordable housing (n=1)
• Help finding work (n=1)
• Assistance with putting bills on hold when sick (n=1)
• Help with cashing in my life insurance (n=1)
• Affordable housing and basic needs when released from prison (n=1)
• More assistance with financial aid as food stamps (n=1)
• Help paying for healthy, fresh foods (n=1)

Counseling and Social Support Needs:
• Updated information on meds and HIV/AIDS in general (n=2)
• Heterosexual support groups (n=1)
• Outreach to the gay community (n=1)
• Self-help through exercise (n=1)
• Help dealing with anxiety, suicidal thoughts and anger (n=1)
• Smoking cessation assistance (n=1)
• Help getting a Metaphysical support group started (n=1)

Other:
• Assistance with all assistance and treatment in prison (n=1)

Question #2: Are there forms of help listed above and on the previous page that you do not need now, but think you may need in the future? If so, please specify them in the space below.

Medical Care and Related Needs:
• Dental care (n=11)
• Eye care (n=8)
• Medical Equipment (n=8)
  □ One respondent has crutches but did not have a wheelchair (n=1)
• Overall medical care (n=5)
• Financial assistance with medications (n=3)
• Financial assistance with medical help (n=3)
• Care giver/nurse assistance (n=3)
- Financial assistance with insurance (n=3)
  - Assistance with Medicare/Medicaid (n=3)
  - Coverage for drugs, doctors (n=1)
- Assistance with co-pays for medication/all medical help (blood work, doctor visits, etc.) (n=2)
- Physical or occupational therapy (n=2)
- Help with spend-down (n=1)
- Financial assistance with non-HIV related prescriptions (n=1)
- Assistance with more invasive medical assistance (colonoscopy, etc.) hospitalization (n=1)

**Basic Assistance Needs:**
- Assistance with paying utility bills (n=12)
- Travel expenses/transportation (n=10)
  - Car insurance (n=1)
  - Help getting car fixed to be more independent (n=2)
- Help with groceries/home delivered meals/food (n=9)
- Financial assistance with utility bills (n=6)
  - Telephone assistance (n=1)
- Assistance with clothing (n=4)
- Assistance with putting bills on hold when sick (n=1)
- Assistance with adopting step children (n=1)
- Assistance with paperwork (n=1)
- Internet assistance (n=1)
- Financial resources in case of emergency; CBOs are restricted in how much & how many times that help can be accessed (n=1)

**Counseling and Social Support Needs:**
- Legal assistance (n=6)
  - Legal assistance not directly related to HIV (n=1)
  - A living Will (n=1)
  - Bankruptcy assistance (n=1)
  - A need to have every one to recognize my love for my partner by being able to marry him.
- Practical support (n=7)
- Support groups/peer counseling (n=6)
- Buddy/companion (n=5)
- Spiritual support (n=3)
- Social/recreation activities (n=2)
- Counseling (n=2)
- Case management (n=1)
  - Help with house cleaning/chores (n=4)
- Assistance with the adoption of a child (n=1)
- Childcare assistance (n=1)
  - Childcare for child when gone (dead) (n=1)

**Other:**
- I will need a lot of help/everything when I am released from prison (n=6)
- All of the above (n=3)
Barriers to Assistance

Respondents were given a list of possible problems that may arise when trying to obtain or use HIV and AIDS services. They were asked to mark an X on the line beside each item to say how big a problem it had been for them. Table 20 explains barriers. Most frequently 'big barriers' are listed first, proceeding to the issue least frequently reported as a 'big barrier'.

Table 20. Barriers

<table>
<thead>
<tr>
<th>Barrier</th>
<th># of respondents</th>
<th>Big Barrier</th>
<th>Small Barrier</th>
<th>Not a Barrier</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Not having insurance coverage.</td>
<td>n=162</td>
<td>34%</td>
<td>11%</td>
<td>52%</td>
</tr>
<tr>
<td>2. The cost of assistance or treatment.</td>
<td>n=163</td>
<td>27%</td>
<td>29%</td>
<td>42%</td>
</tr>
<tr>
<td>3. Not knowing what service or treatment is available to me/lack of services.</td>
<td>n=163</td>
<td>25%</td>
<td>33%</td>
<td>40%</td>
</tr>
<tr>
<td>4. Burnout from dealing with/ talking about HIV.</td>
<td>n=159</td>
<td>25%</td>
<td>33%</td>
<td>39%</td>
</tr>
<tr>
<td>5. My concern that other people may see me when I go to get care or learn about my HIV infection (lack of confidentiality/stigma).</td>
<td>n=162</td>
<td>24%</td>
<td>18%</td>
<td>57%</td>
</tr>
<tr>
<td>6. The location of the organization providing services.</td>
<td>n=162</td>
<td>20%</td>
<td>18%</td>
<td>60%</td>
</tr>
<tr>
<td>7. Not knowing who to ask for help.</td>
<td>n=163</td>
<td>20%</td>
<td>30%</td>
<td>48%</td>
</tr>
<tr>
<td>8. My state of mind or mental ability to deal with the treatment.</td>
<td>n=162</td>
<td>19%</td>
<td>33%</td>
<td>46%</td>
</tr>
<tr>
<td>9. Not having transportation.</td>
<td>n=161</td>
<td>17%</td>
<td>15%</td>
<td>66%</td>
</tr>
<tr>
<td>10. Discrimination I experienced by the persons or organization providing the services.</td>
<td>n=162</td>
<td>15%</td>
<td>14%</td>
<td>69%</td>
</tr>
<tr>
<td>11. Lack of experience or expertise of the person providing services to me.</td>
<td>n=161</td>
<td>13%</td>
<td>22%</td>
<td>62%</td>
</tr>
<tr>
<td>12. The amount of time I had to wait to get an appointment or to see someone.</td>
<td>n=163</td>
<td>11%</td>
<td>22%</td>
<td>65%</td>
</tr>
<tr>
<td>13. The quality of assistance or treatment.</td>
<td>n=160</td>
<td>10%</td>
<td>24%</td>
<td>62%</td>
</tr>
<tr>
<td>14. My physical health.</td>
<td>n=162</td>
<td>10%</td>
<td>31%</td>
<td>57%</td>
</tr>
<tr>
<td>15. Not knowing what medical assistance or treatment I need to treat my HIV or AIDS infection.</td>
<td>n=162</td>
<td>9%</td>
<td>16%</td>
<td>72%</td>
</tr>
<tr>
<td>16. Other</td>
<td>n=15</td>
<td>6%</td>
<td>3%</td>
<td>--</td>
</tr>
<tr>
<td>17. The hours when services were offered were unreliable or inconsistent.</td>
<td>n=162</td>
<td>5%</td>
<td>16%</td>
<td>77%</td>
</tr>
</tbody>
</table>
Other barriers included:

- My mental state in coping with AIDS and what to expect
- Doctors don't follow through
- Neuropathy in feet- do not drive
- Other than Deering Clinic, the lack of understanding and compassion by providers and hospital staff
- Paperwork
- Red tape-too many different agencies doing same thing
- the cost of Medicaid incurred
- The fact that it is still hard to talk and deal with the fact I have HIV/AIDS.
- Not having a reliable car- can’t afford insurance or maintenance.
- Having to drive
- Fear of discrimination biggest barrier
- I have had to pay out of pocket for dental before I found out about Partnership.
- Can’t be employed yet not qualified for SSD.
- The distance I have to travel
- $ for extra alternative support therapies
- This place (prison) sucks and I can’t get answers.
- When working not able to afford treatment.
- My health- dealing with depression.
- Can’t see doc when I want or need to (because I am in prison)
- Attitude of staff and guards (in prison)
- These people (in prison) don’t tell us anything and don’t help us.
- I’m scared to come out and be treated the same way (in prison).
- Service is bad in here- can’t always see doctor (prison)
- Worried about how I will be treated out there (outside prison)
- Discrimination, isolation and bad care in here (prison)
- People’s prejudices
- Lack of anonymity
- Not enough information out there.
- The staff is wonderful but I don’t like running into people I know who have no clue I am HIV+ (Billings)
- Activist groups play politics and double standard

Biggest Barriers

Of all the barriers the survey listed, excluding ‘other’ barriers listed, respondents were asked what they believed to be the biggest barriers faced when trying to get HIV related services.

The number of respondents believing the barrier was the biggest is as follows.
As shown above, the most frequently reported barriers were as follows:

1) Not having insurance coverage (n=28)
2) Burnout from dealing with/talking about HIV (n=26)
3) The cost of assistance or treatment (n=20)

_Prevention and Information Dissemination_

_Prevention_

Respondents (n=157) were asked what kinds of things might have helped them to avoid infection with HIV. See Table 21 for responses:

**Table 21. Avoiding Infection**

<table>
<thead>
<tr>
<th>Things that might have helped</th>
<th>Percent (%)</th>
<th>Frequency (n)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Being more aware that infection with HIV was a possibility for me</td>
<td>58%</td>
<td>n=96</td>
</tr>
<tr>
<td>Knowing the importance of talking to a sex partner about his or her HIV status</td>
<td>36%</td>
<td>n=60</td>
</tr>
<tr>
<td>Being more knowledgeable about how HIV is transmitted</td>
<td>34%</td>
<td>n=56</td>
</tr>
<tr>
<td>Knowing how to bring up the subject of condoms with a sex partner</td>
<td>29%</td>
<td>n=48</td>
</tr>
<tr>
<td>Getting treatment for depression or other emotional problems</td>
<td>20%</td>
<td>n=33</td>
</tr>
<tr>
<td>Getting treatment for a substance abuse problem</td>
<td>14%</td>
<td>n=23</td>
</tr>
<tr>
<td>Knowing where to find clean needles or clean works</td>
<td>7%</td>
<td>n=11</td>
</tr>
<tr>
<td>Other.</td>
<td>32%</td>
<td>n=53</td>
</tr>
</tbody>
</table>

* Percentages do not add up to 100. Respondents checked all that applied.

_Other_ statements included:

- Back in the 80s none of us knew (n=6)
- Knowing my partner was not monogamous
- Drugs and sexual addiction
- I asked my ex- but he lied and told me that he had cancer
- I started having safe sex in 1982. I had no idea I was infected until testing in August or 1987.
- If I would have known he was bisexual
- I knew all of this. Severe drug addiction kept me from caring
- Knowing you get AIDS orally- not a bottom, and always used condoms, bare teeth bleeding
- Social acceptance of gays
- Just not being stupid
- Being told sooner as a health care provider about AIDS and its severity.
- Military (especially overseas) use sterile equipment, using equipment such as needles and syringes only once, follow prescribed infectious disease guidelines of CDC and NIH.
- None- I fell in love! Dumb huh?
- Any education
- My partner is HIV+ and when we met so becoming HIV+ was, I guess you would say, my own doing.
- Being clean and sober.
Was so long ago I was stupid about everything-didn’t know my current partner was HIV+ at that time.

I was well aware of the risk and avoiding it. It was a freak accident- condom broke!

Know partner’s status

Not being a player-sleeping with so many people.

I got mine by not using any type of protection

This was an infection brought home to me- just a betrayal after a 14 year relationship.

Always wear a condom!

No diagnostic tests at that time and as a nurse- came in direct contact with blood on open wound and needle stick.

Media and prevention work focus mainly on MSM community leaves false sense of security

Not believing everything a man says.

**Information Dissemination**

Respondents (n=163) were asked the best way the public health department and the Ryan White Care Program could get information about prevention, treatment, and services to them. Table 22 show results.

**Table 22. Information Dissemination**

<table>
<thead>
<tr>
<th>Information Source</th>
<th>Percent (%)</th>
<th>Frequency (n)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Health care provider – doctors, nurses, etc.</td>
<td>68%</td>
<td>n=112</td>
</tr>
<tr>
<td>Case managers</td>
<td>63%</td>
<td>n=105</td>
</tr>
<tr>
<td>Peers and friends</td>
<td>45%</td>
<td>n=75</td>
</tr>
<tr>
<td>Community educational events like health fairs</td>
<td>40%</td>
<td>n=66</td>
</tr>
<tr>
<td>Movies / television clips / television commercials / magazines</td>
<td>40%</td>
<td>n=66</td>
</tr>
<tr>
<td>Internet / web based information</td>
<td>39%</td>
<td>n=65</td>
</tr>
<tr>
<td>Advertisements or articles in newspapers</td>
<td>34%</td>
<td>n=66</td>
</tr>
<tr>
<td>Billboards</td>
<td>28%</td>
<td>n=46</td>
</tr>
<tr>
<td>Announcements on the radio (Which stations are best?)</td>
<td>27%</td>
<td>n=44</td>
</tr>
<tr>
<td>Other ways that we can get information to you?</td>
<td>12%</td>
<td>n=20</td>
</tr>
</tbody>
</table>

* Percentages do not add up to 100. Respondents checked all that applied.

Radio stations mentioned included:

- Younger crowd music stations
- 93.3- Missoula
- Hot 101.9- Billings

100.5- Missoula
- FM (n=2)
- 97.1- Billings
- All

*Other* statements included:

- All of these can be effective in raising public awareness.
- All of the above
- Information letters as to where the help is located
- Mail (n=6)
- Communicating with each other—just share what you know, what you feel, just communicate
- “Gay friendly” places, bars and bookstores.
Support groups
Families need to know, some think using the same restrooms causes contraction. They have more articles on AIDS than HIV/ HIV patients need more information on HIV.
E-mail
Mail/newsletters/flyers
More media coverage/ focus Montana on spread of HIV community and 3rd world.
Anything you can think of.

Comparison of Sub-Groups of HIV Positive People in Montana

Questionnaire data was used to compare the service needs and the barriers to obtaining services of several sub-groups of HIV positive individuals. The following groups were compared: a) Native Americans compared to whites; b) females compared to males; c) heterosexual males compared to gay males; and d) IDUs to non-IDUs.

When looking at the data comparing sub-groups, it is very important to keep in mind the large differences in the number of people belonging to each sub-group. In sub-groups with a very small number of people, two or three people expressing a need for a service or reporting the existence of a barrier can greatly affect the overall percentage. As a result, it is difficult to interpret this data.

Table 23. Females compared to Males

<table>
<thead>
<tr>
<th>Needs</th>
<th>Female</th>
<th>Male</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>n=35</td>
<td>n=128</td>
</tr>
<tr>
<td><strong>Medical and Related Needs</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Nutritional Counseling</td>
<td>3%</td>
<td>10%</td>
</tr>
<tr>
<td>Help paying for Medical Insurance</td>
<td>20%</td>
<td>29%</td>
</tr>
<tr>
<td>Dental Care</td>
<td>17%</td>
<td>25%</td>
</tr>
<tr>
<td><strong>Basic Needs</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Assistance with paying utility bills</td>
<td>11%</td>
<td>19%</td>
</tr>
<tr>
<td>Transportation</td>
<td>9%</td>
<td>17%</td>
</tr>
<tr>
<td><strong>Counseling, Treatment &amp; Support Needs</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Child Care</td>
<td>9%</td>
<td>1.6%</td>
</tr>
<tr>
<td>Support groups/Peer counseling</td>
<td>11%</td>
<td>27%</td>
</tr>
<tr>
<td>Big Barriers</td>
<td>Female</td>
<td>Male</td>
</tr>
<tr>
<td>-----------------------------------------------------------------------------</td>
<td>--------</td>
<td>-------</td>
</tr>
<tr>
<td>n=35</td>
<td>n=128</td>
<td></td>
</tr>
<tr>
<td>Location of the organization providing the services</td>
<td>14%</td>
<td>21%</td>
</tr>
<tr>
<td>Physical Health</td>
<td>--</td>
<td>13%</td>
</tr>
<tr>
<td>Quality of assistance or treatment</td>
<td>3%</td>
<td>13%</td>
</tr>
<tr>
<td>Not having transportation</td>
<td>6%</td>
<td>19%</td>
</tr>
<tr>
<td>Cost of assistance or treatment</td>
<td>20%</td>
<td>29%</td>
</tr>
<tr>
<td>Not having insurance coverage</td>
<td>23%</td>
<td>37%</td>
</tr>
<tr>
<td>Burnout from dealing with/talking about HIV</td>
<td>11%</td>
<td>28%</td>
</tr>
</tbody>
</table>

**Table 24. Heterosexual Males compared to Gay Males**

<table>
<thead>
<tr>
<th>Needs</th>
<th>Hetero Males</th>
<th>Gay Males</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Medical and Related Needs</strong></td>
<td>n=19</td>
<td>n=98</td>
</tr>
<tr>
<td>Physical or Occupational Therapy</td>
<td>26%</td>
<td>9%</td>
</tr>
<tr>
<td>Financial assistance with medications</td>
<td>5%</td>
<td>12%</td>
</tr>
<tr>
<td>Eye care</td>
<td>11%</td>
<td>16%</td>
</tr>
<tr>
<td>Dental care</td>
<td>16%</td>
<td>25%</td>
</tr>
</tbody>
</table>

| Basic Needs                                      |              |           |
| Assistance with paying utility bills             | 11%          | 20%       |
| Housing or rent assistance                       | 5%           | 20%       |
| Home delivered meals/groceries                  | --           | 5%        |

| Counseling, Treatment & Support Needs            |              |           |
| Case management services                         | --           | 7%        |
| Child Care                                       | 11%          | --        |
| Support groups/Peer counseling                   | 32%          | 24%       |
| Buddy/Companion volunteer support                | 32%          | 24%       |

<table>
<thead>
<tr>
<th>Big Barriers</th>
<th>Heterosexuals</th>
<th>Gay Males</th>
</tr>
</thead>
<tbody>
<tr>
<td>n=19</td>
<td>n=98</td>
<td></td>
</tr>
<tr>
<td>Not knowing what service or treatment is available to me/lack of services</td>
<td>16%</td>
<td>24%</td>
</tr>
<tr>
<td>Location of the organization providing the services</td>
<td>16%</td>
<td>21%</td>
</tr>
<tr>
<td>Quality of assistance or treatment</td>
<td>21%</td>
<td>10%</td>
</tr>
<tr>
<td>Not having transportation</td>
<td>37%</td>
<td>14%</td>
</tr>
<tr>
<td>Not knowing who to ask for help</td>
<td>32%</td>
<td>14%</td>
</tr>
<tr>
<td>Lack of confidentiality/stigma</td>
<td>37%</td>
<td>18%</td>
</tr>
<tr>
<td>Hours when services were offered were unreliable or inconsistent</td>
<td>11%</td>
<td>4%</td>
</tr>
<tr>
<td>Cost of assistance or treatment</td>
<td>37%</td>
<td>25%</td>
</tr>
<tr>
<td>Burnout from dealing with/talking about HIV</td>
<td>21%</td>
<td>28%</td>
</tr>
</tbody>
</table>
Table 25. Native Americans compared to Whites

<table>
<thead>
<tr>
<th>Big Barriers</th>
<th>Native Americans</th>
<th>Whites</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Medical and Related Needs</strong></td>
<td>n=16</td>
<td>n=146</td>
</tr>
<tr>
<td>Physical or Occupational Therapy</td>
<td>6%</td>
<td>14%</td>
</tr>
<tr>
<td><strong>Basic Needs</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Home delivered meals/groceries</td>
<td>13%</td>
<td>3%</td>
</tr>
<tr>
<td>Clothing</td>
<td>--</td>
<td>10%</td>
</tr>
<tr>
<td>Transportation</td>
<td>6%</td>
<td>16%</td>
</tr>
<tr>
<td>Practical support</td>
<td>--</td>
<td>8%</td>
</tr>
<tr>
<td><strong>Counseling, Treatment &amp; Support Needs</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Legal services</td>
<td>25%</td>
<td>19%</td>
</tr>
<tr>
<td>Support groups/Peer counseling</td>
<td>19%</td>
<td>24%</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Big Barriers</th>
<th>Native Americans</th>
<th>Whites</th>
</tr>
</thead>
<tbody>
<tr>
<td>Not knowing what service or treatment is available to</td>
<td>19%</td>
<td>25%</td>
</tr>
<tr>
<td>me/lack of services</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Location of the organization providing the services</td>
<td>25%</td>
<td>19%</td>
</tr>
<tr>
<td>State of mind or mental ability to deal with treatment</td>
<td>6%</td>
<td>20%</td>
</tr>
<tr>
<td>Not knowing who to ask for help</td>
<td>6%</td>
<td>21%</td>
</tr>
<tr>
<td>Hours when services were offered were unreliable or</td>
<td>13%</td>
<td>3%</td>
</tr>
<tr>
<td>inconsistent</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Amount of time to wait to get an appointment or to see</td>
<td>19%</td>
<td>10%</td>
</tr>
<tr>
<td>someone</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Not having insurance coverage</td>
<td>50%</td>
<td>34%</td>
</tr>
<tr>
<td>Cost of assistance or treatment</td>
<td>37%</td>
<td>25%</td>
</tr>
<tr>
<td>Burnout from dealing with/talking about HIV</td>
<td>19%</td>
<td>27%</td>
</tr>
</tbody>
</table>
### Table 26. IDU compared to non-IDU

<table>
<thead>
<tr>
<th>Needs</th>
<th>Non-IDU n=155</th>
<th>IDU n=10</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Medical and Related Needs</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Physical or Occupational Therapy</td>
<td>14%</td>
<td>30%</td>
</tr>
<tr>
<td>Nutritional counseling</td>
<td>10%</td>
<td>-</td>
</tr>
<tr>
<td>Financial assistance with medications</td>
<td>12%</td>
<td>30%</td>
</tr>
<tr>
<td>Medical care</td>
<td>7%</td>
<td>20%</td>
</tr>
<tr>
<td>Help paying for medical insurance</td>
<td>25%</td>
<td>70%</td>
</tr>
<tr>
<td>Eye care</td>
<td>15%</td>
<td>50%</td>
</tr>
<tr>
<td>Dental care</td>
<td>23%</td>
<td>30%</td>
</tr>
<tr>
<td><strong>Basic Needs</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Assistance with paying utility bills</td>
<td>16%</td>
<td>40%</td>
</tr>
<tr>
<td>Housing or rent assistance</td>
<td>17%</td>
<td>40%</td>
</tr>
<tr>
<td>Home delivered meals/groceries</td>
<td>5%</td>
<td>10%</td>
</tr>
<tr>
<td>Transportation</td>
<td>16%</td>
<td>30%</td>
</tr>
<tr>
<td><strong>Counseling, Treatment &amp; Support Needs</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Information and referral for services</td>
<td>9%</td>
<td>20%</td>
</tr>
<tr>
<td>Child Care</td>
<td>3%</td>
<td>10%</td>
</tr>
<tr>
<td>Social/Recreation Activities</td>
<td>25%</td>
<td>50%</td>
</tr>
<tr>
<td>Buddy/Companion volunteer support</td>
<td>27%</td>
<td>20%</td>
</tr>
<tr>
<td>Support groups/peer counseling</td>
<td>23%</td>
<td>50%</td>
</tr>
<tr>
<td><strong>Big Barriers</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Not knowing what service or treatment is</td>
<td>23%</td>
<td>60%</td>
</tr>
<tr>
<td>available/lack of services</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Location of the organization providing the services</td>
<td>17%</td>
<td>50%</td>
</tr>
<tr>
<td>Physical health</td>
<td>9%</td>
<td>20%</td>
</tr>
<tr>
<td>Quality of assistance or treatment</td>
<td>9%</td>
<td>20%</td>
</tr>
<tr>
<td>Not knowing what medical assistance or treatment is needed to treat HIV or AIDS infection.</td>
<td>8%</td>
<td>20%</td>
</tr>
<tr>
<td>State of mind or mental ability to deal with the treatment</td>
<td>16%</td>
<td>70%</td>
</tr>
<tr>
<td>Not having transportation</td>
<td>17%</td>
<td>10%</td>
</tr>
<tr>
<td>Not knowing who to ask for help</td>
<td>19%</td>
<td>30%</td>
</tr>
<tr>
<td>Lack of confidentiality/stigma</td>
<td>23%</td>
<td>30%</td>
</tr>
<tr>
<td>Discrimination experienced by the persons or organization providing services</td>
<td>13%</td>
<td>40%</td>
</tr>
<tr>
<td>Lack of experience or expertise of the person providing services to me</td>
<td>12%</td>
<td>30%</td>
</tr>
<tr>
<td>Hours when services were offered were unreliable or inconsistent</td>
<td>5%</td>
<td>10%</td>
</tr>
<tr>
<td>Amount of time to wait to get an appointment or to see someone</td>
<td>10%</td>
<td>30%</td>
</tr>
<tr>
<td>Cost of assistance or treatment</td>
<td>25%</td>
<td>50%</td>
</tr>
<tr>
<td>Not having insurance coverage</td>
<td>32%</td>
<td>50%</td>
</tr>
<tr>
<td>Burnout from dealing with/talking about HIV</td>
<td>23%</td>
<td>50%</td>
</tr>
</tbody>
</table>
Comparison of the Seven Ryan White Title II Sites

Treatment use and availability was considered for each of the seven health planning regions.

Respondents who answered 'need, can’t get' are noted below.

Table 27. Medical Assistance Needs & Treatment per Region

<table>
<thead>
<tr>
<th>Medical and Related Assistance &amp; Treatment Needs</th>
<th>Gr. Falls n=21</th>
<th>Helena n=10</th>
<th>Butte n=12</th>
<th>Billings n=43</th>
<th>Missoula n=37</th>
<th>Kalispell n=15</th>
<th>Bozeman n=4</th>
</tr>
</thead>
<tbody>
<tr>
<td>Treatment adherence support</td>
<td>5% (n=1)</td>
<td>20% (n=2)</td>
<td>8% (n=1)</td>
<td>--</td>
<td>3% (n=1)</td>
<td>--</td>
<td>--</td>
</tr>
<tr>
<td>Physical or Occupational Therapy</td>
<td>24% (n=5)</td>
<td>30% (n=3)</td>
<td>25% (n=3)</td>
<td>9% (n=4)</td>
<td>14% (n=5)</td>
<td>--</td>
<td>--</td>
</tr>
<tr>
<td>Nutritional counseling</td>
<td>14% (n=3)</td>
<td>20% (n=2)</td>
<td>8% (n=1)</td>
<td>5% (n=2)</td>
<td>8% (n=3)</td>
<td>--</td>
<td>--</td>
</tr>
<tr>
<td>Medical Equipment</td>
<td>--</td>
<td>10% (n=1)</td>
<td>8% (n=1)</td>
<td>2% (n=1)</td>
<td>--</td>
<td>--</td>
<td>--</td>
</tr>
<tr>
<td>Financial assistance with medications</td>
<td>5% (n=1)</td>
<td>20% (n=2)</td>
<td>33% (n=4)</td>
<td>7% (n=3)</td>
<td>11% (n=4)</td>
<td>--</td>
<td>--</td>
</tr>
<tr>
<td>Medical care</td>
<td>--</td>
<td>10% (n=1)</td>
<td>8% (n=1)</td>
<td>7% (n=3)</td>
<td>--</td>
<td>7% (n=1)</td>
<td>--</td>
</tr>
<tr>
<td>Help paying for medical insurance</td>
<td>24% (n=5)</td>
<td>30% (n=3)</td>
<td>50% (n=6)</td>
<td>23% (n=10)</td>
<td>22% (n=8)</td>
<td>40% (n=6)</td>
<td>--</td>
</tr>
<tr>
<td>Eye care</td>
<td>5% (n=1)</td>
<td>10% (n=1)</td>
<td>42% (n=5)</td>
<td>12% (n=5)</td>
<td>11% (n=4)</td>
<td>7% (n=1)</td>
<td>25% (n=1)</td>
</tr>
<tr>
<td>Dental care</td>
<td>10% (n=2)</td>
<td>10% (n=1)</td>
<td>50% (n=6)</td>
<td>14% (n=9)</td>
<td>24% (n=5)</td>
<td>33% (n=5)</td>
<td>50% (n=2)</td>
</tr>
</tbody>
</table>
Table 28. Basic Assistance & Treatment Needs per Region

<table>
<thead>
<tr>
<th></th>
<th>G. Falls n=21</th>
<th>Helena n=10</th>
<th>Butte n=12</th>
<th>Billings n=43</th>
<th>Missoula n=37</th>
<th>Kalispell n=15</th>
<th>Bozeman n=4</th>
</tr>
</thead>
<tbody>
<tr>
<td>Assistance with paying utility bills</td>
<td>24% (n=5)</td>
<td>10% (n=1)</td>
<td>17% (n=2)</td>
<td>19% (n=8)</td>
<td>8% (n=3)</td>
<td>13% (n=2)</td>
<td>25% (n=1)</td>
</tr>
<tr>
<td>Housing or rent assistance</td>
<td>19% (n=4)</td>
<td>30% (n=3)</td>
<td>17% (n=2)</td>
<td>28% (n=12)</td>
<td>3% (n=1)</td>
<td>--</td>
<td>25% (n=1)</td>
</tr>
<tr>
<td>Home delivered meals/groceries</td>
<td>14% (n=3)</td>
<td>20% (n=2)</td>
<td>8% (n=1)</td>
<td>2% (n=1)</td>
<td>--</td>
<td>7% (n=1)</td>
<td>--</td>
</tr>
<tr>
<td>Housing or rent assistance</td>
<td>19% (n=4)</td>
<td>40% (n=4)</td>
<td>17% (n=2)</td>
<td>7% (n=3)</td>
<td>8% (n=3)</td>
<td>20% (n=3)</td>
<td>--</td>
</tr>
<tr>
<td>Transportation</td>
<td>14% (n=3)</td>
<td>30% (n=3)</td>
<td>8% (n=1)</td>
<td>5% (n=2)</td>
<td>3% (n=1)</td>
<td>7% (n=1)</td>
<td>--</td>
</tr>
<tr>
<td>Clothing</td>
<td>14% (n=3)</td>
<td>20% (n=2)</td>
<td>8% (n=1)</td>
<td>9% (n=4)</td>
<td>3% (n=1)</td>
<td>7% (n=1)</td>
<td>--</td>
</tr>
<tr>
<td>Practical support</td>
<td>10% (n=2)</td>
<td>20% (n=2)</td>
<td>8% (n=1)</td>
<td>9% (n=4)</td>
<td>3% (n=1)</td>
<td>7% (n=1)</td>
<td>--</td>
</tr>
</tbody>
</table>

Table 29. Counseling & Other Support Needs per Region

<table>
<thead>
<tr>
<th></th>
<th>G. Falls n=21</th>
<th>Helena n=10</th>
<th>Butte n=12</th>
<th>Billings n=43</th>
<th>Missoula n=37</th>
<th>Kalispell n=15</th>
<th>Bozeman n=4</th>
</tr>
</thead>
<tbody>
<tr>
<td>Case management services</td>
<td>5% (n=1)</td>
<td>--</td>
<td>17% (n=2)</td>
<td>7% (n=3)</td>
<td>5% (n=2)</td>
<td>--</td>
<td>--</td>
</tr>
<tr>
<td>Information and referral for services</td>
<td>5% (n=1)</td>
<td>30% (n=3)</td>
<td>17% (n=2)</td>
<td>2% (n=1)</td>
<td>--</td>
<td>7% (n=1)</td>
<td>--</td>
</tr>
<tr>
<td>Child care</td>
<td>--</td>
<td>20% (n=2)</td>
<td>--</td>
<td>--</td>
<td>3% (n=1)</td>
<td>7% (n=1)</td>
<td>--</td>
</tr>
<tr>
<td>Legal services</td>
<td>24% (n=5)</td>
<td>20% (n=2)</td>
<td>33% (n=4)</td>
<td>9% (n=4)</td>
<td>22% (n=8)</td>
<td>7% (n=1)</td>
<td>25% (n=1)</td>
</tr>
<tr>
<td>Adoption/Foster care for children</td>
<td>--</td>
<td>--</td>
<td>--</td>
<td>7% (n=3)</td>
<td>--</td>
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</tr>
<tr>
<td>Social/Recreation Activities</td>
<td>29% (n=6)</td>
<td>40% (n=4)</td>
<td>25% (n=3)</td>
<td>9% (n=4)</td>
<td>32% (n=12)</td>
<td>20% (n=3)</td>
<td>50% (n=2)</td>
</tr>
<tr>
<td>Buddy/Companion volunteer support</td>
<td>14% (n=3)</td>
<td>20.0% (n=2)</td>
<td>42% (n=5)</td>
<td>21% (n=9)</td>
<td>24% (n=9)</td>
<td>20% (n=3)</td>
<td>75% (n=3)</td>
</tr>
<tr>
<td>Support groups/peer counseling</td>
<td>24% (n=5)</td>
<td>50% (n=5)</td>
<td>25% (n=3)</td>
<td>9% (n=4)</td>
<td>22% (n=8)</td>
<td>13% (n=2)</td>
<td>75% (n=3)</td>
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<tr>
<td>Spiritual support</td>
<td>5% (n=1)</td>
<td>10% (n=1)</td>
<td>8% (n=1)</td>
<td>--</td>
<td>14% (n=5)</td>
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</tr>
</tbody>
</table>

PLWH/A from each of the seven health regions responded to a list of possible barriers to assistance and treatment needs. The percentage of PLWH/A for each region who felt the listed problem was a ‘big barrier’ is listed on the following page:

76
<table>
<thead>
<tr>
<th>Table 30. REGIONAL BARRIERS</th>
<th>Great Falls n=21</th>
<th>Helena n=10</th>
<th>Butte n=12</th>
<th>Billings n=43</th>
<th>Missoula n=37</th>
<th>Kalispell n=15</th>
<th>Bozeman n=4</th>
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</thead>
<tbody>
<tr>
<td>Not knowing what service or treatment is available/lack of services</td>
<td>33% (n=7)</td>
<td>30% (n=3)</td>
<td>25% (n=3)</td>
<td>26% (n=11)</td>
<td>16% (n=6)</td>
<td>7% (n=1)</td>
<td>25% (n=1)</td>
</tr>
<tr>
<td>Location of the organization providing the services</td>
<td>3% (n=6)</td>
<td>30% (n=3)</td>
<td>25% (n=3)</td>
<td>9% (n=4)</td>
<td>11% (n=4)</td>
<td>13% (n=2)</td>
<td>--</td>
</tr>
<tr>
<td>Physical health</td>
<td>10% (n=2)</td>
<td>30% (n=3)</td>
<td>--</td>
<td>7% (n=3)</td>
<td>14% (n=5)</td>
<td>--</td>
<td>--</td>
</tr>
<tr>
<td>Quality of assistance or treatment</td>
<td>19% (n=4)</td>
<td>20% (n=2)</td>
<td>17% (n=2)</td>
<td>12% (n=5)</td>
<td>3% (n=1)</td>
<td>7% (n=1)</td>
<td>--</td>
</tr>
<tr>
<td>Not knowing what medical assistance or treatment is needed</td>
<td>14% (n=3)</td>
<td>20% (n=2)</td>
<td>--</td>
<td>7% (n=3)</td>
<td>--</td>
<td>--</td>
<td>--</td>
</tr>
<tr>
<td>State of mind or mental ability to deal with treatment</td>
<td>43% (n=9)</td>
<td>40% (n=4)</td>
<td>17% (n=2)</td>
<td>7% (n=3)</td>
<td>8% (n=3)</td>
<td>7% (n=1)</td>
<td>--</td>
</tr>
<tr>
<td>Not having transportation</td>
<td>10% (n=2)</td>
<td>30% (n=3)</td>
<td>17% (n=2)</td>
<td>5% (n=2)</td>
<td>16% (n=6)</td>
<td>20% (n=3)</td>
<td>--</td>
</tr>
<tr>
<td>Not knowing who to ask for help</td>
<td>19% (n=4)</td>
<td>40% (n=4)</td>
<td>33% (n=4)</td>
<td>14% (n=6)</td>
<td>14% (n=5)</td>
<td>7% (n=1)</td>
<td>--</td>
</tr>
<tr>
<td>Lack of confidentiality/stigma</td>
<td>14% (n=3)</td>
<td>40% (n=4)</td>
<td>25% (n=3)</td>
<td>21% (n=9)</td>
<td>14% (n=5)</td>
<td>13% (n=1)</td>
<td>--</td>
</tr>
<tr>
<td>Discrimination experienced by the person or organization</td>
<td>29% (n=6)</td>
<td>--</td>
<td>25% (n=3)</td>
<td>9% (n=3)</td>
<td>3% (n=1)</td>
<td>20% (n=3)</td>
<td>--</td>
</tr>
<tr>
<td>Lack of experience or expertise of the person providing services</td>
<td>33% (n=7)</td>
<td>20% (n=2)</td>
<td>--</td>
<td>3% (n=5)</td>
<td>13% (n=1)</td>
<td>13% (n=2)</td>
<td>--</td>
</tr>
<tr>
<td>Hours when services were offered were unreliable or inconsistent</td>
<td>19% (n=4)</td>
<td>--</td>
<td>--</td>
<td>2% (n=1)</td>
<td>3% (n=1)</td>
<td>--</td>
<td>--</td>
</tr>
<tr>
<td>Amount of time to wait to get an appointment to see someone</td>
<td>10% (n=2)</td>
<td>30% (n=3)</td>
<td>25% (n=3)</td>
<td>9% (n=4)</td>
<td>3% (n=1)</td>
<td>--</td>
<td>--</td>
</tr>
<tr>
<td>Cost of assistance or treatment</td>
<td>24% (n=5)</td>
<td>30% (n=3)</td>
<td>25% (n=3)</td>
<td>26% (n=11)</td>
<td>27% (n=10)</td>
<td>7% (n=1)</td>
<td>--</td>
</tr>
<tr>
<td>Not having insurance coverage</td>
<td>29% (n=6)</td>
<td>30% (n=3)</td>
<td>25% (n=3)</td>
<td>33% (n=14)</td>
<td>35% (n=13)</td>
<td>13% (n=2)</td>
<td>--</td>
</tr>
<tr>
<td>Burnout from dealing with/talking about HIV</td>
<td>29% (n=6)</td>
<td>30% (n=3)</td>
<td>17% (n=2)</td>
<td>23% (n=10)</td>
<td>22% (n=8)</td>
<td>7% (n=1)</td>
<td>25% (n=1)</td>
</tr>
</tbody>
</table>
Focus Group and Key Informant Interview Results

Several common themes evolved from the transcriptions of recorded focus group sessions and key informant interviews. Each theme emerged with the help of a topic guided question (Appendix E & G). Topic guided questions asked during focus groups and interviews were reflective of the purpose of the study and the original research questions (Appendix H). The following sections are organized based on topic guided questions and on theme development. Some themes are interchangeable among topic questions and themes are not discussed in order of priority. A separate content analysis of focus group and key informant interviews conducted by contracted research workers revealed similar themes. For this reason, the following results reflect a combination of data from both sources. Direct quotes from project participants are used to illustrate the themes reported in this section.

Description of Participants

Focus Groups

A total of four focus groups were conducted, one group was conducted in each of the following locations: Butte, Billings, Great Falls and Missoula. A total of 17 people participated in these focus groups; eight women and nine men. Age of the participants, male and female, ranged from 20 to 58. The focus group in Missoula consisted only of women, while the group in Butte consisted only of men. Focus groups in Great Falls and Billings consisted of participants of both sexes. The ethnicity of two focus groups participants was 'more than one race', one participant was 'African American' and the rest were 'white'. All of the participants were volunteers and were HIV positive.

Comments from focus group participants were identified by the following:

➢ [FG] = Focus Group Interview
**Key Informant Interviews**

Five key informant interviews were conducted. Three interviews were conducted in person and audio recorded. Two interviews were conducted via e-mail – interviewees were sent the interview questions and an informed consent and were asked to reply to the questions in writing. Three key informants were male and two were female. All of the key informants were individuals who worked closely with PLWH/A.

Comments from interview participants are identified by the following:

- [FF] = Face-to-Face Key Informant interview
- [OL] = Online Key Informant Interview

**Basic Themes Determined from Questions**

<table>
<thead>
<tr>
<th>Question #1: What do you believe to be the three greatest problems for PLWH/A in Montana?</th>
</tr>
</thead>
</table>

**Theme 1: Expenses Related to Medical Care**

Sub-themes related to the expense of medical care are as follows: a) government budget cuts; b) Medicaid spend downs/insurance co-pays; and c) the cost of medications.

**A. Government Budget Cuts for HIV Related Services**

Participants expressed concern with government budget cuts and the effect the cuts would have on service quality and accessibility. The following statements illustrate this concern:

- I am concerned about the future with funding cuts and the current political climate. I have one man who will go off meds when the temporary ADAP medication funding is gone this summer. [OL]
- We have been cut drastically. We used to have free testing. We used to offer everything free. We have to charge forty dollars for it now. I think we’re giving the wrong message to the public. [The government] thinks that if they start charging for it, then it must be important. But I’m afraid we’re giving the wrong message. Forty dollars buys them a lot of food. For people coming into the Poverello Center, HIV testing is the last thing on their mind. Forty dollars will further restrict them from doing testing. [FF]
With [HIV diagnoses] numbers are going up all the time, the costs are going up all the time and level funding is going to be inadequate sooner or later. [FF]

There’s no money for HIV and AIDS anymore due to continual budget cuts. [FG]

There is no help for pharmacology. Anyone that needs medicine or needs health care there’s nothing...This is showing the government doesn’t care. And now they’re cutting and they say, “Uh well, you are from a ‘different island’ and we are cutting the funding form your island”. [FG]

Funds are getting cut everywhere. Assistance with treatment care and stuff like that, it’s just not there anymore. [FG]

We used to get a fifty dollar Albertson’s every three times a year but because of the cuts, you can’t get those anymore. [FG]

The funding is gone. Last month I really needed to come in and see Dr. Risi but there was no gas cards and the gas prices are so high now that it is a concern. A lot of people live out of town and if you could hop on a bus that would be one thing, but I live so far out of town. [FG]

This county’s had funding cuts just like every other Montana county. Our prevention program has been cut by 32% and next week we find out how much more it’s going to be cut. Our Ryan White is fixin g to get cut because of the new clients. [FG]

B. Medicaid Spend Downs/Insurance Co-Pays

A spend-down is like a deductible under a private insurance policy. Just as a person has to meet an insurance deductible before the insurance will pay for medical cost, a person must have medical expenses that equal the spend-down amount before they can get coverage for their medical expenses, such as medications, doctor visits, and blood tests (Illinois Institute of Technology, 2005).

Many focus group participants were frustrated with spend-downs and could not pay them on their allotted income. If they were employed, their social-security was cut, making their monthly income less than if they did not work. This appeared to be a frustrating cycle.

Some folks are now in the crunch of being required to apply for Medicaid but have a huge Medicaid spend down. [OL]

I know a lot of people that come into [YAP] and they can’t get their meds because they can’t afford their co-pays. If you are on disability and you’re getting government money then you can’t use another government agency to help pay your spend down or your co-pays. You cannot go to the CBO to get that money because it’s a government agency thing that pays for that. (FG?)

Because I’m on Medicaid, the state spends me down to poverty before they let me have an income. That’s a big problem with Medicaid. You have to be in absolute poverty. They don’t give you enough money to live on if you’re going to be on Medicaid. You have to have some way
to shelter any kind of money you make, and if you get caught they’ll cancel you wherever you are. They force you to be a criminal. [FG]

C. Cost of Medications

The cost of medications is a burden for many PLWH/A for various reasons. Many do not make enough money to pay for insurance that covers medications, others make too much money to qualify for Medicaid, but cannot afford other necessities, such as food and housing, and other PLWH/A are on the Montana ADAP waiting list.

- One patient of mine is getting his meds through free drug programs by the drug companies because he makes too much money to qualify for Medicaid, but not enough to afford the drugs and his house at the same time. [OL]
- [Medications] are outrageously expensive. You can have good private insurance and your monthly medication co-pay can be six or seven hundred dollars. [FF]
- A couple of the guys that were on disability actually were dropped off because they had been working for so many years full time they were told they don’t need it anymore, but then comes the question of how they are going to pay for their meds. ADAP’s got a waiting list everywhere now. And if you don’t take your meds you’re screwed. [FG]
- I’m going to need a whole lot more services once I get sicker. Once I get sicker I won’t be able to afford things. I have to weigh it out: Do I stay in constant pain for two or three months and see what happens there or go get these x-rays and count on medication. I have to pay one-thousand dollars just for my hip medication. [FG]

Theme 2: Expenses Related to Daily Living

Financial constraint issues often exist before an HIV diagnosis is received and are even greater after the diagnosis. Often times PLWH/A expressed an interest in working at least part-time, and frequently desired full-time employment. However, when they did work part time and/or full time their financial assistance was cut, making them better off financially when they were unemployed.

- [Many of the people I see] have no money. Some of them- most of them- don’t have a job. I mean their living in the streets or in their cars and now that’s a lot of the population that I see too- from the Poverello Center coming off the train. So definitely financial [issues] are a big problem for PLWH. [FF]
- All the layers of difficulties that come. Like the need to be on disability status. You know in Montana you can get disability status and get a stipend and then you have to pay for Medicaid,
which cuts the stipend down, so people get caught in these sort of catch twenty-twos when it comes to being able to move towards work readiness when there in this compromised state in terms of their disease. So all that is really the kind of poverty piece. The money is a huge part in terms of quality of life. [FF]

➢ I can’t ask [my family] for money. So do I want to pay my rent this month? Am I going to be able to pay my electric bill? You know when you think about it I’ve been trying to dig myself out of debt and then something comes up, but the money is already going somewhere else. [FG]

➢ You can’t plan ahead because you can’t invest ahead. You can’t put it away for a rainy day because it’s fucking raining here all the time as far as I’m concerned. A puddle over my head and a puddle at my feet and my shoes are worn out. [FG]

➢ [They give you] $540.00 a month. That’s all you get. Unless you have a kid, then you get $800.00 a month. People can’t grasp what it’s like to live on $540.00 a month. And with this allotted money you have to pay your house payment, your car payment, utilities, and vehicle expenses including gas and maintenance and animal payments. We just need more money. We have to get more money. [FG]

➢ I can’t afford a vehicle. I can’t make that investment because I can’t make the payments. I can’t have an income besides that 540 [a month] and to try and live off that- I’m sorry, it just doesn’t work. I can’t do it. I can do it, but I don’t like it. [FG]

➢ I think that’s what Ryan White or another organization should do: Talk to these places like the gas company and the electric company and if you’re late with your payment [the organization] will help you. Even if you only owe them fifty dollars their banging on your door saying they’ll be turning off your power and turning off your gas. That little game of [randomly picking] what bills will get paid is getting old. [FG]

Theme 3: The Stigma Surrounding HIV

Sub-themes related to stigma include the following: a) confidentiality related to testing and treatment; b) ignorance and fear leading to discrimination; and c) geographical and social isolation. Each of these sub-themes is described below and illustrated with quotes from participants.

A. Confidentially Related to Testing and Treatment

Participants appeared to have two concerns regarding confidentiality. First is the concern that in a rural state such as Montana, it is highly likely that an HIV positive person seeking testing or treatment will encounter someone with whom they are acquainted and acquaintances may find out about their HIV status. The second concern relates to the personal integrity of the staff working in facilities that serve
HIV positive people. Many people who are HIV positive do not trust public health and medical staff to maintain confidentiality regarding their HIV status.

- I think we have stigma for testing too. Some of the Native American won’t go to Missoula Indian Center because of the stigma. They won’t go to their own reservation health care. A lot of people don’t want to go to the Missoula AIDS council because of what it stands for and a lot of them won’t go to FDA Associates because of what it stands for so [Missoula City-County Health Department] is often the safe place. [FF]

- When [newcomers] do come to the community, they often slip in and hide. And that’s why a lot of them go to Spokane to get tested. Just totally go way away where absolutely no one knows them because they feel like Missoula’s small. And especially if you’re a gay man- you start to know everyone and so they’re fearful of that. [FF]

- For the longest time I didn’t want to see anyone in case that someone knew someone. It was a case of confidentiality. Maybe they don’t use your name but they say anything about you and in this little community it’s so easy to figure out who it is. There are people that have lost their jobs because of it. You have to protect yourself and the way to protect yourself is to not get services. [FG]

- There’s fear of somebody finding out. That’s big here. More than it would be in the city because I’ve lived in a big city and you have more people with [HIV] so the stigma is greater out here. [FG]

- Every time I have a medical problem it’s like I have to sit down and think where to go because who knows who and being a medical person myself, I know people can tell people. The gossip life within the medical community is huge. So I started to get treatment out of town, even out of state. I don’t anymore- I just gave up. I don’t have the money or the time. [FG]

- Testing confidentiality is a problem because if I walk into the health department, there’s a pretty good chance someone is going to see me. One of the 100 people in this town is going to see me. And you don’t want people to see you doing that. [FG]

B. Ignorance and Fear Leading to Discrimination

This theme appears to involve several complex issues. One of the issues revolves around HIV negative people’s fear of being associated with people who are known to be HIV positive. Fear of being associated with an HIV positive person appears to be related, in part, to ignorance about how the virus is contracted and spread. On the other hand, participants also spoke about the fears of some medical professionals. Their fear appears to stem from a belief that association with an HIV positive person will adversely affect their medical practice. Ultimately, ignorance and fear, regardless of the basis of that fear, lead to discrimination.
It's ok to acknowledge everything...up to the point of that they're involved in anally penetrating sex. It's like there's so much shame attached to that. You always get the feeling that it's like the taboo unsaid. [FF]

I think one of the biggest problems is stigma and ignorance and the people aren't educated about [HIV]. I think that makes it difficult. [FG]

People don't want to be seen out in public with you because ultimately you're living with HIV and people know that and people fear and they don't want to come to the meetings or to be seen with you at the movies. So there are a lot of social issues for PLWH/A. [FG]

Stigma is a big piece. Bias and prejudice in the culture with a low population and what it means to a person with HIV. Living in the culture whether you're out and about in it or not. All the bias and discrimination and work-related issues and how it affects your family and your children and your kid's. All of that interface between self and community is big in Montana. [FF]

I went to [a doctor] when I first came here and I was asking him questions about HIV and finally he said, "Look, I'm a family doctor, I don't have to deal with this." And I thought to myself, "You don't think families have to deal with this?" [FG]

Doctors are scared to deal with PLWH because they feel that if people in the community found out they'd stop coming to them...people are going to other towns to find help, like mental help. And doctors don't want to deal with the issues of HIV because they don't know much about it. [FG]

The multilayered issues of PLWH makes it so provider[s] don't want people that are dealing with HIV. [FG]

There's still a lot of people afraid of the disease too. I flew on an airplane and sat next to a lady and we had a really good conversation for the first half hour of the flight, but when she found out I was going to Washington DC to participate in the PWHA Conference, she got up and moved. [FG]

Finding a landlord that's not going to care you're HIV positive is hard...Because most of the time when you call, they want to know who you are and that kind of stuff...And if the landlord knows you have HIV and AIDS, well then they think, "What are you going to do in my apartment? And when you move out I'll have to clean it. Fumigate it. And what if you die here? Then I'll have to clean that mess up and I'll have to get it quarantined”. [FG]

I was renting a house and I was living in it and some strangers came to my door asking me about the house: "How much does it cost, what is included...Oh, and by the way, I heard PLWA live here". And I just looked at them and said, "Well, I've lived here for two years". And then they just said, "Oh...Ok." And so it was the stigma. And I'd never seen these people before in my life. I'd only been infected for six months at the time. [FG]

Some of the providers are very good but some [PLWH/A] move out of town because of the stigma. There are some benefits to living out of town: avoiding the stigma. [FG]

C. Social and Geographic Isolation

Geographic isolation contributed to social isolation in that it limited the availability of and attendance at social engagements, including support groups. Many PLWH/A live far from towns that offer socialization opportunities with other PLWH/A. Social isolation also seemed to be rooted in the lack of established HIV/AIDS support systems throughout Montana. Comments were made on the
lack of confidence in the social support groups that are offered, and there is a fear of seeking such services.

- There is a lack of social support. I think there are perhaps classes/gatherings that are offered but many times the patients don’t participate. [OL]
- The gay community does not seem to be very cohesive here in Montana. I don’t know how it is in other places. Many of the men (not all) who I take care of with HIV/AIDS feel isolated and lonely. Fear is a great factor. [OL]
- [PLWH] are isolating themselves because of fear. I think before I joined this group I was more afraid. There is a fear of seeking services. [FG]
- Isolation is an issue. I’d rather stay home than deal with anything. The first few years I hardly saw anybody. It was just easier that way. [FG]
- I’m to the point where I don’t want to meet people anymore. The people I know are the people I know. I’d just as soon go to my job...I just want to be left alone anymore. I’m psychologically diseased. [FG]
- I don’t know if the stigma of being HIV positive has an effect on social interactions, but I suspect so. The number of people in Montana who are positive is low, so there is not a social group or support that there might be in a larger population area. [OL]
- I think individuals not being comfortable enough to be with themselves and the community to come out and participate in the organizations is a huge barrier. [FG]
- Just the geography of the west and rural states just beginning to be recognized nationally as having their own unique set of problems because for so long the focus was on the big urban areas where the epidemic started and was so devastating. [FF]
- Many people feel the low population of Montana contributes to stigma associated with HIV/AIDS and with being gay. More densely populated states often offer more education and have more diverse communities. [FG]
- There are people in small towns that are living there with HIV and that’s pretty much like a rule. That happens a lot out west where there’s few services for PLWH/A and they are isolated in terms of not having any contact with anybody else who has HIV and so they can only use the phone to contact people. [FG]

**Question #2: What do you believe to be the three greatest health problems for PLWH/A in Montana?**

**Theme 1: Complications of HIV Infection and of the Drug Therapies**

Sub-themes related to the complications of HIV infection and of the drug therapies are as followings: a) chronic fatigue; b) medication side effects; c) medication adherence; and d) reinfection and superinfection. Each of these sub-themes is described below and illustrated with quotes from participants.
A. Chronic Fatigue

The most pervasive complaint respondents had regarding their health was the issue of chronic fatigue. Chronic fatigue prevents them from engaging in their usual activities and is a detriment not only to their physical health, but to their emotional health as well.

- It's hard to have the energy to go out and do the things you used to do for yourself. All the things you are used to doing. People that knew you as this outside person, who knew a person that could jump high and climb to the top of a mountain. People don't understand that you this mountain and you think you can hike up it but then there's this thing called HIV and people don't understand. [FG]
- The last couple of years my medicine wasn't bothering me and then all of a sudden it was. It's just giving me a whole different identity and how to think about myself. I'm more tired. It's hard to have enough energy to go out and do the things that you do for yourself. [FG]
- Being sick all the time is hard. There are the swollen glands all the time. There's the night sweats. I mean I can't get rid of it. Or just being tired...I'm tired...I'm wiped out. [FG]
- There's the fatigue. I mean fatigue isn't just being tired. Fatigue is this feeling that your whole head feels so heavy and so tight and cloudy that I look around my house and know that I should be doing this or I should be doing that and it's [too exhausting]. [FG]
- There's not the energy you're used to and I figure I actually fit into a chronic fatigue syndrome category. A lot of PLWH fit into this category. I think whether it's caused by the disease or the meds or a combination of the disease and the meds, it's there. [FG]
- I think [the tiredness] is caused by a combination of the meds and the disease and PLWH face this a lot...I get going and I get tired and I think of a lot of things I just don't feel like doing. [FG]

B. Medication Side Effects

The consequences of HIV treatment are diverse and complicated. Side effects range from migraine quality headaches to persistent diarrhea and contribute to the chronic fatigue discussed above. These side effects not only have devastating physical effects, but emotional effects as well. PLWH/A and their service providers residing in Montana said the following about medication side effects:

- The medications keep people alive, but often with persistent health issues related to the effects of the medicines. This limits vitality. [OL]
- The side effects of medication would be [a] health problem for me. It's all about balancing all the side-effects of this one or that one so this one might be working but it's also giving me this hypodistrophy, which is disfiguring me. So how do I address the hypodistrophy and yet the medication's helping me or. [FF]
It's this whole synergistic problem about the medications and the side effects. The support groups with HIV positive-usually a good one-quarter of the time it's just men talking about all of these dynamics [of medication side effects]. [FF]

I think normalizing the side effects is really helpful. The other night we were talking about hypodistrophy and I was looking around the room and I didn't have any since that the guys were struggling from [hypodistrophy] and 4 out of 5 all pointed to specific parts of their body, like their belly or the wasting in the face they were struggling with and they feel like people are identifying [them by this]. [FF]

We are just starting to deal with the effects of long-term HAART use because they really weren't around until the late 90s and people who have been on a whole host of them are developing certain health side effects that are more than cosmetic...such as internal metabolic side effects like high blood sugars, high triglycerides, high cholesterol and other things they can't control with just their diet. [FF]

If you ask [PLWH/A] what their biggest health problem is they would probably say the side effects of the medication, which is diarrhea and nausea. [FF]

They took me off of the Sustiva- because of the nightmares. And now the side effect of the Viramune is the constant headaches-everyday. It gets so intolerable that it makes me just want to stop [taking the medications]. [FG]

Side effects are one of the biggest health problems. Everyday I spend the first few hours of my day saying, "Get out of my way! Move or it's going to be running down my leg". But I still weigh 165 pounds. I cannot lose this weight unless I go on a stress diet, that's the only time I lose it, but it seems like the pills just make me heavier and heavier. So that's my biggest complaint about the meds. I mean it has to be the medications. [FG]

Sometimes I feel like there are always side effects and there's nothing you can do for them. I think that's detrimental, I really do. The side effects are a big thing...some days they just take it all out of you. [FG]

The meds put wear and tear on your body and some of the meds even limit what you can and can't do. [FG]

If you go to a mental health worker and they're not familiar with HIV and the HIV meds then they treat you like you're a patient that has psychosis or depression and stuff and they don't get across to you as a patient that it's the meds, not you personally. [Mental health workers] need to deal with the mental issues and the meds. HIV alone is not causing the issues. The issue is that I'm on meds that are fucking me up and I need someone to tell me it's ok to be fucked up on these meds and that's normal. [FG]

I think the side effects are what are most disheartening over everything...I [read up on side effects] because you would not believe the side effects of these drugs. [FG]

C. Medication Adherence

HIV medication adherence rates match that of other chronic illness medication adherence rates. Research states that after a year of taking antiretroviral therapy (ART), half of the population will fail. Comments coming from HIV
diagnosed respondents and their service providers living in Montana referenced the importance of medication adherence several times.

- Many of [Deering Clinic] patients have significant substance abuse and mental health issues which make it very difficult for them to comply with visits, treatment, etc. on a long term basis. [OL]
- PLWH/A issues revolve around getting and taking their meds. Most do well if they access regular medical care and follow through with their meds. [OL]
- I feel like helping people understand that medication adherence is important and that it’s a painful dilemma to help with so they can get empathy to stay on course. [FF]

D. Reinfection and Superinfection

Although reinfection does not seem to be an immediate concern for PLWH/A, it was mentioned several times as an emerging concern. Participants made the following comments on this emerging concern.

- [Reinfection] is definitely on its way and it’s scary. In fact the thing in New York, that’s really scaring us because [people in] Missoula seem to travel a lot. We’re just waiting for it to get here. So it’s almost panic phase. [FF]
- I have a sense that [reinfection] is on it’s way. I think there’s a lot of it out there already that hasn’t popped up just because people are reticent to get tested. I think there’s a lot of people out there that could be potentially [reinfected]. [FF]
- Some people’s virus becomes resistant, some don’t. Some become superinfected with resistant virus. Well it’s like, “I’m positive, he’s positive- we don’t need to use protection”. Highly resistant strands- that’s one thing that’s evolving now. We don’t know where that’s going to go. We would hope the virus would continue to respond to the medications we have and we wouldn’t have to end up in a great race to try to keep one step ahead of this. [FF]
- You take the superinfection that we’re hearing about. We’re going to see this next wave of HIV positive people and I’m afraid we’re going to be back to where we were. Maybe not as bad as it was the first time HIV came around, but we’re going to back to losing people. [FG]

Theme 2: Mental Health Issues

Several participants alluded to fact that mental health issues are intimately tied to the stress, fear, and depression associated with having a life threatening disease. Substance abuse is often just a symptom of the multitude of physical, financial and emotional problems that people with HIV must face everyday.

- Mental health issues are huge. Mostly from the meds. There is depression in combination with the tiredness. [FG]
HIV is just one of the things [PLWH] are dealing with, so I feel it's important to deal with the impact of HIV and to deal with the impact of depression. [FG]

Mental and emotional health is the umbrella...and drinking and drugs fall underneath (mental and emotional health). I don't want to feel like crap anymore so I use drugs and alcohol. [FG]

I think there's a lot of fear. There's always this fear of what will happen when my fragile little system breaks down. And so during the day I'm really brave and then at night I'm really scared. [FG]

Self-esteem issues are big... If people have been sexually molested as children or raped or what-not that tends to get a lot of people into the thought of, "Well, that's all that I'm good for. That's the only way I can get that love and affection or what-not". And abandonment issues go along with that...They're looking for some kind of human comfort, compassion, and love and they're looking for it in the wrong ways. [FG]

Anxiety attacks and rage are big for me. Where does this shit come from? There's no self-control at all. I mean I don't know if that's the HIV medication. I don't know if it's the fact that I abused drugs for years. I don't know where it comes from. I'm used to having self-control. The rage is the worst thing for me. That's why I take the psychotropic medications- because I don't like that extreme anger...the rage...the panic attacks. To hell with depression. I can be sad any day of the week. [FG]

My issues revolve around mental health issues. The family issues. It's the stress about not having the money. It's all the things you don't have a proper outlet for. The mental health is a big issue. [FG]

**Question #3: What risky behaviors do you believe PLWH/A engage in that are detrimental to their health?**

**Theme 1: Substance Abuse**

Sub-themes under substance abuse include the following: a) the link between substance abuse and HIV; b) methamphetamines; b)marijuana; c) and alcohol. Each of these sub-themes is described below and illustrated with quotes from participants.

**A. The Link Between Substance Abuse and HIV Infection**

Participants raised several issues related to substance use and HIV. The most pervasive issue seemed to be a concern about how the abuse of all kinds of drugs (legal, illegal and prescription) contributes to HIV positive people's inability to cope with their infection in a constructive and health enhancing manner. A secondary issue was related to the belief that drug abuse promotes risky behaviors and thus contributes to the spread of HIV.
I think HIV cases are going to start going up because of drug use. Drug use is just not slowing down at all. [FF]

I think there's a general tendency to rely on alcohol and speed and different kinds of substances that don't contribute to the healing cycle and really get in the way of the kind of clarity and acceptance and sanity that's required to live with this disease. [FF]

[I think] making it ok to be able to name that there is an addiction problem as a cofactor with HIV for PLWH and not take that on as a mantle of increased shame or self-denigration. And to be able to say, "Obviously there's going to be these addictive issues," and be able to normalize how to work with that. [FF]

So many of the pain management medications that are prescribed are used addictively by the patients. I don't know how to work with that but that's a huge part of the substance abuse issue. There's a major amount of morphine and oxycotton and Lortab that's prescribed to them to deal with...pain related symptoms and what I find a lot of times is that it's being used as a mood stabilizer or being used addictively rather than to address the pain itself. [FF]

Drugs and alcohol are big risky behaviors for PLWH/A. [FG]

My big issue was chemical dependency. That's a big thing. I've been clean now for almost four years, but thank God. I was on a suicide mission. I believe drugs and HIV go hand-in-hand: People get depressed and they don't give a shit anymore and so they turn to substance abuse and then they don't give a shit anymore about anything and then their [CD4] numbers go way down. I hope I can stay clean. [FG]

B. Methamphetamines

More discussion centered on the use of methamphetamines than any other drug. Many of the participants believed the risky sexual activity resulting from methamphetamine use was an HIV time bomb waiting to happen.

In Missoula we've got the methamphetamine. We've got the neighborhoods. We're starting to see certain neighborhoods in little areas that cater to it. If you want to find it you can always find it. Someone's going to tell you what street to go on...We're just waiting for HIV to get in the big drug use ring and it's going to be a bomb and we're probably going to have one-hundred people exposed. [FF]

[Meth] is a cycle and it's a dead end cycle. If you do meth and you stop and finally get your life together and you realize...you have to live in this little square box and you can't get out or else you're going to be screwed. So what do I do? I sit in my little box and two or three years go by and fuck it. Fuck it. And I go to the drug guy because I'm so sick of living in that little fucking box the government put me in and society put me in. It's either that or put a gun to your head. I mean it gets to that point where you just say, "Fuck it". [FG]

I mean crank is the number one [drug] though. Well it goes hand-in-hand [with unprotected sex]. For some reason it stimulates your sex drive. A lot of us went around [high on speed] and that was just a weekend party kind of think and it was maybe more than a weekend party kind of thing, but sometimes it was about everyday of the week we partied.

The meth brings you back to a place you were before you were sick where you could think and work-temporarily. You have to keep on it or you have to quit when it's crash time so in two or three days
you're feeling crappy and depressed for two weeks after that so you have to do more meth to get over that or go through this long drawn out withdraw in the process, which is a pain the ass... [FG]

➢ I've been clean [from meth] for... six months. And I have MERCA infections reoccurring. Meth Affiliated Resistant Staff Infections. You get a sore - a pimple - and it becomes a big nasty. And it really knocks the shit out of me when I get them. [FG]

➢ In Montana we are faced with the big problem of crystal meth. It's just as big here as it is in Seattle. [FG]

C. Marijuana

Participants talked about marijuana as a means to deal with depression, improve mood and increase appetite. They did not, however, associate marijuana with addiction or with an increase in risky sexual behavior. Most of the comments about the use of marijuana were neutral or positive.

➢ I would say substance use [is a risky behavior], but not in an immoral one because I feel like medical marijuana and a lot of the ways that PLWH self-medicate can be very empowering and very helpful to them. [FF]

➢ I think the legalization of medical marijuana goes a long way to help resolve the issue of substance abuse. It helps because it gives people an alternative- a helpful way of looking at substances... I think when all substances were illegal then it created more of a tendency to rely on substances like alcohol or other substances because it's just like, “It's all illegal, so I'll do what I want or do what I need”. [FF]

➢ I actually started smoking marijuana again to get an appetite because I was losing my battle and my daughter was the one who said, ‘Mom, you need to start smoking pot again”. I haven’t done that in years. [FG]

➢ I don’t think marijuana is such a bad and terrible thing. I mean alcohol and the other drugs I think we really want to address as far as coping. I mean marijuana is such a mild thing. It can be habitual but I don’t believe it’s ever totally addictive... I mean if it helps increase your appetite then jeez! I was so happy when they passed that law. [FG]

➢ I personally don’t like marijuana but I’m an advocate for it for people that it works for... My partner smokes it and he doesn’t take any of his depression medications anymore... He’s in a much better mood now. [FG]

➢ Alcohol alone with your meds you’re not supposed to do because it just kills the purpose of taking your meds, so I don’t drink, but I do smoke [marijuana]. [FG]

D. Alcohol

While a few participants addressed the fact that alcohol increases risky behavior, none of the other participants appeared to see alcohol as a major threat to people who are HIV positive or to the spread of the epidemic.
[PLWH/A] are still drinking. They are still going to bars...They are still getting drunk. They are still denying things. [Some] have a problem with alcohol, [some] get drunk...I've [tested] people when they're totally inebriated. They are drinking and losing any sense that they’re exposing other people. [FF]

For me [my risky behavior] was drinking. For years I dealt with my depression by drinking. [FG]

I think [some] drink just to drink and then all [their] inhibitions go out the window and then [they] just stop caring. [They] just stop caring. [They] just don’t care. [FF]

I've already accepted the fact that I don't care if I ever quit drinking...because I stress myself out too much. For more than ten years I've been in and out of AA and treatment programs- so many different treatment programs so many times that I finally just decided I'm not going to stress myself out about being this sober 'happy, joyous and free', as they say in AA. I'm already 'happy, joyous and free', and I'm still going to drink alcohol. And that's what I've accepted for myself. [FG]

I would like to argue the point [that alcohol kills the purpose of taking your meds]. I'm just saying that maybe it's case by case because I always take my meds and I drink. My T-cell has been the highest it's ever been in the last fifteen years last time I checked it and other than a few years ago when I stopped drinking for a little more than a year, I've always drank alcohol. [FG]

Theme 2: Unsafe Sex

Sub-themes related to unsafe sex include the following: a) drugs and sex; b) denial of risk; and c) bug chasers. Each of these sub-themes is described below and illustrated with quotes from participants.

A. Unsafe Sex and Drugs

As discussed above, abuse of drugs was seen as a major contributor to engaging in risky behavior, particularly unsafe sex. One again, methamphetamines were seen as the most dangerous of these drugs.

Meth, ecstasy and MDA are pretty much sexually driven drugs. I mean you take them and you’re going to fuck. You're going to fuck for hours and days. So that’s the high part of those. So if HIV wasn't sexually transmitted it would be a problem, but since it is [the drugs] go hand-in-hand with HIV. [FG]

You are reading about everybody [having anal sex] on these drugs. Even straight guys are [having anal sex]. And they don’t make sure they’re protected. [FG]

The drugs, the crystal meth in particular, and the risky sex go hand-in-hand...most of the kids my age associate crystal meth with sex. [FG]

[People] grab whatever it takes to get high again and then they stay like that for two days and then their body's so exhausted they have to come off of it and then they crash.

I think a huge negative thing that's a time bomb is meth. It is especially popular with gay men and it leads to a lot of risky sex and with all those needles out there. So I think that's a real threat hanging over their heads. [FF]
The fastest rising demographic group is women and if it's a woman with a meth habit she's going to have a lot of risky sex while she's high and she's going to start by having sex in exchange for drugs. So I would expect to see more of that. Substance abuse is a common co-morbidity with all my clients. [FF]

Then they're using Viagra, which seems like the drug of choice, and there they go and they just can't control themselves and they're infecting others - if they're HIV positive.

You put Viagra on top of meth and you've got a monster. It's scary. Well that's why we saw syphilis last year. Cases are way up. Gonorrhea's way up. Chlamydia outrageous. [FK]

B. Denial of Risk

Participants discussed two aspects of denial. The most predominate aspect was the belief by both men and women that people who identify as heterosexual are not at risk for HIV infection. This seemed to be particularly true for men who engaged in sex with other men, but did not consider themselves to be gay. The second aspect of denial discussed by participants related to individuals who were having difficulty accepting their HIV positive status and therefore, unable to face their HIV status, they continued to engage in risky behaviors.

There is an increasing disregard for the risks of heterosexual contact among young women. [OL]

In Montana a fast growing [HIV] group is married men who go to the bookstore on the sly but who have families and don't identify as gay or bisexual. That is a big problem, so in a sense they're really in denial. [FF]

Straight guys are [having anal sex] on meth, ecstasy and MDA and saying, "Well, I'm not gay". [FG]

Married men who have sex with men but do not consider themselves gay or bisexual is common. [OL]

One guy came [to be tested] and he's positive. The wife is not. The daughter is not. But [the wife's] been in twice to get retested and the daughter too, but talk about strain on the marriage. [FF]

Unprotected sex is a big one for PLWH&A. Unprotected sex and not taking care of their sexual health. [FG]

I think there are a lot of people out there too that are still not having unprotected sex. I was married to a guy who didn't want to have protected sex. [FG]

I think what's getting in the way of seeking services is people's tendency to approach denial rather than acceptance. I think that's really the main [issue]. [FF]

[PLWH] will schedule a therapy appointment and they'll come one or two times and they'll get a sense of what it's like to acknowledge that and there will be a real pull-back. That dynamic is really strong in the first part of the crisis of infection and so it's like I don't know if I should [accept it]. I want to accept it but I don't know that I can. [FF]
Something that seems to be a big thing with younger people now is instead of asking if you have AIDS, if they know you have AIDS or they suspect you have it, they don’t ask you if you have the virus. They ask you if you have a viral load because if your viral load is undetectable then they figure they can have unprotected sex with a person with a low or no viral load and they’re not going to get AIDS or HIV. [FG]

C. Bug-Chasers

Comments from participants regarding bug-chasers were limited. However, it is clear from the comments below; there are individuals in Montana who seek to become HIV infected for a variety of reasons.

We have people that come in to get tested and you can tell that they want to get it. You can tell they want to be positive one day. So I guess that’s a bug chaser. And so far they haven’t gotten it but I have frequent people that come in that want to get it. And saying they don’t want to get it, but as your talking to them you realize they want to get it because they just keep doing the same stuff. So we’re seeing those too. [FF]

Unprotected sex would be a risky behavior. It’s out there. And people are actually looking for [HIV]. In my first encounter with a bug-chaser, we weren’t drunk, we weren’t high, and we weren’t stoned. He just didn’t care. [FG]

Bug-chasers have the mentality that they won’t have to worry about catching it if they get the disease. They feel they’re going to get it eventually, so they may as well get it out of the way. And another thing is that there’s a certain amount [of bug-chasers] that feel HIV positive people are getting so much money from the government. And so much care. And so they hear about the meds and then they hear about the housing programs and the food stamps and the Medicaid and then they want HIV. [FG]

Question #4. What are the greatest assistance and/or treatment care needs of PLWH/A in Montana that are not currently being met?

Theme 1: Insurance

Participants talked about not being able to obtain insurance or about the possibility of losing their current insurance. For most people with HIV, paying for health care is not possible without some kind of assistance.

It’s really really hard to get health insurance and if you can get it there’s vulnerability that goes along with it. It’s hard to get life insurance. I left a job that had kick-ass insurance through Cobra. But then there’s that program that I found out about that would help make those payments so I didn’t lose my insurance and that’s coming to an end. But I have a job I’m not very happy with, but that will be the reason I stay with it- because of [health and life insurance]. And I don’t want that to be a deciding factor on why I want to be employed and insured because some days I think it would just
be easier to go down to McDonalds and flip burgers and work a fryer for six hours a day and just go home. [FG]

➢ Right now [Ryan White] is paying [my monthly insurance fee] to keep on it. I think that if I have to go on Medicaid I won’t get the treatment that I’m getting now. I feel that. [FG]

➢ I have insurance right now but it’s from my ex-husband and it’s going to run out pretty soon. But I’m on social security and Medicare right now. But I really don’t want to go on Medicaid. [FG]

➢ I think the government needs to offer insurance differently. I think they need to make the Ryan White funding just like Medicaid and Medicare. For a limited amount of funds everybody gets what they need. [FG]

➢ My insurance is changing. At one time they told me if they knew ahead of time what my dentist was going to charge me they would have given me a check to go and see my dentist, but after I’d already gone there, they couldn’t reimburse me. [FG]

**Theme 2: Support and Preventative Services**

Sub-themes under support and preventative services include the following: a) alternative therapies; b) nutritional foods; d) support groups; and e) health clubs. Each of these sub-themes is described below and illustrated with quotes from participants.

**A. Alternative Therapies**

Participants expressed a great desire for alternative therapies. Several participants stressed the preventative benefits of these therapies. Other participants believed that less expensive alternative therapies could be used to replace conventional treatments thereby saving the insurance industry and other governmental and non-governmental funding agencies money.

➢ Right now I’m taking two different [vitamins and herbs] on top of my HIV meds and I don’t know how I’ll afford them next month and I’ve been doing it for a few months and I’m scared to quit. So I’ll probably come up with the money, but it’s a burden...People would like acupuncture or something more in depth like massage or more supplements. [FG]

➢ There really is no help with alternative [medicine]...There is really pertinent stuff like acidophilus, which helps prevent taking Dilucan, which is ten dollars a pill. I believe that a lot of it can be preventative medicine and it should be paid for or there should be some sort of insurance assistance to be for what is proven preventative things, like acidophilus. Everybody knows it’ll help, but nobody will help buy it. [FG]

➢ Well if the system realized it was cheaper to offer alternative medicine they would help with that. But as of now they are taking for themselves because these medicines actually help in reducing the costs for the health of people in the HIV system. Organizations do not have faith in alternative therapies. We don’t have any [help with alternative therapy] and our government is all Christian, which doesn’t help with alternative therapy. [FG]
Anything like homeopathic or Eastern treatments. That kind of stuff. All that stuff. None of that is covered by Medicare or Medicaid or any of the programs. [FG]

I was going to a chiropractor for awhile and Medicare paid for so many treatments and that's it then you have to pay for the rest...I stopped going because all of a sudden I started to get a bill for two-hundred dollars. You just can’t bill me because I can't pay it, I just can’t pay it. [FG]

Since Ryan White has cut back on a lot of stuff I haven’t received the services I value most. That is acupuncture, massage, naturopathic therapy, etc. All that alternative stuff that truly benefited my life. Especially acupuncture. I want to stress that one the most. Since it's been over a year since I received [acupuncture] and I feel a big difference. A big difference! I've started on psychotropic medication again and when I was doing acupuncture I didn’t have a need for that. And I’m also drinking alcohol again. It also helped me quit smoking. It really improved my life. It wasn’t just the addiction stuff, but it also enhanced my immune system and a list of other attributes that improved my life...that stuff is magic. [FG]

I think that it’s so important for [alternative therapy] to be accessible for anyone that’s HIV positive. Whatever therapy you choose, it should be available. [FG]

It seems like if money were put towards holistic care, it really would be less expensive in the end because it really is cheaper than Western medicine. And if it helps you then why not use it as a compliment or even as a replacement to Western medicine. [FG]

B. Nutritional Foods

Many people living with HIV cannot afford to purchase fresh, nutritionally dense foods. In addition, many people do not have the knowledge or the skills to prepare nutritionally sound meals. Participants spoke about their frustrations in regard to food.

We need help with anything to do with food. I mean nutrition, vitamins and food. Fresh fruit and vegetables. And meat. I mean real meat. Not spam in a can. I can’t afford any of that. [FG]

PLWH/A need help with nutrition. Like nutritional supplements- vitamins and stuff like that. I think it’s important to give people the knowledge of how to cook, how to prepare, what things are good for you, and what things are bad for you. And having the ability to access what’s good for you. To get the food to cook it because who wants to live off canned chicken all the time? [FG]

If you’re living with HIV/AIDS you only get canned and processed foods. Any food bank or CBO or anything like that won’t give you anything else. [FG]

Another thing leading to health problems is nutrition. People don’t know how to prepare food for themselves. They don’t know what things are good to eat. They aren’t taking care of themselves. They don’t have an appetite. They don’t have the income to get good foods. They go to the food bank and get starches. You get starches. That’s all they give you at the food bank. And maybe a couple of vegetables that are canned crap. So I think that nutrition and food availability is important. [FG]
C. Support Groups

While not all participants could agree on the composition or the purpose of support groups, most believed that HIV positive individuals need to have a sense of community and support groups can help provide that sense of community.

➢ The physicians are these core resources for people but a lot of times it creates this private relationship with the physician which is a great thing but a lot of times what it does is reinforces HIV as this private thing you deal with in this very closed setting and I think the challenge of the support group is that link to the broader community. It's that link to the rest of their lives. [FF]

➢ Before my peer group there was a lot of things I didn’t know about because [service providers] don’t tell you about them because they don’t have to give the knowledge to you. [FG]

➢ We do not have a sense of togetherness here in Great Falls, and the only reason you know someone is positive is because you’ve been friends with them and that’s it. There’s no solid calendar for PLWH here. There’s no camaraderie. For awhile there was a small group but not anymore. [FG]

➢ Billings has no community. I lived in here [in Butte] for two weeks and there was an invitation in my mailbox for the men’s group. I lived in Billings for three years and there was never an invitation. And people need these support groups. [FG]

➢ I don’t know if it’s me and the job I’ve got but it seems like everybody I know has HIV/AIDS. I don’t know any normal people anymore. And if I do they’re acquaintances...It’s a weird infrastructure we’re stuck with. And also some [PLWH] don’t want to come to activities so when you do need that support from another positive person they aren’t there. So a support group with ‘normal’ people is what I want. [FG]

➢ It seems [PLWH] don’t want to work with the commonality they have in support groups...They don’t want that to be the focus. They want their personal thing to be the focus. But that’s not the reason for this. The reason is HIV. [FG]

D. Health Clubs

A number of participants stressed the importance of physical fitness and believed that access to a health club would help them regain some of the cardiovascular and muscle strength they lost as a result of their HIV diagnosis.

➢ They could work on giving us help with a health spa so that we can try and build our muscles back up. I would love that because I’m getting pretty thin and loose and I’ve always been pretty active so that would be helpful. [FG]

➢ Some sort of cardiovascular exercise as well as weight training. I’m so adamant about that. I was getting assistance with that for five years straight and now it’s been several months since I’ve done that because I can’t afford it. [FG]

➢ I think access to health clubs greatly affects quality of life. Maybe they could work on a group rate with local health clubs. [FG]

➢ The cuts stink because a health spa really enhances a person’s life. [FG]
Theme 3: Dental Needs

Because most dentists do not accept Medicaid, participants saw a need for affordable dental care. Knowledge about access to affordable dental care through Partnership Health Center in Missoula did not appear to be widespread.

- Lack of dental services adds to health problems. Before I found out about the Partnership's dental services, I didn't get dental help because none of the dentists in my town take Medicaid. None of them. I would say I was held back from getting dental services. [FG]
- Dental issues arise quite a bit. You get decay and stuff going on and it's fast because of the HIV and the meds and stuff. I have dentures now so I'm fine. But if you saw the waiting list here to see the dentist for PLWH you'd be surprised! I think there's a waiting list because dental help is really limited. Some dentists won't work with you...Most places don't take Medicaid or Medicare anymore because they just don't want to take that loss in money. [FG]
- Because Partnership dental services are for the community at large they have some people on the waiting list for so long and so for people that go through their case manager, they should be able to see the dentist sooner. [FG]

Theme 4: Housing

While several participants expressed concern about housing, only one person* mentioned the existence of government assistance for housing.

- *There is nothing with the housing assistance. When I first moved on my own I applied for Section Eight Housing and then I had roommates move in and then I got accepted to the Section Eight, but I couldn't have roommates. So I almost lost my housing and I would have been sunk. [FG]
- I think housing is a big factor for a lot of people...I know people that have a problem with housing...they're struggling just to have a place to stay. [FG]
- Housing. Housing is a big issue for a lot of people. [FG]
- I'm lucky I live with my mom...but if Mom ever dies I'm going to have a house to live in but even though it's a small, little house I don't know if I can afford it when she's gone. I have taxes to pay on it. Heating bills to pay on it. Electric bills to pay on it. All this stuff to pay on it and I don't have the money. [FG]

Question #5. What barriers do you see PLWH/A facing in regards to meeting these needs?

Theme 1: Transportation

The sparse disbursement of towns across Montana poses service access difficulties. Many HIV positive individuals live in rural low-population areas and are required to travel to and
from care. Many, however, cannot afford vehicles or the gas required to drive to towns where services are offered.

- I think just the geographical location of where [services] are makes it difficult because people have to find rides that just makes it hard. People on the reservation. That can be a long way sometimes. When they have to come to Missoula for a [service] visit. So that's difficult because we are so spread out. [FF]
- [Some] people have to drive 120 miles or more to see a doctor so that is a definite barrier, definitely. And a lot of times if they're living in poverty their vehicles aren't really great to begin with. If they have a spiking fever but they don't have a ride in...and they can become ill very quickly so it can be kind of scary to have very frail people very far away with no wheels. [FF]
- My car just broke down and it's going to cost me $300.00 to have it fixed and I won't have that money for at least two weeks and I have a six month old baby I'm supposed to take to doctor's appointments and stuff like that. [FG]
- I didn't know of any of these services until I moved [to Missoula]. I traveled over 200 miles to get to the nearest doctor. [FG]
- The distance from providers, especially the towns in Montana, are so spread out. Then there are places that don't have doctors that PLWH/A can see. [FG]
- Transportation is an issue. I have a vehicle now but when it's done I don't know what I'm going to do. I have no more family left around here, they all moved, so I won't have their help. [FG]
- I think distance is a barrier. It's a big barrier. If you don't own a car, you can't live out of town. I couldn't live out of town without a car. Distance to services can cause big trouble because there aren't services in small towns. [FG]
- Transportation is a big barrier for people. People can't afford a vehicle and the buses are so screwy. Transportation seems to be a big deal all over the state. And gas cards are being cut and that's huge. [FG]
- I think transportation and getting to where you can get good medical help is a problem. I mean you can find a good doctor, but how far are you going to have to travel? [FG]
- I have to go 120 miles to see [my doctor] and in the winter time that's really hard. And with gas. Gas right now is just horrible. [FG]

Theme 2: Bureaucracy/Paperwork

Many participants felt frustrated by the amount of paperwork necessary to apply for any kind of government assistance. Moreover, those individuals who were receiving financial assistance felt the rules and guidelines imposed by the government agencies made it impossible to save any money or to “get ahead.”

- I applied for ADAP and that whole process all because, whoever out of Billings, wanted me to go through the hoops for housing. And so when you do that, when you even talk to those people it's difficult because you know they tell you what they want [for paperwork] and you bring it but it's still not what they told you to bring and you bring all that and it's still not right. And then I do everything they say and mail it to them and do you know? They have no record...ever. [FG]
I think that once you've been diagnosed with HIV/AIDS and you get your disability because you meet the criteria, the infrastructure is so messed up that basically you're stuck at an income level of $540.00 a month. I mean that's the ceiling. Anything you make working part time they take out of your spend down, your food stamps...anything. So any job you work they end up taking all of your income, so you can't get ahead. You can't plan for the future. You can't invest anything because they would see you were making other money. [FG]

I'm on an ADAP waiting list, which mean I had to stop my drugs [medications]. And if I get sick again I'm not on drugs, so I'll have to go through the whole process of applying for disability, but they say they'll get it to you within a month if you reapply, which never seems to be the case, so you're up and down, up and down and you can't make future plans. [FG]

I want someone to help me with the bureaucracy. It took me almost two and a half weeks to figure out the paperwork [for social security] and to make all the copies of the paperwork. And then I did it twice and those people didn't even know what they did with the paperwork. [FG]

I've done the whole ADAP thing. After the first couple hours of trying to figure it out I said, "Forget it". I'll just pay. It was too much of a process. They wanted to know everything. So I just never filled it out. [FG]

**Theme 3: Lack of Coordination of Services**

Because the services in Montana are sparsely distributed and often are located in the larger population centers, participants felt that it was important for service providers to communicate with one another and to coordinate their services.

- It would be more helpful for [Montana] to have more coordination of all of the system's that are working with PLWH. A good example would be like FDH and Associates does a positive's retreat and we a do a group and [Missoula's Ryan White case manager] has contacts with positives right when they're identified and it's like there's no coherent collaboration between those. So it would be awesome to be able to co-collaborate to create this stream of orientation to services. I do feel like more coordination of the environment of care would be great. [FF].

- Given the way the population is distributed it's impossible to not have centers of care. I think the fact that Missoula and Billings are centers of care is a structural reality but it's also a structural barrier. I've had referrals from Helena for men who are in high need of group work and their case workers there would take them and they would come to six or seven sessions and it was really helpful to those guys but there's no way they can follow through just because it's just too complicated for them. There's not enough synergy of providers and stuff happening in Helena or Great Falls and other locations because of the service providers there. [FF]

- Nobody seems to be using each other's information. It would be helpful if they would say, "I've got a survey [directed at the needs of PLWH/A], you've got a survey, let's try and combine these surveys and work off each other's information instead of rewriting the whole deal. There's so much information out there that could be combined. [FG]
Theme 4: Physicians Lack of Knowledge about Resources

Comments were made addressing the lack of education about HIV that was offered to medical professionals who care for PLWH/A. In addition, physicians often do not have the knowledge necessary to direct PLWH/A to sufficient resources, therefore PLWH/A have a lack of awareness about organizations and programs available.

- Many organizations will not allow time for the medical or social education that is needed by staff so that they can be informed about services out there. [OL]
- Part of prevention money should be spent on general education of doctors in Montana so they know how to direct the newly diagnosed to HIV connections and services. [FG]
- If someone were diagnosed in a small town in Montana, a normal doctor in a normal town, then they wouldn’t know where to go for services. [That doctor] isn’t going to know anything, instead they say, “I'm sorry, but you're going to die from this disease.” [FG]
- There may be services but they’re in far away places or you don’t find out about them soon enough. I didn’t find out about the dental care over at Partnership for three years. Nobody ever told me they had dental care. [FG]
- I feel like there's a knowledge break in that people that are closeted about their HIV status and we know about them because of Ryan White, but they don’t really know where to go and what they need. And a lot of times it comes to a crisis situation before it actually comes out of the closet and if they had the knowledge up-front from their doctors, then things would go a lot smoother. [FG]

Theme 5: Quality of Care

Many participants complained about the quality of care for PLWH/A. They felt many Montana physicians were not educated in HIV/AIDS issues and/or they did not take the time needed to learn about their clients as individuals. In addition, the physicians who were knowledgeable were not evenly dispersed throughout Montana towns.

- I don’t know how easy it is to find doctors who are willing to follow HIV/AIDS patients. [OL]
- I think getting really clear and responsive [care] from medical people at the time of diagnosis is huge. Like accurate advice, careful testing. I think it's important to get people hooked up in relationships that are going to go with them for awhile. That's a big problem in Montana. [FF]
- I think one of the environmental factors that affects the crisis of [HIV] infection is the perceived isolation of Montana providers and so they're not seen as accurate or adequate to trust and so the education of the providers is a big thing for a lot of people. [FF]
- People are being trained to offer confidential testing, including doctors and soon there will be more people that know bow to offer these test. But even the doctors that people are referred to don’t always have the knowledge to offer the newly [HIV] diagnosed. [FG]
When I looked for counseling, I wanted someone that knew something about HIV, not just someone that's open to counseling, because that's nice but I need someone that has experience in counseling PLWH and knows the real problems that happen and so many counselors don't know. [FG]

There's the basic fear that comes when you don't have confidence in society or even in the medical people...there's need for to educate medical people and there is a need for understanding from them. [FG]

A lot of [doctors] don't know how to deal with PLWH. My son's doctor doesn't know how to deal with the HIV/AIDS stuff and they weren't going to circumcise him because I was positive and they didn't want to risk infection...I have a problem with the doctors I've taken my son to. They don't listen to me. They treat me like I'm stupid. [FG]

I've heard of PLWH that have had private doctors or physicians that aren't quit sure what to do and don't know what to expect from a PLWH, or if they tell [the doctors] what needs to be done they look at them like they're an idiot. [FG]

Nobody knows anything in this town. We can get emergency care if we need it, but in terms of AIDS, nobody knows anything. [FG]

I think there is a difference between living here and in larger cities. You just have to be more proactive here and you have to know what you're talking about...I just figured my doctor knew everything [in Seattle] and you just can't do that here. [FG]

I see a doctor in my town but he always used to call [a Missoula doctor] because he doesn't know anything. Since I've been going there I am the only patient with HIV. But he doesn't know anything about HIV and I doubt there is anyone in this area that does know. That could be an issue in any town.

I'm doctoring myself. I have a doctor that writes me [prescriptions], but he doesn't know a damn thing about what any numbers mean. If you can justify it, he'll write it...He won't even check me out. And I have to tell him what the numbers mean, which is bullshit. [FG]

You have to take responsibility to look at numbers and see where you are because maybe the numbers are showing how you feel because [the doctors] don't know. You have to explain it to them. [FG]

For awhile I was scared because my numbers dropped over 100 and I didn't know why. Nobody knew why and my doctor didn't know why. [FG]

I think that even sometimes the providers are weak on the knowledge and it's a problem for some of us to communicate exactly what we're feeling to someone who really doesn't know what to expect or when they're learning at the same pace as [their clients]. [FG]

I don't think [my doctor] takes a lot of time with me. He doesn't. And if he does take time with me he's learned that the more complicated things he can put down, the more he can charge me...because he can charge for the time of the visit. [FG]

[My doctor] knows his stuff, but he runs his patients through like cattle. You're lucky if you have ten minutes with him and that's after one and a half hour wait. He overbooks about eight to fifteen patients a day. That's the standard and he's got hospital calls. [FG]

If you're in triage for say, six or eight hours, you're lucky if you get to see your doctor for 20 minutes the whole time you're up there. [FG]

**Theme 6: Self-Esteem**

Participants talked about an HIV positive person's pride being a barrier to asking for assistance – particularly financial assistance for basic needs. Individual who do seek
assistance may experience a loss of pride or self-esteem when they find themselves in the position of having to repeatedly ask for help.

- I know I have a big problem with pride and a lot of people have told me they struggle with pride also. People put [coming in for services] off for so long because they're so afraid to ask and they've waited so long they're really down in the deep hole...if they would have taken care of the issue they would have been ok and whatever it was just kept getting deeper and deeper and they finally had to force themselves to get assistance. [FG].

- I think the pride thing for PLWH/A is a barrier to services. I think people do things they normally wouldn’t, like getting involved with people they don’t know. Or drug dealing because you can make that money and it’s not accountable to anybody. So it’s actually access to money for them. Their level of pride makes [this type of behavior] worth it, rather than asking for money. [FG]

- I think another barrier for some people might just be pride and asking for help. You get to the point where you’re like, “You know, I just asked them for a gas card the other day and you know I really need this, but I just can’t ask them again”. [FG]

- You do lose a lot of pride with the disease. And it just sucks to have to ask for stuff all the time. [FG]

- My biggest problem is that I’ve never had to ask for any of these thing before and so now I’m supposedly at the point in my life where I have all my shit together and to be doing what I’m doing is hard. I have to crawl to [the DPHHS] for help because I need you to help me with [all the basics]. [FG]

**Additional Themes**

**Theme 1: Issues Unique to Women**

Sub-themes related to Women’s Issues include the following: a) stigma associated with being a woman with HIV; and b) medical professionals with expertise in treating women. Each of these sub-themes is described below and illustrated with quotes from participants.

**A. Stigma Associated with being a Woman with HIV**

HIV infection has traditionally been associated with men. And, while in recent years, the number of women infected nationwide has increased dramatically, the number of HIV positive women in Montana remains relatively low. The low incidence of HIV among women in Montana appears to result in increased stigma and social isolation for women who are infected.

- Especially the stigma placed on women living with HIV. The stigma is harder on the women. HIV/AIDS has been known as the disease for men and so when a woman has HIV, the way she
looks at it is so different. [Service providers] are looking at all the different things that go along with being a woman. Women are not talking because they have a disease that is associated with men. And they are hiding. They are hiding from services and hiding from alike populations. [FG]

➢ The stigma is even worse for women. By the time women go in and see a doctor the worst has happened. The disease has progressed. And then they have to deal with the stigma. [FG]

B. Medical Expertise in Treating Women

 Physicians who have expertise in women’s issues and expertise in the treatment of women with HIV appear to be a rare commodity in Montana.

➢ We need somebody that is an HIV specialist in women’s issues so that women can be treated and so they can talk about the issues they are confronted with. [Women need this] so they can explore what is going on for them as linked and as separate from the HIV diagnosis. I would like to see better doctors that know more about women. [FG]

➢ Sometimes you get the best information you can and you just can’t look at an HIV doctor as if they know everything. Especially being a woman. When you are a woman with HIV you have to help the doctor with your issues. [FG]

➢ There is no women’s support group here, but I’m in the process of trying to start one. The only problem is even though we’re positive, we don’t all mesh. We still have personalities and there are still people that drive us nuts and so it’s like when you go to support groups, sometimes you don’t always get along. [FG]

➢ There used to be a psychiatrist or a counselor and I tried to go when he had his little group but I was kind of uncomfortable because I was the only girl... it wasn’t what I thought when I showed up either. I thought it would be a place to discuss whatever was bothering you, but it wasn’t like that at all. [FG]

Theme 2: Quality of HIV Prevention Education in Schools

Participants gave the impression that they were disappointed in current prevention strategies offered in Montana schools. Many participants alluded to the fact that young people thought of HIV as a manageable disease, therefore giving little attention to the few prevention strategies which are offered.

➢ I think we have to focus on the young kids- the teenagers. I just have this feeling that it’s going to start happening. We need someone else to go into the school to say, “I’m positive and I want to talk to you about it”. [FF]

➢ And there’s no prevention and it sucks because it’s not going to get any better without [prevention]. And all it’s going to do is drive up the costs of medical expenses and housing expenses and these waiting lists are just going to get longer and longer. So if they don’t want to spend the money on that then they need to offer prevention money and getting people education and advocacy and talking to people. [FG]
What really scared me is when I was talking to some schools and the kids would say, “Well, I don’t have to worry about HIV because they’ll have a cure by the time I get it.” And I would look at them and say, “We’ve been looking for a cure for 20 years and we don’t have anything yet”. And now it’s even longer than 20 years. [FG]

I did a talk [at Montana schools] and the biggest thing I heard was, “It’s a manageable disease now. We can manage it. People are living with it. Look how long you’ve been alive with it”. [FG]

When they teach HIV issues at the high schools they say, “This is AIDS, this is caused by the HIV virus. If you have this, you’ll need this”. It’s not like, “If you get this, your life is going to be fucked up”. There’s no truth or reality in what they’re talking about with HIV and AIDS. It’s just a bunch of rhetoric and most of it is the same thing we heard ten years ago. [FG]
CHAPTER V

DISCUSSION OF KEY FINDINGS

In this chapter the researchers provide a synthesis of the data from all four sources (questionnaires, *focus groups, interviews and the literature). This chapter begins with a summary of demographic data, and continues with a description of behavioral risk factors. Key findings are reported regarding assistance and treatment service needs of project participants, including the comparisons of sub-populations. Barriers to receiving assistance and treatment services are discussed. Primary prevention, as suggested by study participants is talked about, along with the reported findings on the best channels of information dissemination to PLWH/A in Montana. Strategies to closing the gaps between needs and services are discussed in Section VIII. Conclusions about key findings for this needs assessment are offered. Chapter V is divided into the following sections:

Section I: Summary of Demographics
Section II: Behavioral Risk Factor
    A. Substance abuse
    B. Unsafe sex
Section III: Service Needs
    A. Assistance, Treatment and Service Needs PLWH/A Need and Use
        1) Medical related service needs
        2) Basic living needs
        3) Counseling and other support service needs
    B. Services PLWH/A Need and Can't Get.
        1) Unmet medical related service needs
        2) Unmet basic living needs
        3) Unmet counseling and other support service needs
Section IV: Frequent Barriers to Receiving Assistance, Treatment and/ or Services
Section V: Primary Prevention of HIV Infection
Section VI: Best Channels for Information Dissemination
Section VII: Recommendations for Closing Gaps between Needs and Services
Section VIII: Methodological Considerations of this Study
Section IX: Conclusions

* Focus group participants and key-informant interviewees will be referred to as 'interviewees' in this chapter.
Section I: Summary of Demographics

Below is a description of demographics collected from the *Montana 2005 HIV/AIDS Consumer Questionnaire*. The demographics of the HIV positive individuals who participated in the questionnaire closely mirror the HIV/AIDS epidemic in Montana. Specifically, 77% (n=128) of questionnaire participants were male and 21% (n=35) were female. The gender of recorded adult HIV/AIDS cases in Montana from 1985 to 2003 is 88% male and 12% female. Eighty-seven percent of respondents were white, and in Montana, 85% reported HIV/AIDS cases are white. The average age of study participants was 41, while in Montana, 167 of the 351 PLWH/A are between the ages of 30-39, and 60 individuals are between the ages 40-49. Between these two age groups, the questionnaire results closely match the average age of PLWH/A in Montana. A summary of demographics can be seen below in Table 31.

### TABLE 31. SUMMARY OF DEMOGRAPHICS

<table>
<thead>
<tr>
<th>BASIC DEMOGRAPHICS</th>
<th>PERCENT</th>
<th>NUMBER</th>
<th>TOTAL RESPONDENTS</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>RACE/ETHNICITY</strong></td>
<td></td>
<td></td>
<td>n=166</td>
</tr>
<tr>
<td>Native American/AK Native</td>
<td>10%</td>
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</tr>
<tr>
<td>Asian Pacific Islander</td>
<td>--</td>
<td>--</td>
<td></td>
</tr>
<tr>
<td>African American</td>
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</tr>
<tr>
<td>White</td>
<td>87%</td>
<td>n=146</td>
<td></td>
</tr>
<tr>
<td>Hispanic</td>
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<td>n=2</td>
<td></td>
</tr>
<tr>
<td>Other</td>
<td>1%</td>
<td>n=2</td>
<td></td>
</tr>
<tr>
<td><strong>GENDER</strong></td>
<td></td>
<td></td>
<td>n=166</td>
</tr>
<tr>
<td>Male</td>
<td>77%</td>
<td>n=128</td>
<td></td>
</tr>
<tr>
<td>Female</td>
<td>21%</td>
<td>n=35</td>
<td></td>
</tr>
<tr>
<td>Transgender (male to female)</td>
<td>1%</td>
<td>n=1</td>
<td></td>
</tr>
<tr>
<td>No response</td>
<td>1%</td>
<td>n=2</td>
<td></td>
</tr>
<tr>
<td><strong>SEXUAL ORIENTATION</strong></td>
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<tr>
<td>Heterosexual/straight</td>
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<td></td>
</tr>
<tr>
<td>Gay</td>
<td>60%</td>
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<td></td>
</tr>
<tr>
<td>Bisexual</td>
<td>6%</td>
<td>n=9</td>
<td></td>
</tr>
<tr>
<td>OTHER</td>
<td>2%</td>
<td>n=3</td>
<td></td>
</tr>
<tr>
<td><strong>AGE</strong></td>
<td></td>
<td></td>
<td>n=166</td>
</tr>
<tr>
<td>Youngest</td>
<td></td>
<td>AT TIME OF SURVEY COMPLETION</td>
<td>22</td>
</tr>
</tbody>
</table>
### Oldest

|   | 81 |

### Average

|   | 41 |

#### EMPLOYMENT STATUS

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<thead>
<tr>
<th>Status</th>
<th>Percentage</th>
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<td>Employed full-time</td>
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</tr>
<tr>
<td>Employed part-time</td>
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<td>12</td>
</tr>
<tr>
<td>Not employed</td>
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</tr>
<tr>
<td>Self employed</td>
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<td>10</td>
</tr>
<tr>
<td>On disability</td>
<td>31%</td>
<td>51</td>
</tr>
<tr>
<td>Other</td>
<td>10%</td>
<td>17</td>
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</table>

#### INCOME

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<tr>
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<tr>
<td>Maximum</td>
<td>$3000</td>
</tr>
<tr>
<td>Mean</td>
<td>$816</td>
</tr>
<tr>
<td>Median</td>
<td>$752</td>
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#### LIVING ARRANGEMENTS

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<th>Arrangement</th>
<th>Percentage</th>
<th>Count</th>
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<tr>
<td>Own house or apartment</td>
<td>63%</td>
<td>104</td>
</tr>
<tr>
<td>Friend or relative's house/apartment</td>
<td>28%</td>
<td>46</td>
</tr>
<tr>
<td>Hospice or nursing facility</td>
<td>--</td>
<td>--</td>
</tr>
<tr>
<td>Live on the streets or in a shelter</td>
<td>1%</td>
<td>1</td>
</tr>
<tr>
<td>Jail or prison</td>
<td>4%</td>
<td>6</td>
</tr>
<tr>
<td>Pre-release center</td>
<td>1%</td>
<td>2</td>
</tr>
<tr>
<td>Drug/alcohol treatment center</td>
<td>1%</td>
<td>2</td>
</tr>
<tr>
<td>Living in public housing</td>
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<td>5</td>
</tr>
<tr>
<td>Other</td>
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#### NUMBER OF DEPENDENT CHILDREN

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<tr>
<th>Number of Children</th>
<th>Count</th>
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<tbody>
<tr>
<td>0</td>
<td>143</td>
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<tr>
<td>1</td>
<td>10</td>
</tr>
<tr>
<td>2</td>
<td>7</td>
</tr>
<tr>
<td>3</td>
<td>3</td>
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#### HEALTH INSURANCE/ASSISTANCE

<table>
<thead>
<tr>
<th>Insurance/Assistance</th>
<th>Percentage</th>
<th>Count</th>
</tr>
</thead>
<tbody>
<tr>
<td>Medicaid</td>
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<td>57</td>
</tr>
<tr>
<td>Medicare</td>
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<tr>
<td>Private</td>
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<td>37</td>
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<tr>
<td>ADAP</td>
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<tr>
<td>VA benefits</td>
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<td>Indian Health Services</td>
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<tr>
<td>Other</td>
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#### HIV/AIDS STATUS

<table>
<thead>
<tr>
<th>Exposure Category</th>
<th>Percentage</th>
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<tbody>
<tr>
<td>Sex with a man</td>
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<td>120</td>
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<tr>
<td>Sex with a woman</td>
<td>5%</td>
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</tr>
<tr>
<td>Sex with an injection drug user</td>
<td>4%</td>
<td>6</td>
</tr>
<tr>
<td>Injecting drug use</td>
<td>5%</td>
<td>8</td>
</tr>
<tr>
<td>Blood transfusion</td>
<td>2%</td>
<td>3</td>
</tr>
<tr>
<td>Don't know</td>
<td>5%</td>
<td>9</td>
</tr>
<tr>
<td>Other</td>
<td>4%</td>
<td>7</td>
</tr>
</tbody>
</table>

#### OVERALL HEALTH

<table>
<thead>
<tr>
<th>Health Status</th>
<th>Percentage</th>
<th>Count</th>
</tr>
</thead>
<tbody>
<tr>
<td>Very Good</td>
<td>16%</td>
<td>26</td>
</tr>
<tr>
<td>Good</td>
<td>42%</td>
<td>69</td>
</tr>
</tbody>
</table>
Fair 32% n=53
Poor 8% n=14
Very Poor 1% n=2

**CONCURRENT AIDS & HIV DIAGNOSIS**

<table>
<thead>
<tr>
<th></th>
<th></th>
<th>n=164</th>
</tr>
</thead>
<tbody>
<tr>
<td>No</td>
<td>76%</td>
<td>n=126</td>
</tr>
<tr>
<td>Yes</td>
<td>19%</td>
<td>n=32</td>
</tr>
<tr>
<td>Can't Remember</td>
<td>4%</td>
<td>n=6</td>
</tr>
</tbody>
</table>

**CURRENTLY DIAGNOSED WITH AIDS**

<table>
<thead>
<tr>
<th></th>
<th></th>
<th>n=165</th>
</tr>
</thead>
<tbody>
<tr>
<td>No</td>
<td>49%</td>
<td>n=82</td>
</tr>
<tr>
<td>Yes</td>
<td>46%</td>
<td>n=77</td>
</tr>
<tr>
<td>Can't Remember</td>
<td>4%</td>
<td>n=6</td>
</tr>
</tbody>
</table>

**KNOW CURRENT CD4 COUNT/VIRAL LOAD**

<table>
<thead>
<tr>
<th></th>
<th></th>
<th>n=164</th>
</tr>
</thead>
<tbody>
<tr>
<td>No</td>
<td>16%</td>
<td>n=27</td>
</tr>
<tr>
<td>Yes</td>
<td>82%</td>
<td>n=136</td>
</tr>
</tbody>
</table>

**KNOW TWELVE MONTH CD4/VIRAL LOAD**

<table>
<thead>
<tr>
<th></th>
<th></th>
<th>n=164</th>
</tr>
</thead>
<tbody>
<tr>
<td>No</td>
<td>5%</td>
<td>n=8</td>
</tr>
<tr>
<td>Yes</td>
<td>94%</td>
<td>n=156</td>
</tr>
</tbody>
</table>

**HIV/AIDS CASE MANAGER**

<table>
<thead>
<tr>
<th></th>
<th></th>
<th>n=164</th>
</tr>
</thead>
<tbody>
<tr>
<td>Ryan White Case Manager</td>
<td>81%</td>
<td>n=134</td>
</tr>
<tr>
<td>No longer have a case manager</td>
<td>6%</td>
<td>n=10</td>
</tr>
<tr>
<td>Have never had a case manager</td>
<td>12%</td>
<td>n=20</td>
</tr>
<tr>
<td>No response</td>
<td>1%</td>
<td>n=2</td>
</tr>
</tbody>
</table>

**REASONS FOR NO CASE MANAGER**

<table>
<thead>
<tr>
<th></th>
<th></th>
<th>n=30</th>
</tr>
</thead>
<tbody>
<tr>
<td>I don't need services</td>
<td>13%</td>
<td>n=4</td>
</tr>
<tr>
<td>I can get services myself</td>
<td>13%</td>
<td>n=4</td>
</tr>
<tr>
<td>I didn't know one was available</td>
<td>20%</td>
<td>n=6</td>
</tr>
<tr>
<td>I live too far away</td>
<td>10%</td>
<td>n=3</td>
</tr>
<tr>
<td>I'm worried people will find out I have HIV/AIDS</td>
<td>27%</td>
<td>n=8</td>
</tr>
<tr>
<td>I don't know how a case manager could help me</td>
<td>33%</td>
<td>n=10</td>
</tr>
<tr>
<td>A different service provider helped me get services</td>
<td>3%</td>
<td>n=1</td>
</tr>
<tr>
<td>They don't speak my language</td>
<td>--</td>
<td>--</td>
</tr>
<tr>
<td>They don't understand my culture</td>
<td>3%</td>
<td>n=1</td>
</tr>
<tr>
<td>Use alternative therapy/standard medicine too harsh</td>
<td>--</td>
<td>--</td>
</tr>
<tr>
<td>Confidentiality</td>
<td>17%</td>
<td>n=5</td>
</tr>
<tr>
<td>Other</td>
<td>17%</td>
<td>n=5</td>
</tr>
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</table>

**BEHAVIORS SINCE HIV POSITIVE**

**SEXUAL ACTIVITY**

<table>
<thead>
<tr>
<th></th>
<th></th>
<th>n=165</th>
</tr>
</thead>
<tbody>
<tr>
<td>Stopped having sex</td>
<td>34%</td>
<td>n=56</td>
</tr>
<tr>
<td>Never use condoms</td>
<td>10%</td>
<td>n=16</td>
</tr>
<tr>
<td>Sometimes use condoms</td>
<td>25%</td>
<td>n=41</td>
</tr>
<tr>
<td>Always use condoms</td>
<td>31%</td>
<td>n=53</td>
</tr>
</tbody>
</table>

**SITUATIONS WHEN CONDOMS ARE NOT USED**

<table>
<thead>
<tr>
<th></th>
<th></th>
<th>n=57</th>
</tr>
</thead>
<tbody>
<tr>
<td>With my regular partner who is HIV+</td>
<td>26%</td>
<td>n=15</td>
</tr>
<tr>
<td>When my viral load is undetectable</td>
<td>2%</td>
<td>n=1</td>
</tr>
<tr>
<td>With any sex partner who is HIV+</td>
<td>16%</td>
<td>n=9</td>
</tr>
<tr>
<td>Event</td>
<td>Percentage</td>
<td>n</td>
</tr>
<tr>
<td>----------------------------------------------------------------------</td>
<td>------------</td>
<td>----</td>
</tr>
<tr>
<td>When my sex partner refuses to use condoms</td>
<td>19%</td>
<td>11</td>
</tr>
<tr>
<td>When I feel uncomfortable bringing up condoms</td>
<td>14%</td>
<td>8</td>
</tr>
<tr>
<td>Other</td>
<td>21%</td>
<td>12</td>
</tr>
<tr>
<td><strong>Disclosure of Status</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>No</td>
<td>3%</td>
<td>5</td>
</tr>
<tr>
<td>Yes</td>
<td>63%</td>
<td>105</td>
</tr>
<tr>
<td>Sometimes</td>
<td>8%</td>
<td>14</td>
</tr>
<tr>
<td>Not sexually active</td>
<td>24%</td>
<td>40</td>
</tr>
<tr>
<td><strong>Ask Partner to Disclose</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>No</td>
<td>15%</td>
<td>24</td>
</tr>
<tr>
<td>Yes</td>
<td>34%</td>
<td>56</td>
</tr>
<tr>
<td>Sometimes</td>
<td>15%</td>
<td>25</td>
</tr>
<tr>
<td>Not sexually active</td>
<td>31%</td>
<td>51</td>
</tr>
<tr>
<td><strong>Sexually Transmitted Diseases</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Not testing + positive for STDs</td>
<td>84%</td>
<td>140</td>
</tr>
<tr>
<td>Testing + for STDs</td>
<td>15%</td>
<td>24</td>
</tr>
<tr>
<td><strong>Type of STD</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Syphilis</td>
<td>--</td>
<td>--</td>
</tr>
<tr>
<td>Genital warts</td>
<td>25%</td>
<td>6</td>
</tr>
<tr>
<td>Gonorrhea</td>
<td>13%</td>
<td>3</td>
</tr>
<tr>
<td>Herpes</td>
<td>29%</td>
<td>7</td>
</tr>
<tr>
<td>Chlamydia</td>
<td>8%</td>
<td>2</td>
</tr>
<tr>
<td>Other</td>
<td>4%</td>
<td>1</td>
</tr>
<tr>
<td><strong>Medical Illnesses</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>No</td>
<td>40%</td>
<td>66</td>
</tr>
<tr>
<td>Yes</td>
<td>59%</td>
<td>98</td>
</tr>
<tr>
<td><strong>Type of Medical Illnesses</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Hepatitis B/C</td>
<td>41%</td>
<td>40</td>
</tr>
<tr>
<td>Diabetes</td>
<td>10%</td>
<td>10</td>
</tr>
<tr>
<td>Alcoholism</td>
<td>18%</td>
<td>18</td>
</tr>
<tr>
<td>Drug dependency</td>
<td>20%</td>
<td>20</td>
</tr>
<tr>
<td>Heart disease</td>
<td>1%</td>
<td>8</td>
</tr>
<tr>
<td>Mental illness</td>
<td>36%</td>
<td>35</td>
</tr>
<tr>
<td>Opportunistic infection</td>
<td>24%</td>
<td>23</td>
</tr>
<tr>
<td>other</td>
<td>39%</td>
<td>38</td>
</tr>
<tr>
<td><strong>Substance Use</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Used substances in the past year</td>
<td>40%</td>
<td>67</td>
</tr>
<tr>
<td>Have not used substances in the past year</td>
<td>58%</td>
<td>97</td>
</tr>
<tr>
<td><strong>Type of Substances Used</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Alcohol</td>
<td>67%</td>
<td>65</td>
</tr>
<tr>
<td>Marijuana</td>
<td>67%</td>
<td>65</td>
</tr>
<tr>
<td>Crack</td>
<td>3%</td>
<td>3</td>
</tr>
<tr>
<td>Cocaine</td>
<td>5%</td>
<td>5</td>
</tr>
<tr>
<td>Heroin</td>
<td>2%</td>
<td>2</td>
</tr>
<tr>
<td>Meth/crystal</td>
<td>29%</td>
<td>28</td>
</tr>
<tr>
<td>Downers</td>
<td>7%</td>
<td>7</td>
</tr>
<tr>
<td></td>
<td></td>
<td>n=11</td>
</tr>
<tr>
<td>--------------------------</td>
<td>--------</td>
<td>------</td>
</tr>
<tr>
<td><strong>IDU USE</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>No</td>
<td>93%</td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>6%</td>
<td></td>
</tr>
<tr>
<td><strong>SHARED NEEDLES</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>No</td>
<td>99%</td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>1%</td>
<td></td>
</tr>
<tr>
<td><strong>SUBSTANCE ABUSE IS A PROBLEM</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>11%</td>
<td></td>
</tr>
<tr>
<td>Unsure</td>
<td>5%</td>
<td></td>
</tr>
<tr>
<td>No</td>
<td>82%</td>
<td></td>
</tr>
<tr>
<td><strong>EMOTIONAL CONCERNS</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>No</td>
<td>27%</td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>72%</td>
<td></td>
</tr>
<tr>
<td><strong>TYPE OF EMOTIONAL ISSUES</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Stress</td>
<td>51%</td>
<td></td>
</tr>
<tr>
<td>Depression</td>
<td>84%</td>
<td></td>
</tr>
<tr>
<td>guilt</td>
<td>24%</td>
<td></td>
</tr>
<tr>
<td>Suicidal tendencies</td>
<td>28%</td>
<td></td>
</tr>
<tr>
<td>Anger/resentment</td>
<td>38%</td>
<td></td>
</tr>
<tr>
<td>Anxiety</td>
<td>77%</td>
<td></td>
</tr>
<tr>
<td>loneliness (isolation)</td>
<td>59%</td>
<td></td>
</tr>
<tr>
<td>other</td>
<td>1%</td>
<td></td>
</tr>
<tr>
<td><strong>TREATMENT FOR EMOTIONAL PROBLEMS</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>No</td>
<td>46%</td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>54%</td>
<td></td>
</tr>
<tr>
<td><strong>TYPE OF TREATMENT FOR EMOTIONAL PROBLEMS</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Prescription medicine</td>
<td>83%</td>
<td></td>
</tr>
<tr>
<td>Alternative therapies</td>
<td>5%</td>
<td></td>
</tr>
<tr>
<td>Counseling</td>
<td>38%</td>
<td></td>
</tr>
<tr>
<td>Medical marijuana</td>
<td>11%</td>
<td></td>
</tr>
<tr>
<td>Other</td>
<td>5%</td>
<td></td>
</tr>
<tr>
<td><strong>PROBLEMS IN CLOSE RELATIONSHIPS</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>No</td>
<td>56%</td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>43%</td>
<td></td>
</tr>
<tr>
<td><strong>SPECIFIC PROBLEMS</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Stress or isolation in family relationships</td>
<td>34%</td>
<td></td>
</tr>
<tr>
<td>Difficulties in relationship with spouse/partner</td>
<td>27%</td>
<td></td>
</tr>
<tr>
<td>Involvement with bug chasers</td>
<td>2%</td>
<td></td>
</tr>
<tr>
<td>Difficulties in relationship(s) with children</td>
<td>7%</td>
<td></td>
</tr>
<tr>
<td>Other</td>
<td>13%</td>
<td></td>
</tr>
<tr>
<td><strong>TYPE OF COUNSELING PREFERRED</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Individual</td>
<td>66%</td>
<td></td>
</tr>
<tr>
<td>Group</td>
<td>33%</td>
<td></td>
</tr>
</tbody>
</table>
Section II: Behavioral Risk Factors

Focus group participants, key informants, and questionnaire respondents were asked to identify behaviors HIV positive people engage in that are detrimental to their health. In this section, data from all of those sources and from the literature will be used to increase understanding of those behaviors.

A. Substance Abuse

Table 32 shows the most frequently used substances by study participants.

Table 32. Type of substances used by those who reported using substances

<table>
<thead>
<tr>
<th>Substance</th>
<th>% of Respondents (n=97)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Alcohol</td>
<td>67% (n=65)</td>
</tr>
<tr>
<td>Marijuana</td>
<td>67% (n=65)</td>
</tr>
<tr>
<td>Methamphetamines</td>
<td>29% (n=28)</td>
</tr>
</tbody>
</table>

Fifty-eight percent (n=97) of the questionnaire participants reported using substances in the past year. Three drugs, alcohol, marijuana and methamphetamines, were overwhelmingly the drugs of choice among those who were using substances. Two-thirds of the participants reported using alcohol and marijuana, while nearly a third acknowledged using methamphetamines. These three drugs also emerged as the main topics of discussion among interviewees. And, while interviewees believed the abuse of all kinds of drugs (legal, illegal, and prescription) contributes to HIV positive people's inability to cope with their infection in a constructive manner, and promotes risky...

And in Missoula we've got the methamphetamines. We've got the neighborhoods. We're starting to see certain neighborhoods in little areas that cater to it. If you want to find it you can always find it. Someone's going to tell you what street to go on...We're just waiting for HIV to get in the big drug use ring and it's going to be a bomb and we're probably going to have one-hundred people exposed. [FF]
behaviors, the greatest risk was incurred with the use of methamphetamines. In fact, one interviewee described methamphetamine use and HIV as "a time bomb waiting to happen." Increased sexual drive and the use of needles to inject methamphetamines were the major concerns of the focus group and key informant interviewees.

Meth, ecstasy, and MDA are pretty much sexually driven drugs. I mean you take them and you're going to f**k. You're going to f**k for hours and days. So that's the high part of those. So if HIV wasn't sexually transmitted it would be a problem, but since it is [the drugs] go hand-in-hand with HIV. [FG]

The discussion regarding alcohol was fairly limited. Although alcohol was reported as a more frequently used drug, it appears alcohol use was seen as much less of a problem than methamphetamine use. Only one interviewee suggested that individuals who use alcohol may be more likely to expose others to HIV. Other individuals alluded to the fact that people use alcohol to cope with their situation, but did not indicate that alcohol was a destructive coping mechanism.

I've already accepted the fact that I don't care if I ever quit drinking...because I stress myself out too much. For more than ten years I've been in and out of AA and treatment programs- so many different treatment programs so many times that I finally just decided I'm not going to stress myself out about being this sober 'happy, joyous and free', as they say in AA. I'm already 'happy, joyous and free', and I'm still going to drink alcohol. And that's what I've accepted for myself. [FG]

The discussion regarding marijuana was surprising in that most of the comments about the use of marijuana were neutral or positive. Participants talked about marijuana as a means to deal with depression, improve mood and increase appetite. They did not, however, associate marijuana with addiction or with an increase in risky sexual behavior. In fact, even individuals who did not personally use marijuana were happy that its use had been legalized, making it more available to those who needed it.

I don't think marijuana is such a bad terrible thing. I mean alcohol and the other drugs I think we really want to address as far as coping. I mean marijuana is such a mild thing. It can be habitual but I don't believe it's ever totally addictive... I mean if it helps increase your appetite then jeez! I was so happy when they passed that law. [FG]
Focus group participants did not talk a great deal about injecting drug use. Although injecting methamphetamines was briefly mentioned, information about the risky behavior was not forthcoming in either questionnaire or focus group data. However, several key informants spoke at length about this issue and cautioned against underestimating the prevalence of injecting drug use based on data from this project. It seems that the stigma associated with injecting drug use exists, not only among non-users, but among users as well. One key informant had this to say, “Injecting drugs is seen by many users as indicating that the person is totally lost, out of control and at an all time low. Admitting to injecting drugs puts extra stigma on the user.” It is important to recognize that injecting drug may be vastly underreported. Certainly, questionnaire and focus group participants were reticent to talk about injecting drug use even when asked directly about behaviors that put people at risk of for HIV infection.

B. Unsafe Sex

The issue of unsafe sex came up in both questionnaire data analysis and in interviewee data analysis. Questionnaire results revealed fifty-seven of the 109 sexually active respondents did not always use condoms. Table 33 explains the most frequent situations where respondents claimed they did not use condoms.
Table 33. Frequent Situations when Condoms are NOT Used. (n=57)

<table>
<thead>
<tr>
<th>Frequent Situations where Condoms are NOT used</th>
<th>% of Respondents (n)</th>
</tr>
</thead>
<tbody>
<tr>
<td>With my regular partner who is HIV positive.</td>
<td>26% (n=15)</td>
</tr>
<tr>
<td>Other (including ‘when drugs and alcohol are involved’ and ‘drugs’).</td>
<td>21% (n=12)</td>
</tr>
<tr>
<td>When my sex partner refuses to use condoms</td>
<td>19% (n=11)</td>
</tr>
</tbody>
</table>

All of these situations were alluded to by interviewees. Interviewees felt that much of the time apathy and/or denial were at the root of situations leading to unprotected sex. Many comments were made regarding the denial of risk and the denial of sexual orientation leading to unprotected sex. One interviewee stated, “In Montana a fast growing [HIV] group is married men who go to the bookstore on the sly but who have families and don’t identify as gay or bisexual. That is a big problem, so in a sense they’re really in denial.”

PLWH/A also expressed experience with encountering bug-chasers, or people interested, for one reason or another, in contracting HIV. Seemingly, drugs and alcohol are not always an element with bug-chaser encounters. Specifically, one participant stated, “Unprotected sex would be a risky behavior. It’s out there. And people are actually looking for [HIV]. In my first encounter with a bug-chaser, we weren’t drunk, we weren’t high, and we weren’t stoned. He just didn’t care.” Again, apathy was the foundation for this bug-chaser encounter. The questionnaire referenced bug-chasers under the question, ‘Has becoming HIV positive caused problems in your close relationships?’ Although only four (2%) of the 89 participants who respondents who answered yes to this question stated they had been involved with people who wanted to be infected (bug-chasers), the dialogue of bug-chasers by interviewees led researchers to believe the issue could be an emerging concern.
Although only one questionnaire respondent reported not using condoms when his viral load was undetectable, this was an issue that interviewees discussed. This is a dangerous matter because when two HIV positive people engage in unprotected sex, even when their viral load is low, it can lead to an HIV superinfection. When the discussion of superinfection arose in one focus group, somebody commented, “Some people’s virus becomes resistant, some don’t. Some become superinfected with resistant virus. [It’s the idea that] ‘I’m positive, he’s positive, we don’t need to use protection…’”. Whether the lack of condom use with a sex partner results from refusal from partners or is a choice of both partners, it is a risky behavior prevalent among PLWH/A. Superinfection is a concern for many PLWH/A in the United States. As stated in the literature review, superinfection is a great danger for PLWH/A because the reinfection is often resistant to medications, and when someone living with HIV is resistant to drugs, their diagnosis can quickly move into an AIDS diagnosis, which threatens death (2004). Because Superinfection is often caused by unprotected sex and unprotected sex is often facilitated by substance abuse, there is a vicious cycle involving substance abuse, unprotected sex, and consequently, superinfection. Methamphetamine seems to be the current drug of choice and this drug, as stated before, is considered by most to be linked to unsafe sex.
Section III: PLWH/A Service Needs

A. Services PLWH/A Need and are Able to Get

Questionnaire participants were asked to identify the services they currently need and use.

The tables below describe the percentage and frequency of participants who indicated a need for each service. Services were divided into one of three categories: medical related services, basic living services, and counseling and other support services. Focus group and interviewee’s thoughts about the services listed in the tables are discussed following each table.

1) Medical Related Service Needs

The most outstanding medical services needed and used by PLWH/A can be seen below in Table 34.

Table 34. Most Frequently Used Medical Related Services

<table>
<thead>
<tr>
<th>Type of Service</th>
<th>% of Respondents (n)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Medical Care (doctor, nurse, etc.)</td>
<td>75% (n=124)</td>
</tr>
<tr>
<td>Financial Assistance with Medications</td>
<td>64% (n=106)</td>
</tr>
<tr>
<td>Dental Care</td>
<td>52% (n=87)</td>
</tr>
<tr>
<td>Eye Care</td>
<td>49% (n=81)</td>
</tr>
<tr>
<td>Help Paying for Medical Insurance</td>
<td>31% (n=51)</td>
</tr>
</tbody>
</table>

All of the medical needs in Table 34, except the need for eye care, were discussed at length by interviewees. Medical care is the most widely used service need of PLWH/A, but many expressed several concerns regarding medical care. First, participants commented about the quality of care for PLWH/A. They felt many Montana physicians were not educated
about HIV/AIDS issues and/or did not take the time to learn about their clients as individuals. Furthermore, PLWH/A felt physicians who were knowledgeable about HIV were not evenly dispersed throughout Montana towns.

Second, interview participants expressed concern about expenses related to medical care; specifically, government budget cuts, Medicaid spend downs/insurance co-pays, and the cost of medications. Individuals with private medical insurance worried about losing their insurance or about the ability to make co-payments, while individuals who received Medicare and Medicaid found it very difficult to provide for their basic living needs when dependent on government programs.

And finally, interviewees were concerned about the lack of dental care. Few dentists were willing to accept Medicaid or Medicare patients, and it seems participants were either unaware dental care was available at reduced cost, or they were aware, but were skeptical because of the long waiting lists.

These medical concerns of PLWH/A are shared by people in Montana working with HIV assistance and prevention. As stated in Chapter II, 69 of 120 people surveyed in the Montana Governor's Counsel in 2004 believed medical care to be the number one concern for PLWH/A in Montana. Even with the assistance of HAART therapy for PLWH/A, medical care is a concern coinciding with and HIV diagnosis. In fact, HAART often compounds medical care concerns because of its high cost.
2) Basic Living Needs

According to questionnaire participants, the three most frequently used basic living assistance services can be seen in Table 35:

Table 35. Most Frequently Used Basic Living Assistance Services

<table>
<thead>
<tr>
<th>I NEED THESE SERVICES AND USE THEM</th>
<th>% of Respondents (n)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Type of Service</td>
<td></td>
</tr>
<tr>
<td>Assistance with Paying Utility Bills</td>
<td>36% (n=60)</td>
</tr>
<tr>
<td>Housing or Rent Assistance</td>
<td>34% (n=57)</td>
</tr>
<tr>
<td>Transportation</td>
<td>11% (n=19)</td>
</tr>
</tbody>
</table>

The three services listed in Table 35 were discussed in some detail by focus group and interview participants. PLWH/A again referenced financial concerns. It seems a diagnosis of HIV often exacerbates financial issues that exist prior to the diagnosis. Some individuals stated they were forced to make choices between paying for medications or paying for basic necessities such as utilities and rent.

Several participants noted the impossibility of getting ahead financially when money from gainful employment resulted in a reduction of Medicaid or Medicare benefits. Quality of life appeared to be greatly diminished by the lack of money to meet the basic needs of daily living.

Transportation needs also were cited by interviewees as one of the greatest basic needs of people with HIV. Medical and other support services are often not available in the more sparsely populated regions of Montana. One individual reported having to drive 120 miles to see his physician, and traveling...
long distances like this seemed to be the problem for several focus group participants. Although what transportation was available was used, transportation is an issue because many individuals reported not having the resources to buy and maintain a car, and those fortunate enough to own a car often did not have the money to buy gas.

3) Counseling and Other Support Service Needs

According to questionnaire participants, the five most frequently used counseling and other support services can be seen in Table 36:

Table 36. Most Frequently Used Counseling and Other Support Services

<table>
<thead>
<tr>
<th>Type of Service</th>
<th>% of Respondents (n)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Case Management Services</td>
<td>72% (n=120)</td>
</tr>
<tr>
<td>Information and Referral for Services</td>
<td>57% (n=95)</td>
</tr>
<tr>
<td>Spiritual Support</td>
<td>26% (n=43)</td>
</tr>
<tr>
<td>Support Groups/Peer Counseling</td>
<td>21% (n=34)</td>
</tr>
<tr>
<td>Social and Recreational Activities</td>
<td>13% (n=21)</td>
</tr>
</tbody>
</table>

With the exception of case management and spiritual support, all of the needs listed in the table above were discussed among focus group and interview participants. It is interesting to note that while case management is the most widely used service, it was not a topic of discussion in the focus groups or interviews. For the most part, participants had neither good nor bad things to say about case management. They did, however, express a strong need for information and referral services. Several individuals believed physicians would be the best people to dispense information about referral services, but also commented that physicians in Montana rarely have knowledge about services for people with HIV.

If someone were diagnosed in a small town in Montana, by a normal doctor in a normal town, then they wouldn't know where to go [for services]. [That doctor] isn't going to know anything, instead they say, 'I'm sorry, but you're going to die from this disease.' [FG]

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The need for support groups and social and recreational activities was discussed by interviewees at some length. While twenty percent of the questionnaire respondents reported using support groups, and it is apparent some of towns offer functioning support groups, most of the interviewees still talked about the lack of community and the social and geographical isolation that has a dramatic effect on the quality of life for people living with HIV in Montana. Qualitative analysis echoes quantitative research in the definite need for improvement in community building throughout Montana.

**B. Services PLWH/A Need and Can’t Get**

Questionnaire participants were asked to identify the services they currently need but cannot get. The tables below describe the services that were checked most frequently by participants. Again, services were divided into one of three categories: medical related services, basic living needs, and counseling and other support services. Focus group and key informants’ explanations of why they believe they cannot get the services are summarized and discussed following each table.

1) **Unmet Medical Related Service Needs**

The most outstanding unmet medical services needed, by PLWH/A can be seen below in Table 37.

<table>
<thead>
<tr>
<th>Type of Service</th>
<th>% of Respondents (n)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Help Paying for Medical Insurance</td>
<td>28% (n=46)</td>
</tr>
<tr>
<td>Dental Care</td>
<td>24% (n=40)</td>
</tr>
<tr>
<td>Eye Care</td>
<td>17% (n=29)</td>
</tr>
<tr>
<td>Physical or Occupational Therapy</td>
<td>15% (n=24)</td>
</tr>
<tr>
<td>Nutritional Counseling</td>
<td>10% (n=16)</td>
</tr>
</tbody>
</table>
When asked “why they needed but did could not get services” many of the questionnaire participants’ and interviewees talked about their lack of knowledge about how to access the services, their lack of money to pay for the services, the lack of transportation and the great distances many people must travel to access services.

Once again, Medicaid and Medicare spend downs and insurance co-pays presented barriers to service utilization. The reluctance of providers, particularly dentists, to accept Medicaid patients was mentioned by many of the participants. Insurance barriers are ubiquitous for PLWHA throughout the United States. As stated in the literature review, HRSA revealed one of every two PLWHA living below the Federal Poverty Level that left fewer than one in ten with private health insurance, and only 27.9% enrolled in Medicaid (2002). Insurance is just too expensive for PLWHA.

**Alternative Therapies:**

In addition to asking about unmet medical needs, the questionnaire asked participants whether they used Non-Western Therapies as their primary form of medical assistance.

Although only 16 of the 114 respondents said Non-Western Therapy was primary, alternative therapy was an evident theme in interview sessions. It is possible that only 16 people reported relying on alternative therapies because of the way the question was worded.
Had the question asked if respondents needed alternative therapy services, rather than asking whether or not it was their primary form of medical care, results may have revealed a greater need for alternative therapy. This was evident by the number of people who reported ‘no’ to the question, but wrote in a number of alternative therapies they prefer.

In any case, interview participants suggested government funds be used to pay for non-western therapy. Many individuals talked about the benefits of these therapies. In fact, some believed if there was government funding for non-western therapies, there would be less financial burden for the government because alternative therapies are often cheaper than conventional therapies. One focus group participant stated, “It seems like if money were put towards holistic care, it really would be less expensive in the end because it really is cheaper than Western medicine. And if it helps you then why not use it as a compliment or even as a replacement to Western medicine.”

One of the ‘alternative’ therapies mentioned in both interview sessions and questionnaire responses was the unmet need for nutritional therapy. This unmet need is linked to the poverty surrounding people living with HIV because without money, people tend to buy foods that are inexpensive, but often these foods are not nutritious. For HIV positive people, nutritional

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Since Ryan White has cut back on a lot of stuff I haven't received the services I value most. That is acupuncture, massage, naturopathic therapy, etc. All that alternative stuff that truly benefited my life. Especially acupuncture. I want to stress that one the most. Since it's been over a year since I received [acupuncture] and I feel a big difference. A big difference! I've started on psychotropic medication again and when I was doing acupuncture I didn't have a need for that. And I'm also drinking alcohol again. It also helped me quit smoking. It really improved my life. It wasn't just the addiction stuff, but it also enhanced my immune system and a

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Another thing leading to health problems is nutrition. People don't know how to prepare food for themselves. They don't know what things are good to eat. They aren't taking care of themselves. They don't have an appetite. They don't have the income to get good foods. They go to the food bank and get starches. You get starches. That's all they give you at the food bank. And maybe a couple of vegetables that are canned crap. So I think that nutrition and food availability is important. [FG]
meals are often considered a form of alternative therapy because nutrition is not easily accessible and because nutrition plays a huge role in maintaining a strong immune system.

2) Unmet Basic Living Needs

According to questionnaire participants, the three most frequently unmet basic assistance needs are viewed below in Table 38.

Table 38. Unmet Basic Living Needs

<table>
<thead>
<tr>
<th>Type of Service</th>
<th>% of Respondents (n)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Housing or Rent Assistance</td>
<td>19% (n=31)</td>
</tr>
<tr>
<td>Assistance with Paying Utility Bills</td>
<td>18% (n=30)</td>
</tr>
<tr>
<td>Transportation</td>
<td>16% (n=19)</td>
</tr>
</tbody>
</table>

When asked “why they needed but could not get services” many of the questionnaire participants’ talked about not knowing basic living services were available. Those who were aware of the services spoke about their income or other factors that made them ineligible for services such as housing assistance.

Housing is a concern for PLWH/A across the nation. According the U.S. Department of Housing and Urban Development [HUD], approximately one-third of one-half of persons living with HIV/AIDS in the United States are homeless or threatened by the loss of their housing (2004). According to the Montana needs assessment research and HUD research, this is a multilayer issue linked to medical cost, financial limitation, and the inability to keep employment by PLWH/A because of their illness. To compound the issue, the nation is experiencing a decrease in low-income housing. This trend is also affecting PLWH/A in Montana.
3) Unmet Counseling and Other Support Service Needs

According to questionnaire participants, the five most frequently unmet counseling, and support service needs are listed in Table 39.

Table 39. Unmet Counseling and Other Support Service Needs

<table>
<thead>
<tr>
<th>Type of Service</th>
<th>% of Respondents (n)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Social and Recreational Activities</td>
<td>27% (n=45)</td>
</tr>
<tr>
<td>Buddy/Companion volunteer Support</td>
<td>26% (n=44)</td>
</tr>
<tr>
<td>Support Group/Peer Counseling</td>
<td>27% (n=45)</td>
</tr>
<tr>
<td>Legal Services</td>
<td>19% (n=32)</td>
</tr>
<tr>
<td>Information and Referral for Services</td>
<td>10% (n=16)</td>
</tr>
</tbody>
</table>

When asked “why they needed but could not get services” many of the questionnaire participants’ simply stated that these support services did not exist in the areas in which they lived. Several people noted that when social activities were offered, they required traveling some distance and once again transportation posed a problem. The unmet need for legal services seemed to be tied, once again, to a lack of knowledge about where and how to access these services.

Questionnaire results showed 45 participants needed but could not access peer counseling or a support group. Interviewees added to this problem of bringing up the idea that even when people could access social support, it wasn’t always the support they were looking for. One interviewee stated, “It seems [PLWH] don’t want to work with the commonality they have in support groups…They don’t want that to be the focus. They want their personal thing to be the focus. But that’s not the reason for this. The reason is HIV.” This brings up the idea that many PLWH/A want their support to revolve around

We do not have a sense of togetherness here in this town, and the only reason you know someone is positive is because you’ve been friends with them and that’s it. There’s no solid calendar for PLWH here. There’s no camaraderie. For awhile there was a small group but not anymore. [FG]
them, and not an entire group of PLWH/A. Questionnaire participants reinforced this issue in that sixty-six percent of the 165 respondents reported the desire for individual counseling.

In general, the importance of some kind of social support/counseling is evident. One interviewee participant called attention to the importance of counseling, individual or group, by stating, “The physicians are these core resources for people but a lot of times it creates this private relationship with the physician which is a great thing but a lot of times what it does is reinforces HIV as this private thing you deal with in this very closed setting and I think the challenge of the support group is that link to... the rest of their lives.”

Research literature also reinforces the importance of social support groups for PLWH/A. In a longitudinal study conducted by Burgoyne and Renwick (2004), researchers found specified counseling services, particularly social support groups, significantly improve the quality of life for PLWH/A. The importance of support offered to women also is reinforced by the research literature. Women need support because they are more likely to care for dependent children (Gielen et al., 2001 and Kaiser Family Foundation, 2003). This is true for women in Montana where, of the 35 female questionnaire respondents, 14 (40%) of them were living with at least one dependent child. Of the 128 male respondents, six (5%) lived with at least one dependent child. When questionnaire participants were asked if they needed help with child care, nine percent of the 35 females responded they needed help, but could not get it, while only two percent of the 128 men had this same response.

The idea that women in Montana need support, but can’t get it, was reinforced by several focus group members. Women talked about the “extra stigma” attached to being a woman with HIV in a state where the majority of infected people are male. They also

There is no women’s support group here, but I’m in the process of trying to start one. The only problem is even though we’re positive, we don’t all mesh. We still have personalities and there are still people that drive us nuts and so it’s like when you go to support groups, sometimes you don’t always get along. [FG]
spoke about being uncomfortable in support groups in which both men and women participated. One HIV positive woman commented on her participation in a co-ed support group, “There used to be a psychiatrist or a counselor and I tried to go when he had his little group, but I was kind of uncomfortable because I was the only girl…it wasn’t what I thought when I showed up either. I thought it would be a place to discuss whatever was bothering you, but it wasn’t like that at all.” So, while it seems that women would prefer support groups made up entirely of women, expectations even in those groups can differ greatly. It would seem there is a need for not only support groups and/or counseling for people living with HIV, but support groups and/or counseling that meet the individuals’ needs and expectations. Service providers who attempt to organize support groups should be aware of the variety of expectations HIV positive individuals may have for such groups, and should provide participants with a purpose and clear outcomes for group participation.

Section IV. Frequent Barriers to Receiving Assistance, Treatment, and Services

Table 40 describes the most frequently reported barriers to assistance, treatment and services.

Table 40. Frequent Barriers

<table>
<thead>
<tr>
<th>Barriers to Services and Treatment Assistance</th>
<th>% Percent</th>
<th>(n)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Not having insurance coverage</td>
<td>34%</td>
<td>(56)</td>
</tr>
<tr>
<td>The cost of assistance or treatment</td>
<td>27%</td>
<td>(45)</td>
</tr>
<tr>
<td>Burnout from talking about HIV</td>
<td>25%</td>
<td>(41)</td>
</tr>
<tr>
<td>The concern that other people may see me when I go to get care and will learn about my HIV status</td>
<td>24%</td>
<td>(35)</td>
</tr>
<tr>
<td>The location of the organization providing services</td>
<td>20%</td>
<td>(33)</td>
</tr>
<tr>
<td>Not Knowing who to ask for help</td>
<td>20%</td>
<td>(33)</td>
</tr>
<tr>
<td>My state of mind or mental ability to deal with the treatment</td>
<td>19%</td>
<td>(31)</td>
</tr>
<tr>
<td>Not having transportation</td>
<td>17%</td>
<td>(28)</td>
</tr>
</tbody>
</table>

It is not surprising that many of the barriers to obtaining services are difficult to separate from the unmet needs listed in the tables above. Several of the barriers and/or unmet needs
I think distance is a barrier. It's a big barrier. If you don't own a car, you can't live out of town. I couldn't live out of town without a car. Distance to services can cause big trouble because there aren't services in small towns. [FG]

seem to arise repeatedly in different contexts and appear to be interrelated. For example, the concern regarding health insurance is directly related to the cost of assistance and treatment. The concern about the location of services is also directly related to the need for transportation. Transportation is a common barrier for PLWH/A in rural areas. In 2000, the Northeast Conference on Rural HIV Service Delivery established four primary barriers to the access and use of assistance and treatment services. One of these barriers was low population density, which was found to increase travel distance to obtain medical and/or service care, and reduce public transportation options. The transportation obstacles that exist for people living with HIV in most rural areas also ring true throughout Montana.

In addition, lack of knowledge of resources, or “not knowing who to ask for help”, is a theme that runs through much of the data collected from participants in this project. These needs/barriers have been discussed previously.

The concern that other people may find out about an individual’s HIV status is one that was addressed extensively by the interviewees. Participants appeared to have two fears regarding confidentiality. First is the fear that in a rural state such as Montana, it is highly likely that an HIV positive person seeking testing or treatment will encounter someone with whom they are acquainted and that acquaintance may find out about their HIV status. The second fear relates to the personal integrity of the staff working in facilities that serve HIV positive people. Many people who

For the longest time I didn’t want to see anyone in case that someone know someone. It was a case of confidentiality. Maybe they don’t use your name but they say anything about you and in this little community it’s so easy to figure out who it is. There are people that have lost their jobs because of it. You have to protect yourself and the way to protect yourself is to not get services. [FG]
are HIV positive do not trust public health and medical staff to maintain confidentiality regarding their HIV status.

About one-fifth of the questionnaire participants indicated their “state of mind and ability to deal with treatment” is a barrier. Interviewees did not discuss this topic as a direct barrier to services, although they did talk at length about the role that pride and self-esteem play in asking for assistance and services. Mental health was also discussed as one of the major health issues facing people with HIV.

Almost three-fourths of the questionnaire respondents (n=120) reported they had “emotional concerns.” Over one-half of the respondents reported suffering from depression, anxiety and fear. Loneliness, isolation and stress also were issues for approximately one-third of the respondents. Without a doubt, these emotional issues pose a barrier to seeking assistance.

About one-fourth of the questionnaire participants indicated that they were simply “burned out from talking about HIV.” Surprisingly, this issue did not arise within the context of the focus group or key informant interviews. Burnout may not have been discussed at length by interviewees because PLWH/A willing to participate in a focus group may be the PLWH/A most willing to discuss their HIV diagnosis. Since they have the motivation and mental capability to participate in focus groups or interviews, they are most likely not “burned out from talking about HIV”, nor do they feel their “state of mind and ability to deal with treatment” is a barrier to accessing services.

Two major barriers to treatment and care expressed primarily in the women’s focus group focus group were the stigma associated with women and HIV and the lack of medical
expertise in treating women. Increased HIV related stigma for women and lack of medical expertise may be attributed, in part, to the fact that since the first diagnosis, HIV has been associated with males. However, because female HIV incidence more than tripled between 1986 and 2001, and is continuing to rise, it is becoming more and more important to stress women’s issues related to HIV. Research completed by the Kaiser Family Foundation (2003:2) lends support to Montana’s focus group themes in that they found “many women with HIV/AIDS encounter barriers to treatment and do not receive optimal levels of care.” Although males in Montana living with HIV have many needs and experience barriers to accessing services, it is important to address women’s needs with the same degree of immediacy that we have traditionally addressed those issues confronting men.

Section V: Primary Prevention of HIV Infection

Questionnaire participants were asked to indicate what might have kept them from being infected with HIV. The top three responses all alluded to the need for greater awareness and education about HIV and AIDS. Data found here suggest that education must include communication and safer sex negotiation skills training.

Table 41. Preventing HIV Infection

<table>
<thead>
<tr>
<th>Prevention Strategy</th>
<th>%</th>
<th>(n)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Being more aware that infection with HIV was a possibility for me</td>
<td>58%</td>
<td>(n=96)</td>
</tr>
<tr>
<td>Knowing the importance of talking to a sex partner about his or her HIV status</td>
<td>36%</td>
<td>(n=60)</td>
</tr>
<tr>
<td>Being more knowledgeable about how HIV is transmitted</td>
<td>34%</td>
<td>(n=56)</td>
</tr>
<tr>
<td>Getting treatment for depression or other emotional problems, and/or substance abuse</td>
<td>34%</td>
<td>(n=56)</td>
</tr>
<tr>
<td>Knowing how to bring up the subject of condoms with a sex partner</td>
<td>29%</td>
<td>(n=48)</td>
</tr>
</tbody>
</table>
The need for more education was strongly reinforced by the focus group and key informant participants. They were particularly disappointed in current prevention strategies offered in Montana schools. Although, it is apparent from looking at questionnaire data, that HIV/AIDS awareness and education is important for people of all ages, not just children and adolescents.

Another prevention issue that was deemed important by about one-third of the participants was related to the treatment of both mental illness and substance abuse problems. The issues of mental illness and substance abuse were also discussed at some length by the focus group and key informant participants. However, most of their discussion centered on the effect that these two issues have on the lives of people who are already HIV positive.

Very few individuals commented on how these issues may contribute to becoming infected with HIV. Although several individuals did comment about how the lack of self-respect and self-esteem in some individuals can lead to risky sexual behaviors.

**Section VI: Best Channels for Information Dissemination**

Questionnaire respondents were asked to indicate the best way the public health department and the Ryan White Care Program could get information about prevention, treatment, and services to them. Approximately two-thirds of all respondents indicated that the best way to disseminate information would be through personal contact with a service provider.
Specifically, they indicated that the following service providers were in the best position to provide HIV positive individuals with information:

- **Health care provider** 68% (n=112)
- **Case managers** 63% (n=105)

Focus group participants and key informants strongly reinforced the notion that health care providers would be the best people to disseminate information. It is, however, important to note that these same individuals talked at length about the need to educate health care professionals about care and treatment for people with HIV and about the services that are available to people with HIV. It appears that in most of the rural areas of Montana, health care providers do not have resource and referral information to offer their HIV positive patients.

Nearly one-half of the respondents believed family and peers were in the best position to provide information. They also indicated a need for information about HIV at community educational events and health fairs.

- **Peers and friends** 45% (n=75)
- **Community educational events** 40% (n=66)

These responses may indicate a need for more support groups or other organized events where people with HIV and service providers can get together to share their knowledge and experiences related to HIV medical care and other services.

The last five channels of communication were of a more impersonal nature. Approximately 40% of the respondents indicated that movies, television, and the internet would be channels through which they could get information about HIV related treatments and services. Newspaper articles, billboards and radio announcements were endorsed by about one-third of the respondents. All of these responses point to a need to develop a
variety of vehicles through which information can be disseminated to people living with HIV.

Section VII. Recommendations for Closing Gaps between Needs and Services

When comparing this study to an assessment conducted three years ago, it becomes apparent many of the same issues are still prevalent. For example, social stigma, finances, social support, and lack of proficient education are still issues for PLWH/A. Results show the majority of PLWH/A in Montana are receiving the services they "need and use" and that Montana service providers, in general, do a fair job of meeting the needs of PLWH/A given the rural characteristics of the state. However, even though service providers are doing a fine job, there is still room for improvement, since the same issues, among other concerns continue to arise. Improvement can be made in terms of medical care, basic living assistance, and social support. The following recommendations will be given to the Ryan White Program staff and members of the Montana's HIV Prevention Community Planning Group as they approach the next planning cycle. In no order of priority, recommendations include:

Streamlining Resources

Montana services need to be streamlined. This can be done with the development of a resource directory that is comprehensive, current, and accessible. It is recommended the directory be available on an internet web site, as well as available in hard copy form in medical facilities, clinics, and all agencies that serve people with HIV. Community events, especially health fairs, should incorporate information about HIV issues. See appendix J for examples of specific strategies that can be implemented to streamline resources.
Education

Health Care Providers

Health care providers are need to be better educated in the care and treatment of people living with HIV. Training programs should be offered with incentives for participation.

General

Awareness regarding prevention of HIV and the relationship of drug use, particularly methamphetamines to HIV infection, needs to be offered to the all people, including both adolescents and adults. HIV prevention education must include skills training in communication and safer sex negotiation.

Eliminate Social Stigma

The social stigma associated with HIV continues to be a concern for PLWH/A. For this reason it is crucial to develop programs to reduce, and ultimately eliminate stigma. HRSA recommends a variety of strategies designed to work towards combating everlasting HIV related stigma. These strategies include, but are not limited to, media campaigns, speakers bureaus, and education. Appendix J details these strategies.

Social Support

Social support for PLWH/A is essential. This includes both individual and group support and support that is targeted at sub-populations of PLWH/A, including groups consisting of all women, gay men, and/or co-ed groups. Individual counseling as well as a peer mentoring or peer advocacy program is another form of support. Appendix J addresses peer support and strategies to implement this type of social support.
Transportation

Because Montana is a sparsely populated low incidence state, isolation due to lack of transportation is often an issue for PLWH/A. For this reason, transportation to health care and other related appointments is critical. The needs assessment research team recommends organizing a network of volunteers or service providers who can assist HIV positive people in dealing with the transportation barriers that prevent them from accessing services.

Financial Concerns

Financial issues continue to curse PLWH/A. Addressing this issue is difficult. Service providers may find it necessary to take political action that not only increases decision makers' awareness of the financial plight of PLWH/A, but also increases the likelihood of funding that is adequate to address the increasing numbers of PLWH/A. Regardless, it is clear funding needs to be top priority.

Section VIII. Methodological Consideration of this Study

The major methodological consideration for this study involves a lack of focus group and/or key informant interviews with the following sub-populations: Native American HIV positive group, PLWH/A in Northwestern Montana, specifically the Flathead Valley, and an HIV positive IDU group.

Native American HIV positive Focus Group

Although questionnaire return rates fairly represented Native Americans in this study, this population represents a unique sub-population of PLWH/A. More qualitative perspective from this sub-population could have enhanced the research findings, enabling researchers to better define the needs of Native American PLWH/A.
PLWH/A in Northwestern Montana

Judging by quantitative results, PLWH/A in Northwestern Montana experienced many barriers to needed services. More thorough qualitative data collection could have improved the research findings in this area, helping to improve quality of life for PLWH/A in Northwestern Montana.

HIV positive IDU Group

This study’s qualitative and quantitative data was lacking when considering IDU PLWH/A. It seems IDU do not often discuss their drug use, therefore, it may be difficult to organize an IDU focus group session. However, researchers feel the needs of HIV positive IDU could be better assessed if a future study could arrange an IDU HIV positive group.

If this study is replicated, these methodological considerations should be taken into account.
Section IX. Conclusions

People diagnosed with HIV are living long lives because of effective treatment regimens. With longer life expectancy, many people struggle to manage their health and to maintain their quality of life. For this reason, this project attempted to identify the medical care, basic living, and social support needs of PLWH/A, as well as the barriers to accessing these services. Ultimately, a better quality of life will result from identifying and addressing the needs of people who are HIV positive living in Montana.

In this Needs Assessment, many people residing in Montana diagnosed with HIV/AIDS conveyed their thoughts about both the adequacy and the inadequacy of the resources and services in Montana designed to improve the quality of their lives. While many participants were able to access the services they needed to cope with the complex issues associated with the HIV infection, there were undoubtedly medical, basic and social support needs that were unmet. Some of the following issues are not unique to Montana, and national research should be examined when addressing these needs.

In particular, and in no order of priority, unmet needs included qualified health care professionals, an adequate resource guide, financial assistance, social support, and affordable housing as the primary needs of PLWH/A in Montana. Barriers to these services were not surprising in that they were interrelated to the unmet needs. Specifically and again in no order of importance, primary barriers included financial difficulties, HIV/AIDS-related stigma, transportation issues, burn-out from talking about HIV and mental health issues, and the lack of information about resources.

Primary prevention was also examined in this needs assessment. When participants were asked what might have prevented their HIV diagnosis, many replied with the need for education of both adults and school age children.
PLWH/A in Montana evaluated in this needs assessment also answered the question of the best way DPHHS could get information to them about treatment and services. Most respondents agreed their case managers and their physicians would be the best source of information dissemination. However, most also felt most physicians in Montana are not adequately educated in HIV/AIDS issues, which inhibits their ability to inform HIV positive people. Many participants called attention to the internet as a primary and current source for information dissemination and education for both PLWH/A and service providers.

In summary, this study does not appear to unveil any surprises in terms of the needs of PLWH/A in Montana. In 2003, the last HIV needs assessment was conducted in Montana, which disclosed many of the same issues. Judging by this study, the majority of HIV positive people residing in Montana are receiving most of the services they need. In fact, it seems that Montana service providers are, for the most part, meeting the needs of PLWH/A given the typical rural HIV characteristics of the state, or in other words, given the sparsely populated low HIV incidence nature of Montana.

However, even though it seems most PLWH/A reported they 'need and use services' over 'needing services and cannot get them', there is still room for improvements in medical care, basic living assistance, and social support in this state. Regardless of the seemingly positive report from PLWH/A in Montana, there are still respondents who claimed they could not get services.

In conclusion, there are still gaps to service and treatment assistance in Montana. The first step to filling these gaps comes with prioritizing finances, seeing as this, in the end, seems to be the largest concern for PLWH/A. By prioritizing funding towards assistance, such as an sufficient statewide resource guide, there can be a break the lack of knowledge about resources for both HIV/AIDS service providers and PLWH/A, and the needs of
PLWH/A in Montana can be better met, and ultimately the quality of their lives can be improved. Because funding is limited and there are many needs, prioritizing funding is a crucial step in designing programs which will improve the quality of life for HIV positive individuals in Montana.
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U.S. Department of Health and Human Services, Health Resources and Services


APPENDIX A

THE UNIVERSITY OF MONTANA INSTITUTIONAL REVIEW BOARD APPROVAL
Date: March 4, 2005

To: K. Ann Sondag, HHP

From: Sheila Hoffland, UM IRB Chair

RE: IRB approval of your proposal titled "An Assessment of the Needs of HIV+ People Living in Montana"

The documents that you have submitted satisfactorily address the conditions that the IRB placed on approval of the above referenced proposal. Approval for this study is granted as of the date of this memo and continues for one year from the date of the Conditional Approval. If the study runs more than one year, a continuation must be requested. Please use the attached, signed and dated Informed Consent Forms as the "masters" for preparing copies for your study. Also, you are required to notify the IRB if there are any significant changes in the study or if unanticipated or adverse events occur during the study.

[Signature]
Sheila Hoffland

Attachments
APPENDIX B

NEEDS ASSESSMENT QUESTIONNAIRE
Montana 2005 Consumer Questionnaire

Let your needs be known! Influence funding decisions that affect you!

- The purpose of this survey is to determine the health care needs of people who have HIV/AIDS in Montana.
- Your participation in this study will help plan programs for you and others living with HIV/AIDS.

- Your participation is VOLUNTARY.
- All responses are strictly ANONYMOUS.
- Please DO NOT put your name on this survey.

Please return this survey to your case manager or mail in the self-addressed stamped envelope by APRIL 15, 2005.

THANK YOU VERY MUCH!
1. In general, how would you rate your overall health?  
   □ Very good  
   □ Good  
   □ Fair  
   □ Poor  
   □ Very poor

2. How do you believe you became infected with HIV?  
   □ Sex with a man  
   □ Sex with a woman  
   □ Sex with an injection drug user  
   □ Injecting drug use  
   □ Blood transfusion  
   □ Don’t know  
   □ Other (please specify): __________

3. How many years ago did you learn you were HIV positive?  ________

4. When you found out you were HIV+, were you also diagnosed with AIDS?  
   □ No  
   □ Yes  
   □ Can’t remember

5. Are you currently diagnosed with AIDS?  
   □ No  
   □ Yes  
   □ Don’t know

6. Do you know your current CD4 count and/or your viral load?  
   □ No  
   □ Yes

7. Have you had a CD4 count or viral load in the last 12 months?  
   □ No  
   □ Yes

8. Have you ever had a case manager?  
   □ I have one now  
   □ I no longer have one  
   □ I never had one

   If you answered “no longer” or “never,” why not?  (check all that apply)  
   □ I don’t need services  
   □ I can get services myself  
   □ I didn’t know one was available  
   □ I live too far away  
   □ I’m worried people will find out I have HIV or AIDS  
   □ I don’t know how a case manager could help me  
   □ A different service provider helped me get services  
   □ They don’t speak my language  
   □ They don’t understand my culture  
   □ Use alternative therapy/standard medicine too harsh  
   □ Confidentiality  
   □ Other ____________________________
PART 2: WHAT ASSISTANCE & TREATMENT ARE YOU USING? WHAT CAN'T YOU GET?

STEP 1:
On the following pages, you'll find a list of assistance and treatment opportunities. For each opportunity listed, put an "X" in one of the three boxes.

STEP 2:
If you check the box "need can't get," tell us the reason you can't get this assistance or treatment.

If you don't tell us what's wrong, we can't fix it!

Some of the reasons other people have mentioned include:

- Can't afford it
- Live too far away
- Don't feel welcome at the agency
- Not sick enough
- Don't know where to get it
- The service doesn't meet my needs

Please feel free to mention other reasons.

EXAMPLE:

<table>
<thead>
<tr>
<th>Assistance/Treatment</th>
<th>Need and Use</th>
<th>Don't Need</th>
<th>Need can't get</th>
<th>Why can't get?</th>
</tr>
</thead>
<tbody>
<tr>
<td>Dental care</td>
<td></td>
<td></td>
<td>X</td>
<td>Can't afford it</td>
</tr>
<tr>
<td>Support groups</td>
<td></td>
<td></td>
<td>X</td>
<td></td>
</tr>
</tbody>
</table>
If you are currently using naturopathy, herbal medicine, acupuncture or other non-Western therapies, do you consider this to be your primary form of medical care?

- **NO**
- **YES**

If "YES", please specify which therapies are most important to you:

---

### Basic Needs and Assistance & Treatments

<table>
<thead>
<tr>
<th>Assistance / Treatment</th>
<th>Need and use</th>
<th>Done and need</th>
<th>Need can't get</th>
<th>Why can't get? (Please let us know so we can help!)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Assistance with paying utility bills</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Housing or rent assistance</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Home delivered meals/groceries</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Clothing</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Transportation</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Practical support (help with shopping, cooking, cleaning, laundry, chores, moving, pets, etc.)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Other (please specify):</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Form of Help</td>
<td>Access</td>
<td>Use</td>
<td></td>
<td></td>
</tr>
<tr>
<td>--------------</td>
<td>--------</td>
<td>-----</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Support groups/ peer counselling</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Spiritual support</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Other (please specify):</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

- Are there other forms of help we have not mentioned that you would like to have access to, or are currently using?

- Are there forms of help listed above and on the previous page that you do not need now, but think that you may need in the future? If so, please specify them in the space below.
PART 3:
BARRIERS TO ASSISTANCE & TREATMENT

Below is a list of possible problems that may arise when trying to obtain or use HIV and AIDS services. Mark an X on the line beside each item to say how big a problem it has been for you.

**Big Barrier:** Stopped you from getting services.
**Small Barrier:** Caused minor concern and delays in obtaining service(s).

<table>
<thead>
<tr>
<th></th>
<th>Big Barrier</th>
<th>Small Barrier</th>
<th>Not a Barrier</th>
</tr>
</thead>
<tbody>
<tr>
<td>1.</td>
<td>Not knowing what service or treatment is available to me/ lack of services.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>2.</td>
<td>The location of the organization providing services.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>3.</td>
<td>My physical health.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>4.</td>
<td>The quality of assistance or treatment.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>5.</td>
<td>Not knowing what medical assistance or treatment I need to treat my HIV or AIDS infection.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>6.</td>
<td>My state of mind or mental ability to deal with the treatment.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>7.</td>
<td>Not having transportation.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>8.</td>
<td>Not knowing who to ask for help.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>9.</td>
<td>My concern that other people may see me when I go to get care or learn about my HIV infection (lack of confidentiality/stigma).</td>
<td></td>
<td></td>
</tr>
<tr>
<td>10.</td>
<td>Discrimination I experienced by the persons or organization providing the services.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>11.</td>
<td>Lack of experience or expertise of the person providing services to me.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>12.</td>
<td>The hours when services were offered were unreliable or inconsistent.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>13.</td>
<td>The amount of time I had to wait to get an appointment or to see someone.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>14.</td>
<td>The cost of assistance or treatment.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>15.</td>
<td>Not having insurance coverage.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>16.</td>
<td>Burnout from dealing with/ talking about HIV.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>17.</td>
<td>Other (please specify):</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Of the barriers listed above, which two do you believe are the biggest barriers you have faced when trying to get HIV related services?

a) _____________________________

b) _____________________________

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**PART 4:**
**TELL US ABOUT YOUR BEHAVIORS SINCE BECOMING HIV POSITIVE**

9. Which best describes your sexual activity since becoming HIV positive?
   - □ Stopped having sexual relations (I am abstinent)
   - □ Never use condoms
   - □ Sometimes use condoms
   - □ Always use condoms

   If you use condoms "sometimes", in what situations do you NOT use them?
   - □ With my regular partner who is HIV positive
   - □ When my viral load is low or undetectable
   - □ With any sex partner who is HIV positive
   - □ When my sex partner refuses to use condoms
   - □ When I feel uncomfortable bringing up condoms
   - □ Other ______________________________________

10. Does your partner(s) know your HIV status?
    - □ No
    - □ Yes
    - □ Sometimes
    - □ Not sexually active

11. Do you ask the HIV status of your sex partners:
    - □ No
    - □ Yes
    - □ Sometimes
    - □ Not sexually active

12. Have you tested positive for sexually transmitted diseases in the last two years?
    - □ No
    - □ Yes
    - If "yes", which did you test positive for? (check all that apply)
      - □ Syphilis
      - □ Genital warts
      - □ Gonorrhea
      - □ Herpes
      - □ Chlamydia
      - □ Other (please specify): ________________________

13. Do you have any other medical illnesses besides HIV/AIDS?
    - □ No
    - □ Yes
    - If "yes", what illnesses do you have? (check all that apply)
      - □ Hepatitis C/Hepatitis B
      - □ Diabetes
      - □ Alcoholism
      - □ Drug dependency
      - □ Heart disease
      - □ Mental illness
      - □ Opportunistic Infection(s)
      - □ Other (please specify): ________________________

14. Have you used substances in the past year?
    - □ No
    - □ Yes

    - If "yes", check all substances you have used:
      - □ Alcohol
      - □ Marijuana
      - □ Crack
      - □ Cocaine
      - □ Heroin
      - □ Meth/Crystal
      - □ Downers
      - □ Other (please specify): ________________________
15. Have you injected any substances in the past year?
   - □ No
   - □ Yes
   
   If "yes", have you shared needles while injecting drugs in the past year?
   - □ No
   - □ Yes

16. Do you believe your substance use to be a problem?
   - □ No
   - □ Yes
   
   □ Not sure

17. Do you have emotional concerns which have caused a problem for you in the last 6 months?
   - □ No
   - □ Yes
   
   If "yes", what are your emotional concerns? (check all that apply)
   - □ Stress
   - □ Depression
   - □ Guilt
   - □ Suicidal tendencies
   - □ Anger/resentment
   - □ Anxiety/fear (concern about the future)
   - □ Loneliness (isolating yourself)
   - □ Other (please specify): ____________________

18. Are you receiving any treatment for emotional or stress related problems (depression)?
   - □ No
   - □ Yes
   
   If "yes", what treatment are you using? (check all that apply)
   - □ Prescription medicine
   - □ Alternative therapies
   - □ Counseling
   - □ Medical Marijuana
   - □ Other (please specify) _________________

19. Has becoming HIV+ caused problems in your close relationships?
   - □ No
   - □ Yes
   
   If "yes", what problems has it caused? (check all that apply)
   - □ Stress or isolation in relationships with family
   - □ Difficulties in relationship with spouse/partner
   - □ Involvement with people who want to be infected (bug chasers)
   - □ Difficulties in relationship(s) with children
   - □ Other (please specify): ____________________

20. What type of counseling do you prefer? (check all that apply)
   - □ Individual (counselor and me)
   - □ Group counseling (with other HIV+ people)
   - □ Peer counseling (by other HIV+ people)
   
   □ Religious or pastoral counseling
   □ I don't prefer counseling
   □ Other (please specify): ____________________
21. What is your sex? (check one)
- Female
- Male
- Transgender (male to female)
- Transgender (female to male)

22. What is your race/ethnicity? (check all that apply)
- Native American/AK Native
- Asian/Pacific Islander
- African American
- White (non-Hispanic)
- Hispanic
- Other (please specify): __________

23. What is your age? ___

24. How do you identify yourself?
- Heterosexual/Straight
- Gay
- Lesbian
- Bisexual
- Other: _______

25. What is your current employment status?
- Employed full-time
- Employed part-time
- Not employed
- Self-employed
- On disability
- Other (please specify): __________

26. What is your monthly income? _______

27. Where are you living now? (check all that apply)
- Your own house or apartment
- Jail or prison
- In a friend or relative’s house/apartment
- Drug/alcohol treatment center
- Hospice or nursing facility
- Living in public housing
- Live on the streets or in a shelter
- Other: _______
- Pre-release center

28. Do you have any dependent children living with you?
- No
- Yes
  If "yes", how many dependent children are living with you? ___

29. Do you have health insurance or other assistance?
- No
- Yes
  If "yes", what kind of insurance or other assistance do you have?
- Medicaid
- Medicare
- Private insurance
- Ryan White Title II &/or Title III Assistance (ADAP)
- Veterans benefits
- Indian Health Service or Tribal Health
- Other: _______
1. What kinds of things might have helped you avoid infection with HIV? (check all that apply)

- □ Being more aware that infection with HIV was a possibility for me
- □ Being more knowledgeable about how HIV is transmitted
- □ Knowing where to find clean needles or clean works
- □ Getting treatment for depression or other emotional problems
- □ Getting treatment for a substance abuse problem
- □ Knowing how to bring up the subject of condoms with a sex partner
- □ Knowing the importance of talking to a sex partner about his or her HIV status
- □ Other. Please describe any of the issues checked above in more detail or describe other things that may have been helpful to you.

2. What is the best way that the public health department and the Ryan White Care Program can get information about prevention, treatment, and services to you? (check all you think would be helpful)

- □ Billboards
- □ Health care provider – doctors, nurses, etc.
- □ Internet / web based information
- □ Community educational events like health fairs
- □ Movies / television clips / television commercials / magazines
- □ Announcements on the radio (Which stations are best? ____________)
- □ Advertisements or articles in newspapers
- □ Case managers
- □ Peers and friends
- □ Other ways that we can get information to you? ____________

3. What is the single most important change you would suggest to improve the quality of life for individuals or families living with HIV?

________________________________________________________________________

________________________________________________________________________

If you do not currently have a case manager but are interested in obtaining one, you are welcome to call the HIV/AIDS hotline with complete ANONYMITY and CONFIDENTIALITY! The number is:

1-800-233-6668

Someone will direct you to assistance.

THANK YOU!!
THANK YOU!!
APPENDIX C

QUESTIONNAIRE COVER LETTER
Hello.

Please allow me to introduce myself. My name is Rick Holman and I live in Butte. I have been involved with the Statewide Planning Group in the fight against HIV/AIDS and I volunteer with the Butte AIDS Support Services. Recently Dr. Annie Sondag with the University of Montana asked me to help with a Needs Assessment document for the year 2005. This questionnaire is very important to YOU and everyone fighting the battle against HIV/AIDS. The Ryan White office will use this document when funding is requested. It will also be used by the Department of Public Health and Human Services to find out what services are needed and in what part of the state. The State of Montana will use the information that is compiled to try to access more funds from the Centers for Disease Control and Prevention. So this is a win-win situation for people living with HIV/AIDS.

Enclosed you will find a copy of the new Needs Assessment questionnaire. I cannot over emphasize the importance of this questionnaire to any person living with HIV/AIDS.

Do not put your name anywhere on the questionnaire. I assure you that the questionnaire is completely anonymous.

PLEASE FILL OUT THE QUESTIONNAIRE AND RETURN IT AS SOON AS YOU RECEIVE IT AS WE ARE ON AN EXTREMELY TIGHT SCHEDULE. You may return it in the enclosed self-addressed stamped envelope, or you can return it to me, your Ryan White case manager, or the person who gave it to you.

Thank you in advance for this. And if I can be any assistance or can answer any questions please feel free to contact me at home at 406-723-5242.

Sincerely,

Rick Holman
APPENDIX D

QUESTIONNAIRE CONSENT FORM
TITLE
   • Determining the Needs of HIV Positive People in Montana

PROJECT DIRECTOR
   • Dr. Annie Sondag: UM, McGill Hall, Missoula, MT 59812; (406) 243-5215

The language in this consent form may be unfamiliar to you. If you read any words that are not clear to you, please ask the person who gave this form to you to explain or contact Dr. Annie Sondag at (406) 243-5215 or Senna Towner at (406) 396-0782.

PURPOSE
The purpose of this project is to collect information about the health and service related needs of people living with HIV and/or AIDS in Montana. Information gathered will be made available to the Montana Department of Public Health and Human Services (DPHHS) and the Ryan White Title II and Title III Care Program. Information will be used to identify the needs of HIV positive people, and determine the gaps between needs and the services and assistance actually being offered. By completing this questionnaire you will help provide valuable information that will be used to provide better services and care for people living with HIV in Montana.

PROCEDURES
Questionnaire participation for this study is voluntary. You are asked to read this consent form. If you agree to participate, this questionnaire will ask a number of questions regarding your health related and service related needs. The questionnaire will take approximately twenty minutes to complete. A ten dollar cash incentive is included for your participation in the questionnaire.

RISKS/DISCOMFORTS
You may find some of the questions personal, you may feel you do not know the answer, or some of the questions may make you feel uncomfortable. However, you are welcome to refrain from answering any question for any reason, or to discontinue your participation at any time.

BENEFITS
Your help with this study will provide valuable information to DPHHS and Ryan White staff. By participating in this study, your answers will help staff offer services and develop programs to meet the needs of HIV positive people in Montana.
CONFIDENTIALLY
Please do not place your name anywhere on the questionnaire. All questionnaire participants in this study will remain anonymous. Researchers will avoid identifying any of the participants. They will not use your name or any other identifying information in reports or any other materials related to this study. Specifically:

- The identities of all questionnaire participants will remain anonymous and will not be associated with research findings in any way.
- All the data collected during this study will be reported and examined as group data.

COMPENSATION FOR INJURY
The project team believes the risk of taking part in this study is minimal. However, the following liability statement is required in all University of Montana consent forms:

In the event that you are injured as a result of this research you should individually seek appropriate medical treatment. If the injury is caused by the negligence of the University or any of its employees, you may be entitled to reimbursement by the department of Administration under the authority of MCA, Title 2, Chapter 9. In the event of a claim of such injury, further information may be obtained from the University's claims Representative or University Legal Counsel.

VOLUNTEER PARTICIPATION/WITHDRAWAL
Your decision to take part in this research study is entirely voluntary. You are free NOT to answer any question and to discontinue participation at any time.

QUESTIONS
If you have any questions about the research now or later, you may contact Dr. Annie Sondag at (406) 243-5215 or Annie's Research Assistant Senna Towner at (406) 396-0782.

I have read the above description of this project. I have been informed of the risks and benefits involved, and all of my questions have been answered to my satisfaction. Furthermore, I have been assured that any future questions I may have will be answered by a member of the project team. I voluntarily agree to take part in this study. I am at least 18 years old. I understand this is my copy to keep of this consent form.

THANK YOU VERY MUCH FOR YOUR PARTICIPATION!
If you have questions or concerns about HIV/AIDS please contact one of the following national organizations or an organization in your area.

**HIV/AIDS SENSITIVE SERVICES**

**National:**
- CDC National AIDS Hotline 1-800-342-2437
- National Association of People with AIDS (202)-898-0414
- National Native American AIDS Prevention Center (510) 444-2051
- Gay Men’s Health Crisis, Inc. 1-800-243-7692
- Project Inform National Hotline 1-800-822-7422

**Montana:**
- Missoula AIDS Hotline 1-800-233-6668
- Montana Targeted Outreach Program (MTAP) (406) 543-4770
- Montana STD/HIV Information Line 1-800-233-6668
- Gay Men’s Task Force 1-800-713-GMTF

**MONTANA HIV/AIDS INFORMATION AND PREVENTION SERVICES**

**Missoula AIDS Council**
415 N. Higgins
Missoula, MT 59802
(406) 543-2296

**Missoula City-County Health Department**
**Partnership Clinic**
323 West Alder
Missoula, MT 59801
(406) 829-4163

**Montana Targeted Outreach Program (MTAP)**
415 N. Higgins
Missoula, MT 59802
(406) 543-4770

**Lewis & Clark City-County Health Department**
1930 9th Ave.
Helena, MT 59601
(406) 433-2584

**Yellowstone City-County Health Department**
123 S. 27th St.
Billings, MT 59101
(406) 247-3350

**Butte-Silverbow Health Department**
25 West Front St.
Butte, MT 59701
(406) 723-3274

**Cascade City-County Health Department**
115 4th St. South
Great Falls, MT 59401
(406) 433-2584

**Flathead City-County Health Department**
723 5th Ave. East
Kalispe, MT 59901
(406) 758-5750
APPENDIX E

FOCUS GROUP QUESTIONS
People living with HIV or AIDS in Montana (PLWH/A)

Focus group will begin with an ICEBREAKER:
*Determining your color-personality test.*

1. **Quality of Life Issues:**
   1.1. What do you believe to be the three greatest problems for those PLWH/A in Montana?
   1.1.a. What do you believe the major concerns are regarding poverty, social isolation, geographic isolation, unemployment, and/or social stigma for those PLWH/A?

   1.2. What would be the single most important change you would suggest to improve the lives of PLWH/A in Montana?

2. **Health Problems:**
   2.1. What do you believe to be the three greatest health problems for PLWH/A in Montana?
   2.1.a. What do you believe the major concerns are regarding compromised immune systems, re-infection, transmission to uninfected individuals and/or depression for those PLWH/A?

3. **Behaviors and Environmental Factors Related to the Health Problems:**
   3.1. What risky behaviors do you believe PLWH/A engage in that might be detrimental to their health?

   3.2. What risky behaviors do you believe PLWH/A engage in that might put other people’s health at risk?

   3.3. What are the best ways to reach PLWH/A in Montana who are not currently being served?

   3.4. What are the greatest assistance and/or treatment needs of PLWH/A in Montana that are not currently being met?
   3.4.a. How satisfied do you think PLWH/A in Montana are with assistance and/or treatment services?
   3.4.b. Are there any types of assistance and/or services that PLWH/A in Montana need but can’t get?
    3.4.a. What barriers do you see PLWH/A facing in regards to obtaining assistance and/or services?
    - structural barriers?
    - organizational barriers?
    - individual barriers, such as knowledge, physical or mental well-being, community etc.?

4. **What other thoughts do you have regarding the needs of PLWH/A in Montana?**
APPENDIX F

FOCUS CONSENT FORM
FOCUS GROUP

PARTICIPANT INFORMATION AND CONSENT FORM

TITLE
- Determining the Needs of HIV Positive People in Montana

PROJECT DIRECTOR
- Dr. Annie Sondag: UM, McGill Hall, Missoula, MT 59812; (406) 243-5215

The language in this consent form may be unfamiliar to you. If you read any words that are not clear to you, please ask the person who gave this form to you to explain.

PURPOSE
The purpose of this project is to collect information about the variety of health and service related needs of people living with HIV and/or AIDS in Montana. Information gathered will be made available to the Montana Department of Public Health and Human Services (DPHHS) and the Ryan White Title II and Title III Care Program. Information will be used to identify the needs of HIV positive people, and determine the gaps between needs and the services and assistance actually being offered. By participating in this focus group you will help provide valuable information that will be used to provide better services and care for people living with HIV in Montana.

PROCEDURES
Focus group participation for this project is voluntary. You are asked to read this consent form. If you agree to participate you and your group will be asked a number of questions regarding your perceptions of the needs of HIV positive individuals living in Montana. The group discussion will take approximately one hour. The session will be audio recorded and transcribed for accuracy of responses. You will receive $25.00 cash for participating in this focus group.

RISKS/DISCOMFORTS
You may find some of the group questions personal, you may feel you do not know the answer, or some of the questions may make you feel uncomfortable. You are welcome to refrain from answering any question for any reason or to discontinue your participation at any time.

We ask that all group members keep the identities of the participants and the information shared the focus groups confidential. We cannot, however, guarantee the confidentiality of statements made in the focus groups. You may be concerned that other participants in the group may disclose your identity or statements made in the focus groups, outside the session.

BENEFITS
Your help with this study will provide valuable information to DPHHS and Ryan White staff. By participating in this study, your answers will help staff offer services and develop programs to meet the needs of HIV positive people in Montana.
CONFIDENTIALITY
All information collected during this focus group will be confidential. Researchers and facilitators of the group will avoid identifying any of the participants. They will not use your name or any other identifying information in reports or any other materials related to this study. Specifically:
- The identities of all focus group participants will remain confidential and will not be associated with research findings in any way.
- Audio tapes will be destroyed as soon as they are transcribed.
- No information related to participants' identities will appear in the transcription of the audiotapes.
- All the data collected during this study will be reported and examined as group data.

COMPENSATION FOR INJURY
The project team believes the risk of taking part in this study is minimal. However, the following liability statement is required in all University of Montana consent forms:

In the event that you are injured as a result of this research you should individually seek appropriate medical treatment. If the injury is caused by the negligence of the University or any of its employees, you may be entitled to reimbursement by the department of Administration under the authority of MCA, Title 2, Chapter 9. In the event of a claim of such injury, further information may be obtained from the University's claims Representative or University Legal Counsel.

VOLUNTEER PARTICPATION/WITHDRAWAL
Your decision to take part in this research study is entirely voluntary. You are free NOT to answer any question and to discontinue participation at any time. You also may withdraw from this study for any reason.

QUESTIONS
If you have any questions about the research now or later, you may contact Dr. Annie Sondag at (406) 243-5215 or Annie's Research Assistant Senna Towner at (406) 396-0782.

I have read the above description of this project. I have been informed of the risks and benefits involved, and all of my questions have been answered to my satisfaction. Furthermore, I have been assured that any future questions I may have will be answered by a member of the project team. I voluntarily agree to take part in this study. I am at least 18 years old. I understand this is my copy to keep of this consent form.

THANK YOU VERY MUCH FOR YOUR PARTICIPATION!
HIV/AIDS SENSITIVE SERVICES

National:
CDC National AIDS Hotline 1-800-342-2437
National Association of People with AIDS (202)-898-0414
National Native American AIDS Prevention Center (510) 444-2051
Gay Men's Health Crisis, Inc. 1-800-243-7692
Project Inform National Hotline 1-800-822-7422

Montana:
Missoula AIDS Hotline 1-800-233-6668
Montana Targeted Outreach Program (MTAP) (406) 543-4770
Montana STD/HIV Information Line 1-800-233-6668
Gay Men's Task Force 1-800-713-GMTF

MONTANA HIV/AIDS INFORMATION AND PREVENTION SERVICES

Missoula AIDS Council
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115 4th St. South
Great Falls, MT 59401
(406) 433-2584

Flathead City-County Health Department
723 5th Ave. East
Kalispell, MT 59901
(406) 758-5750

If you have questions or concerns about HIV/AIDS please contact one of the following national organizations or an organization in your area.
APPENDIX G

KEY INFORMANT INTERVIEW QUESTIONS
Professionals that have communication with persons living with HIV or AIDS in Montana.

Interview will begin with an ICEBREAKER:
How did you become involved with people living with HIV/AIDS (PLWH/A) in Montana?

1. **Quality of Life Issues:**
   1.1. What do you believe to be the three greatest problems for those PLWH/A in Montana?

   1.1.a. What do you believe the major concerns are regarding poverty, social isolation, geographic isolation, unemployment, and/or social stigma for those PLWH/A?

2. **Health Problems:**
   2.1. What do you believe to be the three greatest health problems for PLWH/A in Montana?

   2.1.a. What do you believe the major concerns are regarding compromised immune systems, re-infection, transmission to uninfected individuals and/or depression for those PLWH/A?

3. **Behaviors and Environmental Factors Related to the Health Problems:**
   3.1. What risky behaviors do you believe PLWH/A engage in that are detrimental to their health?

   3.2. What risky behaviors do you believe those PLWH/A engage in that put other people’s health at risk?

   3.3. How should PLWH/A in Montana who are not currently being served be reached?

   3.3.a. Do you feel there is the capacity in Montana to meet the needs of those PLWH/A without treatment and/or assistance care?

   3.4. What are the greatest assistance and/or treatment care needs of PLWH/A in Montana that are not currently being met?

   3.4.a. What barriers do you see PLWH/A facing in regards to obtaining these needs?

   - structural barriers?
   - organizational barriers?
   - individual barriers, such as knowledge, physical or mental well-being, community etc.?

4. **Do you have any more thoughts regarding the needs of PLWH/A?**
APPENDIX H

KEY INFORMANT INTERVIEW CONSENT FORM
KEY INFORMANT INTERVIEW

TITLE
- Determining the Needs of HIV Positive People In Montana

PROJECT DIRECTOR
- Dr. Annie Sondag: UM, McGill Hall, Missoula, MT 59812; (406) 243-5215

The language in this consent form may be unfamiliar to you. If you read any words that are not clear to you, please ask the person who gave this form to you to explain.

PURPOSE
The purpose of this project is to collect information about the needs of people living with HIV and/or AIDS in Montana. Information gathered will be made available to Montana's Department of Health and Human Services (DPHHS) and Ryan White's Title II and Title III Care Program. Information will be used to identify the needs of HIV positive people, and determine the gaps between needs and the assistance and treatments actually being offered. By participating in this interview you will help provide valuable information that will be used to provide better services and care for people living with HIV in Montana.

PROCEDURES
Interview participation in this project is voluntary. You are asked to read this consent form. If you agree to participate you will be asked to answer a number of questions covering various topics concerning your HIV positive clients. The interview will take approximately one hour. The session will be audio recorded and transcribed for accuracy of responses.

RISKS/DISCOMFORTS
You may feel you do not know the answer to some of the questions or that some of the questions may make you feel uncomfortable. You are welcome to refrain from answering any question for any reason and to withdraw from participating at any time.

BENEFITS
Your help with this study will provide valuable information to Montana DPHHS and Ryan White staff. By participating in this study you will assist in determining the needs of HIV positive people in Montana as to ultimately improve the availability of HIV related services, which in turn will improve the quality of life for those living with HIV.
CONFIDENTIALITY
Your participation in this interview will be confidential. We will not use your name, or any other identifying information in reports or other materials related to this study. Specifically:
- The identities of all interview participants will remain confidential and will not be associated with research findings in any way.
- At the conclusion of the project, any and all data containing information about participants will be destroyed.
- All the data collected during this project will be reported and examined as group data.

COMPENSATION FOR INJURY
The project team believes the risk of taking part in this study is minimal. However, the following liability statement is required in all University of Montana consent forms:

In the event that you are injured as a result of this research you should individually seek appropriate medical treatment. If the injury is caused by the negligence of the University or any of its employees, you may be entitled to reimbursement by the department of Administration under the authority of MCA, Title 2, Chapter 9. In the event of a claim of such injury, further information may be obtained from the University’s claims Representative or University Legal Counsel.

VOLUNTEER PARTICPATION/WITHDRAWAL
Your decision to take part in this research project is entirely voluntary. You are free NOT to answer any question and to discontinue participation at any time. You also may withdraw from this study for any reason.

QUESTIONS
If you have any questions about the research now or later, you may contact Dr. Annie Sondag at (406) 243-5215 or Annie’s Research Assistant Senna Towner at (406) 396-0782.

I have read the above description of this project. I have been informed of the risks and benefits involved, and all of my questions have been answered to my satisfaction. Furthermore, I have been assured that any future questions I may have will be answered by a member of the project team. I voluntarily agree to take part in this study. I am at least 18 years old. I understand this is my copy to keep of this consent form.

THANK YOU VERY MUCH FOR YOUR PARTICIPATION!
APPENDIX I

CONTACT SUMMARY SHEET
Focus Group and Key Informant Contact Summary Sheet

Date: 

Location: 

Number of Participants: 

General Impression: 

Specific theme/tone to interview: 

Additional constructs that emerged not already noted: 

Interview time length: 

176
APPENDIX J

EXAMPLES OF THEORY BASED INTERVENTIONS
The PRECEDE-PROCEED Model of Health Program Planning is an approach to identifying a target population's needs by systematically assessing their quality of life, epidemiological status, behaviors, lifestyle, environment, and the factors that predispose, enable, and reinforce behaviors. Once factors that contribute to risky behaviors are identified, strategies can be developed to alter those factors and ultimately change behavior. The model refined by Green and Kreuter is illustrated below in its 1999 version.

The Montana's Needs Assessment Work Group used the first three phases of this model as a guide for data collection. In other words, through the literature review,
questionnaires, focus groups and key informant interviews researchers collected data regarding PLWH/A's perceptions regarding their quality of life and the health issues they face. PLWH/A were also asked about behaviors and environmental conditions that contributed to their health problems and to a diminished quality of life. An analysis of this data led to the following recommendations.

**Information Technology to Address Medical Care Needs and Barriers to Services**

Information technology has the potential to address two major issues identified by participants in this project. The first issue is related to HIV positive people's lack of knowledge about existing resources and services that can assist them in improving their health and their quality of life. The second issues related to medical care providers' lack of knowledge about HIV and about effective treatments for HIV. This concern is not unique to Montana as is evidenced by the guidelines issued by U.S Department of Health and Humans Services (DHHS) that were designed to help medical professionals treat people with HIV (CDC, 2004). These guidelines include information on the following topics:

- The goals of anti-HIV therapy
- When to start treatment
- Monitoring of patient health
- Medication side effects and their management
- Anti-HIV medications for use during pregnancy
- Diagnosis of HIV infection in infants

Given the complexity of treating people with HIV, service providers consistently struggle with finding time to care for their clients/patients and time to educate themselves. Even for experts in chronic disease the effort to stay updated and unhurried is a challenge. Kukafka (2003), states that for HIV/AIDS service providers to stay updated they would have to recognize 10,000 plus diseases and syndromes and
approximately 3,000 medications existing for the purpose of assisting PLWH/A. Every month new HIV/AIDS care research is published, doubling the amount of literature on the subject every 22 months. In other words, information overload is a term common in the new millennium. This brings us to the conclusion that today’s HIV/AIDS medical world thrives on information technology (IT) systems.

IT systems imply immediate knowledge, accessibility, and dissemination (HRSA, 2004). They can be tailored to educate not only service providers, but their patients as well, about HIV, medications, treatment, and other resources and services. IT also has the characteristic of combining tailored education with behavioral science theory to reduce suboptimal behaviors, such as substance abuse and unsafe sex (Kukafka, 2003).

Unfortunately, there are drawbacks to current HIV/AIDS IT systems. When HIV is typed into a Google search engine, 62,900,000 hits appear (2005). This number is on the rise indicating the apparent excess of sites produced on HIV/AIDS. The real consequence is that many people believe, without question, that most of the sites are credible. For these reasons, it essential that people living with HIV and service providers have access to a practical, reliant IT resource. Case in point, both service providers and HIV positive people should possess a single, manageable source for information. Kukafka (2003) believes one IT system founded on behavioral science theory is the key to effective clinical support systems designed to help people living with HIV. In Montana, fusing Kukafka’s principle idea with the target population’s request for more knowledge about available services could result in a local IT system that is easily accessible, well advertised, and user friendly for both HIV positive people and medical care providers.

In this new millennium information technology (IT), which is defined as “all matters concerned with the furtherance of computer science and technology and with the design,
development, installation, and implementation of information systems and applications” is the powerhouse for knowledge dissemination (ICH Architecture Resource Center, 2005). Computers, specifically the internet, compliment and often replace libraries. However, with such rapid movement from books to modems, one cannot assume everyone has access to IT. For this reason, it is important to assess how often and how many PLWH/A have access to computers and how confident they are with internet services before implementing an IT plan.

According to PLWH/A in Montana, IT is often used by this population and with great skill. In the Butte focus group, only one of the five participants was without home internet service and this individual was working on installing it at the time of the meeting. Statements by people living with HIV about IT systems were as follows:

- Oh yeah- I think that it is the big thing anymore for PLWH/A. [FG]
- I still think we need the [non-internet] pamphlets [but] there’s no reason that someone who’s not internet savvy can’t go down to the health department and [the service provider] can go- “here...print.” And have it. It doesn’t have to be in pamphlet form. [FG]

One key informant shared an enthusiastic impression of people living with HIV and the internet:

- I think [PLWH/A] are a high functioning group; they’re able to become well-informed [and] internet savvy. They’re very capable of gathering that information. So that’s a positive thing. [FG]

These responses initiated the consideration of using the internet as a strategy to target the needs of people living with HIV addressed in this assessment. However, it is important to consider people who do not have access to, or are not knowledgeable about, IT by offering the online information in hard-copy pamphlet form.
Implementing with the Social Marketing Theory.

Social Marketing has become the modern medium for disseminating and acquiring information. Minds of this century have adapted to fast-pace images and the versatility of the World Wide Web. Thus, any health program planner targeting a population at this time is wise to use the same strategies and methods that marketers use to sell a product. In the case of social marketing the product is the healthy behavior that benefits both the individual and the society at large. This theory works well with models of behavior change.

In the case of HIV positive people in Montana, social marketing strategies can be used to address many of the factors that contribute to risky behaviors. On the following page is a brief overview of the steps in social marketing. Service providers who would like to implement social marketing strategies would do well to consult with individuals who have some expertise in this area.
Choose a behavior that you want to address in your Social Marketing Campaign

- Specify the behaviors that lead to HIV infection.
- Identify the external factors (i.e. peer pressure, access to drugs) and the internal factors (i.e. low self-esteem, lack of knowledge) that contribute to or cause the behavior in questions. Use behavioral science to help you understand the behavior and its causes.

Conduct a needs assessment.

- Get a picture of the community in which you will be working: its politics, its consumers, and their habits (what they buy, what they do for fun, etc.). Analyze your audience to know what they need to know to design an audience centered prevention program.

Define who you will target with your campaign

- Use demographics and lifestyle factors to segment your audience. In other words, use sex, age, race, sexual orientation, income level, and lifestyle factors, etc. to determine exactly who you will target with your campaign.

Plan the Content

- Set specific, measurable and realistic prioritized goals for each segment of your target audience.
- Outline specific strategies and methods for delivering your messages as well as an evaluation plan that includes process and outcome measures.

Design and test strategies and materials for effectiveness.

- Assess delivery effectiveness, communication effectiveness, and effectiveness in influencing audience behaviors.

Determine product, price, promotion, & place.

- Know what your audience believes about the behavior, what they are willing to do to adopt the behavior, and how and where you can best appeal to them.

Put the program to work

- Distribute materials and messages and generate support

Monitor the program.

- Use both process and outcome criteria
Peer Advocacy to Address the Need for Social Support

Another reoccurring theme derived from qualitative and quantitative data analysis was the need for social support, both individual and group support. In many cases, social support for people living with HIV is either not available, or the support offered does not always meet the needs of the HIV positive person. Often, people want a support group and/or counselor who is familiar with HIV. When traditional counseling or support groups are not available, a peer advocacy program may be an effective alternative. Peer advocates can tailor their support to the specific needs of the individual or individuals with whom they are working. Advocacy is a form of support that encourages people living with HIV, who are knowledgeable about the issues that arise related to the disease, to advice and aid individuals who are not as familiar with the disease. HIV positive individuals, who have higher self-efficacy in regard to coping with their infection, could be trained as advocates and placed with positive people who have lower self-efficacy. Peer advocacy in this form was supported by the following comments gathered from the focus groups:

- If you don't have the support on the first one then you don't have the support to keep you from taking risky behaviors. [Support] in itself is [going to help you]. [FG]
- We've got the group advocated by doctors, which is an HIV positive men's group and we talk and it's a great community builder; it's a great way to educate each other about whatever. It's...peer modeling. [FF]
- With us as a group we're an excellent resource for each other. We should be getting paid. The universities that these doctors went to should be paying us for continued education. [FG]
- Before my peer group there was a lot of things I didn't know about because [service providers] don't tell you about them because they don't have to give knowledge to you. [FG]

When I looked for counseling, I wanted someone that knew something about HIV, not just someone that's open to counseling, because that's nice but I need someone that has experience in counseling PLWH and knows the real problems that happen and so many counselors don't know. [FG]
Peer advocacy may also be a means for addressing the mental health issues that are prevalent in HIV positive people in Montana, just as in the rest of the United States and Europe. In 2004, HRSA reported 20 to 50 percent of people living with HIV in these two countries experienced mental illness including, but not limited to depression, anxiety, panic disorder, posttraumatic stress disorder; impulsivity or personality disorder, and/or drug related disorders and psychosis. Montana questionnaire results revealed that out of 166 respondents 118 (72%) had mental health concerns. While these “concerns” do not necessarily indicate a mental illness, the issues that were raised by participants need to be addressed. Of those 118 who had concerns, 101 (84%) reported suffering from depression, 92 (77%) reported suffering from anxiety/fear, 71 (60%) reported experiencing loneliness/isolation, and 61 (51%) reported being under stress. These numbers go beyond HRSA’s estimate of the number of people living with HIV who are afflicted with mental health issues, and make it apparent that HIV positive people in Montana need emotional support. While it would be irresponsible to suggest that a peer advocate can resolve the mental and emotional issues experienced by many people living with HIV, the Needs Assessment Work Group recommends strengthening peer advocacy as one of many strategies that are targeted to address this issue.

**Peer advocacy implemented using the Transtheoretical Model.**

The Transtheoretical Behavior Model, or Stages of Change Model, suggests that individuals go through several stages in the process of changing their behavior (Prochaska, Johnson, and Lee, 1998). This process begins with precontemplation and ends with termination, but the movement through the stages fluctuates from person to person. Not every person will be ready to take action or continue on an
upward spiral once they begin to change. Relapse, as a component of this model, is an accepted part of behavior change. Using this model reminds implementers that knowing what stage of change individuals are in is the best indicator for knowing how to approach them and assist them in the process of changing their behavior.

In relation to the people living with HIV in Montana, peer advocates could be trained to quickly assess an HIV positive person’s stage of change in regard to a particular behavior, and then implement the strategies associated with the model in order to facilitate positive movement through the stages of change away from the behaviors that put one at risk for HIV infection.

The diagram below briefly describes each stage of change and provides an example of the strategies associated with that stage. Service providers who wish to use this model to facilitate behavior change should familiarize themselves with all of the strategies associated with each stage.

Programs and Service Interventions to Address Stigma

Although stigma is primarily stressed when discussing the needs and issues of women with HIV in this report, according to research literature and this study, stigma is a reoccurring concern affecting the quality of life for many people living with HIV. It is such a prevalent and ongoing issue that HRSA has outlined programs and service interventions to address stigma in their 2003 report titled, *Stigma & HIV/AIDS: a review of literature* (Brimlow et al, 2003), and their 2004 report titled *HIV/AIDS Stigma: theory, reality, and response* (Holloway et al, 2004). In the latter report HRSA offers six strategies, the rationale behind the strategy, and the intervention correlating the strategy. Strategies, rationale and refined strategies can be viewed in Table 42, however, the Montana HIV Needs Assessment team recommends DPHHS, the Montana HIV Prevention Planning Committee, and Ryan White Consortia examine these reports in an effort to continue to minimize HIV-related stigma in Montana. It is also important to note that some of the listed interventions are already being implemented in Montana.
### Table 42. Ways to Address HIV/AIDS-Related Stigma

<table>
<thead>
<tr>
<th>STRATEGY</th>
<th>RATIONALE</th>
<th>INTERVENTION</th>
</tr>
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</table>
| Provide knowledge and education to the public. | Increasing the public's basic knowledge about HIV/AIDS helps address the misinformation and fear that underlie stigma. | ➤ Science-focused, school-based AIDS education.  
➤ Public information programs, materials  
➤ Community or peer-led population education activities  
➤ Workplace education programs |
| Humanize the stigmatized population.    | Stigma thrives on perception of "otherness." Putting the general public in contact with HIV+ population can help humanize them. | ➤ HIV+ speakers' bureau.  
➤ HIV+ people disclosing to family, friends, workplace and community  
➤ HIV+ spokespeople in the media.  
➤ AIDS quilts |
| Challenge the social acceptability of stigma. | Campaigns and materials can change social norms and community attitudes that drive stigma an discrimination. | ➤ Explicit declarations of welcome from faith groups, businesses.  
➤ Creation of community coalitions and alliances  
➤ Needle-exchange programs  
➤ Provider training and sensitization. |
| Help people affected by stigma develop the tools to survive it- and combat it. | Help PLWH/A cope in a stigmatizing environment so they are less likely to internalize stigma and discrimination. | ➤ Self-help and support groups.  
➤ Employment training  
➤ PLWH/A leadership training  
➤ Positive-only social activities and dating services |
| Develop legal and regulatory responses to protect people from stigma and discrimination. | Stigma often manifests itself in discrimination. Though legal and regulatory efforts, we can create a more welcoming and safe environment for PLWH/A, sending a message of social inclusion and challenging the acceptability of stigma and discrimination. | ➤ State and local antidiscrimination laws  
➤ Workplace policies  
➤ Codes of practice  
➤ Medical confidentiality laws and policies |
| Provide effective HIV/AIDS care and treatment. | Effective treatment challenges the fatalistic view of HIV/AIDS as inevitably degenerative. Treatment advances also allow PLWH/A to be- and to be viewed as productive, contributing members of society, not as a burden on others. | ➤ Prevention program content restrictions  
➤ State criminalization laws  
➤ Community-based care and treatment programs  
➤ Public Health messages and programs  
➤ Public information programs, materials |

* This table is adapted from *HIV/AIDS Stigma: theory, reality, and response.* (Holloway et al., 2004:18-19)