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A NEEDS ASSESSMENT OF PEOPLE LIVING WITH HIV IN MONTANA

By

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Bachelor of Science, The University of Montana, Missoula, Montana, 2007

Thesis

Presented in partial fulfillment of the requirement
for the degree of

Master of Science
in Community Health

The University of Montana
Missoula, Montana

May 2012

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ABSTRACT

Epperson, Emily, Master of Science, May 2012 Community Health

A Needs Assessment of People Living with HIV in Montana

Chairperson: Dr. Annie Sondag

The purpose of this study was to assess the HIV testing, prevention, and treatment needs of people living in Montana who are infected with HIV. This study identified the demographic characteristics, the unmet needs, and the barriers to accessing assistance, prevention, and treatment services for people living with HIV in Montana. Qualitative data was collected in the form of focus group and key informant interviews and quantitative data was collected in the form of a questionnaire. The results of this assessment identified successful services that contribute to the improved mental, emotional, and physical health of people living with HIV including case managers, health care providers, and HIV-positive retreats. This assessment also identified three important objectives to best meet unmet service needs and address barriers to accessing available services. These objectives included working toward increasing the general public's awareness of HIV through educational strategies, to improve access to health care providers who are holistic, caring and current in their knowledge about treating HIV, and to maintain or increase the available or existing case management services and HIV-positive retreats. To best address these objectives there must be continued diligence toward overall empowerment of people living with HIV in Montana as well as efforts to decrease cultural stigma, discrimination, and fear surrounding HIV. The findings of this study will be used by the Montana Department of Public Health and Human Services and the Montana HIV Prevention Community Planning Group to further shape the assistance, prevention, and treatment services available to people living with HIV.

Acknowledgements

None of this would have been possible without the assistance of Montana's Ryan White case managers, important key informants to the HIV-positive community, and the people living with HIV in Montana who were courageous enough to share their experiences, stories, perspectives and fears with me. Also, a huge thank you to everyone who helped to organize and facilitate focus groups and to those persons across the state who helped me disseminate questionnaire packets; your assistance was priceless. Without you, this needs assessment would have been dead at the beginning, your work made this possible.

Another enormous thank you to the Montana Department of Public Health and Human Services and the Montana HIV Prevention Community Planning Group for allowing me the opportunity to be included in this project.

I owe thanks to all my Health and Human Performance Graduate Student classmates for their support, but most notably to Emily Williams, Kelly Hart, and Blair Snyder. Thank you for sharing an office with me, your insights, shared knowledge, and being an integral part of the retention of my sanity.

Thank you to my committee members Dr. Valerie Moody and Dr. Christopher Preston for your guidance, presence, expertise, and direction. Thank you to my committee chair, advisor, boss, and mentor, Dr. Annie Sondag, for guiding me toward Community Health, for trusting in my knowledge enough to be a part of this project, for your time and attention, and for guiding me through the process of research toward a successful outcome.

Thank you to the friends and family that have supported me, even those I lacked the time to interact with. Most importantly, thank you to my parents for inspiring me to be a better person and pursue my dreams. Without your support, encouragement, patience, and belief in my abilities, I could have never been successful.

Not to be forgotten, thank you to Joe for embarking on this journey with me, for understanding and accepting my stress, and for believing in my abilities all along.

My success belongs in part to all of you, thank you from the bottom of my heart.

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CHAPTER ONE

Introduction to the Study

Almost four decades have passed since the first known cases of Human Immunodeficiency Virus (HIV) and Acquired Immunodeficiency Syndrome (AIDS) appeared. HIV mortality rates rose steadily through the 1980's and peaked in 1995. By the end of 2008 over 600,000 people had died from the disease. Fortunately, mortality related rates have declined significantly in the past 15 years. Much of this decline is due to Highly Active Antiretroviral Therapy (HAART) and to decreasing incidence since the 1980's (Kaiser Family Foundation, 2011). Because of the dramatic decline in mortality more people with HIV are living longer and with improved health status, sense of well-being, and energy (Kim, Del Rio, & Havlir, 2003). The benefits of HAART have allowed many people living with HIV to continue to pursue normal life activities, including being sexually active (Kim et al., 2003). As the numbers of people living with HIV have increased, the focus of prevention efforts have shifted from prevention targeted toward people who are not infected to a focus on those who are infected with HIV. This approach, referred to as "treatment as prevention" is a cornerstone of the recently released National HIV/AIDS Strategy (2010).

Released in July 2010, the National HIV/AIDS Strategy's vision statement says:

> "The United States will become a place where new HIV infections are rare and when they do occur, every person, regardless of age, gender, race/ethnicity, sexual orientation, gender identity or socio-economic circumstance, will have unfettered access to high quality, life-extending care, free from stigma and discrimination."

The three primary goals of this strategy, as set forth by President Obama, are: 1) Reducing the number of people who become infected with HIV; 2) Increasing access to care and optimizing health outcomes for people living with HIV; and 3) Reducing HIV-related health disparities (*National HIV/AIDS Strategy*, 2010).

This strategic focus is especially important in states such as Montana, that are vastly rural, making access to proper care and treatment services limited. Montana has reported 1,025 cases of HIV infection since 1985, with the majority of people living with HIV residing in Yellowstone, Missoula, Gallatin, Flathead, Cascade, Lewis & Clark, and Ravalli counties at the time of diagnosis. Although women are affected by HIV/AIDS, men constitute 88% of the 1,025 reported cases, making men more at-risk in Montana than women for HIV infection. As of December 2010 there were 532 people living with HIV in Montana (Montana DPHHS, 2012). In order to move toward fulfilling the primary goals set forth by the National HIV/AIDS Strategy, more information needs to be gathered related to risk factors for transmission, barriers to testing, care, and continued treatment, as well as other health disparities that contribute to HIV infection transmission. Health disparities can affect how frequently HIV affects persons with high risk behaviors, the number of persons infected or spreading HIV, and how often HIV leads to death – all factors which contribute to barriers to testing, prevention, and treatment services and care.

There are many barriers to seeking or accessing prevention and/or treatment services directed at decreasing the spread of HIV infection. In 2006 an assessment of the needs of HIV positive individuals living in Montana found that the main barriers to services and treatment were associated with lack of insurance coverage, the cost of treatment or assistance, not knowing who to ask for help, mental health issues, and a lack of transportation (Towner, 2006). Towner (2006) also found that a lack of knowledge of resources and fear associated with accessing treatment were major barriers to accessing the prevention and/or treatment services necessary to effectively treat HIV and deal with the associated burdens to quality of life (Towner, 2006). These barriers identified by people living with HIV in Montana mirror barriers to treatment and services that have been identified in other states. Bravo et al. (2010) found that fear of discrimination, psychological pain, negative stigma, and social isolation were major barriers to testing and treatment for HIV (Bravo et al., 2010). Other barriers that were found relate to a lack of health insurance, lack of money to pay for services, low education, an inability to navigate the complex care delivery system, and a lack of knowledge about eligibility for services and drug treatment protocols and efficacy (Schwarz et al., 2011; Wohl et al., 2011).

People living with HIV are likely to encounter multiple social, emotional, and physical problems that adversely affect their quality of life. The weight of negative external and internal stigmas, depression and other mental health issues, employment hardships, health-related concerns aside from HIV-status, and barriers to receiving prevention and/or treatment care are just a few concerns that people living with HIV must face and deal with on a regular basis. In order to fully comprehend the barriers that effect people living with HIV in Montana, it was imperative to work with people living with HIV as well as the Ryan White Title II Consortium case managers who coordinate services for people living with HIV in Montana. This collaboration helped to enhance the identification of the gaps between needs and the prevention and treatment services that already exist in the state. This information was used to improve linkage to testing and prevention and/or treatment services.

Purpose of the Study

The purpose of this study was to assess the HIV testing, prevention, and treatment needs of people living in Montana who are infected with HIV. Specifically, information from this study was used to describe the demographic characteristics of people living with HIV; the behaviors and barriers that contribute to reinfection and/or transmission of the virus to others; barriers to accessing HIV testing, prevention and/or treatment services; and barriers to maintaining treatment and/or services.

The last needs assessment of people living with HIV in Montana was conducted in 2005-2006. Since that time the shift to “treatment as prevention” has altered the course of fund allocation from the Centers for Disease Control and Prevention (CDC) to state agencies for the funding of HIV-related services. The focus of this study was to identify barriers to testing, prevention, and treatment services in order to effectively alter and enhance provided services to better assist people living with HIV in Montana. Results from this study provided the Montana Department of Public Health and Human Services (DPHHS) and Ryan White Title II Consortiums information that will be used to enhance prevention and treatment efforts and services for people living with HIV and persons who are unsure of their HIV status but are at high risk for infection in Montana.

Statement of the Problem

As people living with HIV are living longer lives due to effective treatment it is important to get them into care early after infection and keep them in care to protect their health and to reduce their potential of transmitting the virus to others. The key to the success of this “treatment as prevention” focus is identifying barriers to accessing treatment as well as barriers to continuing treatment. Overcoming these barriers is imperative for people living with HIV to be well supported in a regular system of care that will ultimately improve the quality of their lives and reduce their chances of transmitting the virus to others.

Research Questions

The research questions examined in this study focused on people living with HIV in the state of Montana. They were as follows:

1. What are the demographic characteristics of people living with HIV in Montana?
2. What are the risk behaviors associated with reinfection or transmission of the virus?
3. What are the prevention and/or treatment needs of people living with HIV in Montana?
4. What prevention and/or treatment and care services are preferred by people living with HIV in Montana?
5. What are the barriers to accessing and/or continuing HIV prevention and/or treatment?
6. What resources are available for people living with HIV in Montana?
7. What are the identified gaps between needs and prevention and/or treatment services?

Delimitations

The delimitations of the study are as follows:

1. The study was delimited to persons who are HIV-positive living in Montana.
2. Data was collected via online and hard-copy questionnaires, focus groups, and key informant interviews.
3. Data was restricted to what participants self-reported in the questionnaires, focus groups, and key informant interviews.
4. The participants in the study were limited to volunteers.

Limitations

The limitations of this study are as follows:

1. Information gathered for the study via online and hard-copy questionnaire were limited to the voluntary action of participants completing the questionnaire.
2. Information gathered for the study via focus groups and key informant interviews were 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 key informant interviews.
4. Data gathered for this study was limited to those individuals who were recruited by Ryan White case managers, key informants, the University of Montana and Montana’s DPHHS needs assessment team.

Definition of Terms

Human Immunodeficiency Virus (HIV): HIV damages a person's body by destroying specific blood cells, called CD4+ T cells, which are crucial to helping the body fight diseases and will eventually lead to AIDS (CDC, 2011a).

Highly Active Antiretroviral Therapy (HAART): The use of three of more anti-HIV drugs at one time (*Introduction to HIV and AIDS Treatment,* 2012).

Key Informant: *Key informants* are persons who are in contact with people living with HIV in Montana who are knowledgeable about the issues being researched and able and willing to communicate with the researchers about them**.** They are utilized when more in-depth information is needed than can be acquired from the population being studied.

Needs Assessment*:* A *needs assessment* is a planned process that identifies the reported needs (whether real or perceived) of an individual or a group (Gilmore & Campbell, 2005).

Stigma: Stigma is known as the situation of the individual who is disqualified from full social acceptance (Rao et al., 2008).

Ryan White Program: The Ryan White Program works with cities, states, and local community-based organizations to provide HIV-related services to more than half a million people each year. The program is for those who do not have sufficient health care coverage or financial resources for coping with HIV. Ryan White fills gaps in care not covered by these other sources (*About the Ryan White*, 2011).

Serostatus Approach to Fighting the HIV Epidemic (SAFE): SAFE is a strategy that was launched by the CDC in 2001 targeting HIV prevention. SAFE is aimed at those who are infected with HIV – including those currently unaware of their serostatus – as well as those who have been tested and found to be uninfected but are at continued high behavioral risk. The CDC’s strategies consist of 5 action steps that focus on diagnosing HIV infection in all infected individuals, linking them to appropriate high-quality care and prevention services, and supporting them in adhering to treatment regimens and in adopting and sustaining HIV risk reduction behavior (Janssen et al., 2001, p. 1019).

CHAPTER TWO

Introduction of Literature Review

In July of 2001 the CDC put forth a new protocol called the Serostatus Approach to Fighting the HIV Epidemic (SAFE), altering the fight against HIV. The five steps in the SAFE protocol are: (1) Increase the number of HIV-infected persons who know about their serostatus; (2) Increase the use of health care and preventive services; (3) Increase high-quality care and treatment; (4) Increase adherence to therapy by individuals with HIV; and (5) Increase the number of individuals with HIV who adopt and sustain HIV-STD risk reduction behavior (Janssen et al., 2001). This strategy focuses efforts on increasing the availability of prevention services for people already diagnosed with HIV, teaching health care practitioners how to perform HIV and sexually transmitted disease (STD) risk assessments in HIV-infected patients, and on increasing delivery of prevention messages to HIV-infected patients by health care workers (Kim et al., 2003, p. 141).

More recently, the National HIV/AIDS Strategy (2010) put forth by the Obama Administration focuses efforts on ensuring that new prevention methods are identified and that prevention resources are more strategically concentrated in communities where HIV transmission is greatest due to high risk behaviors (*National HIV/AIDS Strategy*, 2010). Prevention strategies that target individuals who are infected with HIV are a major focus of the National Strategy for HIV prevention. Previously resources were allocated toward HIV prevention; however, these resources are now being reallocated toward prevention, as well as treatment. Based on this shift, the CDC has two important goals – to increase the proportion of those who know they are infected and to increase the proportion of infected individuals who are linked to appropriate care, prevention services, and treatment services (Kim et al., 2003). With a focus on “treatment as prevention” it is imperative to get people with HIV into care early after infection to protect their health and also reducing their potential of transmitting the virus to others (*National HIV/AIDS Strategy*, 2010).

This chapter is an overview of the current literature on people in the United States who are currently living with HIV. The chapter is divided into five sections: 1) Epidemiology of HIV; 2) Quality of Life Issues for People Living with HIV**;** 3) Risk Behaviors of People Living with HIV; 4) Barriers to Testing, Treatment and Other Services; 5) Prevention/Treatment Efforts; and 5) Conclusion.

Epidemiology of HIV

Global and National HIV Cases

According to the World Health Organization (WHO) and the Joint United Nations Programme on HIV/AIDS (UNAIDS), in a 2009 global report, there are a total of 33.3 million people living with HIV, 2.6 million having been newly infected in 2009, and 1.8 million AIDS-related deaths in 2009 (WHO, 2011). The greatest burden of the HIV epidemic is seen in sub-Saharan Africa with approximately 68% of the total number people living with HIV globally. While the epidemic has remained relatively stable and largely concentrated among high-risk groups in Asia, people living with HIV in Eastern Europe and Central Asia has tripled since 2000 (*AVERTing HIV and AIDS*, 2011).

Figure 1. Regional statistics for HIV and AIDS, end of 2009

Region	Adults & children living with HIV/AIDS	Adults & children newly infected	Adult prevalence*	AIDS-related deaths in adults & children
Sub-Saharan Africa	22.5 million	1.8 million	5.0%	1.3 million
North Africa & Middle East	460,000	75,000	0.2%	24,000
South and South-East Asia	4.1 million	270,000	0.3%	260,000
East Asia	770,000	82,000	<0.1%	36,000
Oceania	57,000	4,500	0.3%	1,400
Central & South America	1.4 million	92,000	0.5%	58,000
Caribbean	240,000	17,000	1.0%	12,000
Eastern Europe & Central Asia	1.4 million	130,000	0.8%	76,000
North America	1.5 million	70,000	0.5%	26,000
Western & Central Europe	820,000	31,000	0.2%	8,500
Global Total	33.3 million	2.6 million	0.8%	1.8 million

* Proportion of adults aged 15-49 who are living with HIV/AIDS (*AVERTing HIV and AIDS*, 2011).

In the United States, national data shows that since the first reported case of AIDS in June 1981, over one million people have been infected with HIV, which includes almost 550,000 who are deceased and over one million living with HIV/AIDS today (*Ryan White CARE Act – Implementation of the New Minority AIDS Initiative Provisions*, 2009). According to CDC data, 60% of all estimated AIDS cases occur among racial and ethnic minorities, with 2006 data showing 69% of AIDS cases and 67% of estimated new HIV infections in these populations (*Ryan White CARE Act – Implementation of the New Minority AIDS Initiative Provisions* 2009).

Between 2005 and 2008, in the United States, rates of HIV infection among whites remained stable, while rates among American Indians/Alaska Natives (AI/AN), Asians, blacks/African Americans increased (CDC, 2010a). The CDC HIV Surveillance

Report for 2008 showed that the largest percentage of people living with HIV were aged 40-44 during 2007, 48% being blacks/African Americans. Also, males accounted for 75% of all HIV diagnoses among adults and adolescents, representing a 7% increase among males, while the rate among females remained stable. There was also an increase in the number of annual HIV diagnoses among Men who Have Sex with Men (MSM) and males, females, and adolescents exposed via heterosexual contact. There was a decrease of HIV infection diagnoses among male and female adult and adolescent persons who inject drugs, MSM who inject drugs, and children. As of 2008, MSM (54%) and persons exposed through heterosexual contact (32%) accounted for 86% of all diagnoses of HIV infection in the 37 states using confidential name-based reporting (CDC, 2010a).

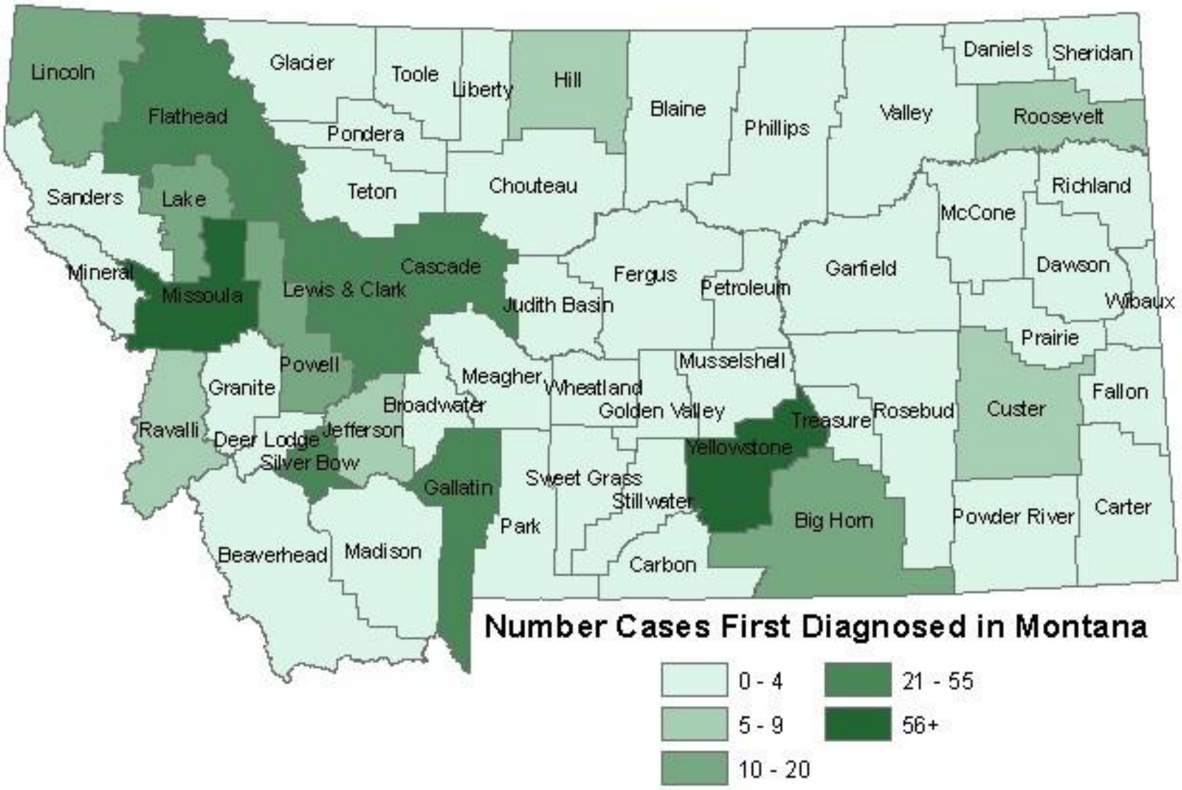
Although gay, bisexual, and MSM represent only 2% of the US population, they are the most severely affected population and the only group with high-risk behaviors for transmission continuing to see a steady increase in HIV infection since the early 1990s (CDC, 2010b). Between 2005 and 2008, there was an estimated 17% increase in HIV infection diagnosis among MSM, with 2008 data showing an estimated 17,940 MSM having been diagnosed with AIDS in the 50 states, the District of Columbia, and the US dependent areas, representing a 6% increase since 2005 (CDC, 2010b). This increase in HIV diagnoses was likely due to a combination of an increase in new infections, increased testing, and earlier HIV diagnosis (CDC, 2010b).

Demographics of HIV/AIDS in Montana

The CDC reports that people living with HIV residing in nonmetropolitan areas are generally dispersed throughout an entire state, creating unique challenges in access to HIV-related services and care (CDC, 2000). Although large metropolitan areas usually have larger HIV case numbers, the smaller numbers in medium-size and nonmetropolitan areas are also of importance and should be noted and addressed with the same urgency and care.

Montana is considered a low-HIV-incidence state, with only 16-31 newly diagnosed cases of HIV reported each year (Montana DPHHS, 2012). Montana has reported 955 cases of HIV infection since 1985, with the majority of people living with HIV residing in Yellowstone, Missoula, Gallatin, Flathead, Cascade, Lewis & Clark, and Ravalli counties at the time of diagnosis (Montana DPHHS, 2012). As of December 2009 there were 532 people living with HIV in Montana (Montana DPHHS, 2012). Although women are affected by HIV in Montana, men constitute 88% of the 955 reported cases, making men more at-risk in Montana than women for HIV infection. The greatest percentage of HIV infection was seen in persons classified as White non-Hispanic (90%), representing 90% of the population. However, 7% of reported cases occurred in AI/AN, constituting 6% of Montana’s population (Montana DPHHS, 2012).

Figure 2. County of residence for cases of HIV infection (n=595) diagnosis - Montana. 1985-2009. (Montana DPHHS, 2010).



According to the Montana Department of Public Health and Human Services (Montana DPHHS), most persons in Montana living with HIV were between 30 and 39 years of age at the time of diagnosis, with nine of every 10 reported cases occurring in men. Risk factors that were identified for these people living with HIV were heterosexual contact, MSM who inject drugs, persons who inject drugs, MSM, and no risk factor specified (NRS). MSM accounted for 66% in males, with the second being MSM who inject drugs at 13% (Montana DPHHS, 2012).

Montana HIV Cases

Montana began reporting AIDS in 1985 and HIV infection in 2000. The HIV surveillance system in use collects demographic, risk factor, treatment, vital status, and laboratory information using a standard case report form (Montana DPHHS, 2012). In 2007, of those respondents to the Behavioral Risk Factor Surveillance System (BRFSS), 35% of Montana residents aged 18-65 years old reported previous HIV testing as compared to 42% of the US population (Montana DPHHS, 2010).

Of the 1,025 cases of HIV infection in Montana since the AIDS epidemic began in 1985, new infections continue to be reported each year, with the mortality rate continuing to decrease. At the time of Montana's DPHHS's 2010 report, 62% of the 532 people infected with HIV had been diagnosed with AIDS. However, in 2010 an estimated 80% of people living with HIV sought medical treatment. In Montana, MSM account for above 50% of the reported cases of HIV infection, with the average age at time of infection since 2000 being in the upper thirties (Montana DPHHS, 2012).

Health Problems of People Living with HIV in Montana

People living with HIV are in need of and just as deserving of the basic health care services as persons not directly affected by an HIV diagnosis. However, people living with HIV have health risks and therefore health care needs that go beyond those most Americans deal with on a regular basis. Some of the medical conditions that effect people living with HIV are seen in the HIV-negative population as well; however, the burden of these health problems are usually greater in the HIV-positive population. Some Medicaid claims show depressive disorder, hepatitis C infection, and diabetes mellitus to be health issues that negatively affect people living with HIV and their overall health status (Montana DPHHS, 2011).

Nationwide, the Ryan White Comprehensive AIDS Resource Emergency (CARE) Act provides funds to clinics in order to help defer some of the costs of treatment and prevention efforts so that people living with HIV can decrease some of the burden that these health care issues take on them financially. In Montana, Ryan White CARE funds support seven clinics, aiding in drug assistance, public clinics, and program planning and evaluation (Montana DPHHS, 2011). The paragraphs below describe common health issues experienced by people living with HIV.

Neurocognitive Impairment(s)

The latest research shows 10-60% of people living with HIV as living with some form of neurocognitive impairment (NCI), depending on the stage of their disease (Singh et al., 2009). There are a few different stages of HIV-associated neurocognitive disorders (HAND) – asymptomatic neurocognitive impairment (ANI), minor neurocognitive disorder (MND), and HIV dementia (HAD) – respectively (Singh & Mandela., 2009, p.30). Those individuals experiencing HAND experience impairments in multiple cognitive domains, which include attention, concentration, memory, executive function, motor function and speed of information processing, as well as sensory perceptual/motor skills deficits (Singh & Mandela, 2009).

The less severe forms of HAND, ANI and MND, occur in 30-60% of people living with HIV, dependent on the stage of their HIV infection (Singh & Mandela, 2009). HAD, the most progressed stage of HAND, occurs in approximately 10-15% of people living with HIV and is seen more commonly in the later stages of HIV infection (Singh &

Mandela, 2009). While the introduction of HAART led to a major decline in the incidence of HAD (Singh & Mandela, 2009), a lowered incidence of HAND and improved some patient outcomes, it is not universally successful in preventing or reversing HAND (Singh & Mandela, 2009). Factors such as an incomplete reversal or prevention of cognitive impairment, a longer survival rate due to HAART and other treatments, and an increase in HIV prevalence are just some influences that may be contributing the continued rise in the overall prevalence of HAND (Singh & Mandela, 2009).

HCV/STD Infections

Due to shared route of transmission, hepatitis C (HCV) and sexually transmitted diseases (STD) infections can be common among people living with HIV and pose a greater health risk as compared to those who are HIV-negative. The prevalence of HCV among people living with HIV in the US is estimated to be between 30-35%, as compared to 1.6% in the HIV-negative population (Proeschold-Bell et al., 2010). Research also shows that among the AI/AN population there are high rates of *Chlamydia trachomatis* infection, gonorrhea, and syphilis. This suggests that the sexual behaviors among the AI/AN population that also facilitate the spread of HIV are common (CDC, 2008).

There is a disconnect between knowledge of transmission of HCV and/or STD infections and safe practices to reduce transmission risk, leaving people living with HIV at continued risk for transmission of these infections, as well as HIV. These gaps in knowledge can be seen among people living with HIV receiving HIV primary care, where 37% of participants reporting HIV monoinfection were unaware that HCV is transmitted through blood, which in turns leaves them uninformed on how to properly protect themselves from HCV infection (Proeschold-Bell et al., 2010). Of people living with HIV reporting HIV monoinfection, 51% were unaware people living with HIV with an HCV co-infection could benefit from HCV treatment, and 89% were unaware that HCV could be cured (Proeschold-Bell et al., 2010). According to 2005 surveillance data by race/ethnicity by the Montana DPHHS, the second highest rates of gonorrhea and *Chlamydia trachomatis* infection and the third highest rate of syphilis were seen in the AI/AN population (CDC, 2008). Without the proper knowledge about transmission and/or treatment, people living with HIV may be discouraged from being tested for HCV or STDs (Poreschold-Bell et al., 2010).

NADMs

Non-AIDS-defining malignancies, or NADMs, have been steadily increasing while there has been a dramatic decrease in AIDS-related malignancies, according to studies linking HIV/AIDS databases and cancer registries (Nguyen, Farrell, & Gunthel, 2010). Within the HIV-negative population, NADMs have increased, mostly among infection-related cancers such as anal cancer, Hodgkin lymphoma, and liver cancer (Nguyen et al., 2010). Cancer is usually diagnosed at a much younger age among people living with HIV, although advanced age is a risk predictor as well, and has a more aggressive course as compared to the HIV-negative population (Nguyen et al., 2010).

Among people living with HIV, low CD4 cell counts were associated with a higher risk for NADM, however, those people living with HIV receiving HAART, presenting a higher CD4 cell count, were likely to be at a reduced risk for NADM (Nguyen et al., 2010). In order to continue quality treatment options for people living with HIV, more vigilant screenings and interventions are needed for cancers associated with NADMs, as evidenced by their changing epidemiology (Nguyen et al., 2010). Identifying the oncogenic and immune mechanisms of NADM malignancies will play a crucial role in further identifying at what stage of HIV infection it is most beneficial to implement HAART as a prevention strategy for NADMs (Nguyen et al., 2010). As the proportion of deaths due to AIDS-defining conditions among people living with HIV decreases, the proportion of deaths due to other causes, such as NADMs, liver disease, pulmonary diseases, and cardiovascular disease has increased (Pines, Koutsky, & Buskin, 2011).

Lung Cancer. Of the NADMs, lung cancer is the most common among people living with HIV, at two to six times that of the HIV-negative population (Nguyen et al., 2010). Although lung cancer can develop at any point during the course of HIV, there is somewhat of an increase in the time immediately before and after an AIDS diagnosis (Nguyen et al., 2010). Within the HIV-negative population, overall prognosis for lung cancer is not good, and within the HIV-positive population, it is much worse, possibly due to the advanced stage of presentation (Nguyen et al., 2010). However, Hessol et al. showed that with at least six months of HAART use, people living with HIV can improve their cancer survival time (Nguyen et al., 2010).

Hodgkin Lymphoma. Although the introduction of HAART has slowed the progression of some HIV-related diseases and infections, the incidence of Hodgkin lymphoma (HL) among people living with HIV has increased significantly in the HAART era (Nguyen et al., 2010). In the pre-HAART era, the survival outcome of AIDS associated HL was short, possibly attributed to AIDS-associated mortality and a short disease free interval from HL (Nguyen et al., 2010). Response rates to therapy were greater than 60%, with complete remission rates between 40% and 50%, and the median overall survival at approximately 18 months (Nguyen et al., 2010). However, HAART has allowed for the administration of more aggressive therapies for HL among people living with HIV, dramatically improving the survival of these patients (Nguyen et al., 2010).

*Anal Cancer***.** The introduction of HAART does not reflect any significant changes in the epidemiology of anal cancer among people living with HIV (Nguyen et al., 2010). However, based on data taken from the largest AIDS cancer registry, the incidence of invasive anal cancers has increased among men with statistical significance during the HAART era as compared to numbers from the pre-HAART era (Nguyen et al., 2010). When compared to the HIV-negative population, people living with HIV have a standardized incidence ratio of up to a 50 for increased risk of developing anal cancer (Nguyen et al, 2010).

Anal cancer, like cervical cancer, is associated with the oncogenic types of HPV (HPV 16 and HPV 18) (Nguyen et al., 2010). This has the potential to affect all people living with HIV; however, it is especially likely to affect MSM (Nguyen et al., 2010). The prevalence of anal HPV is high in HIV-positive women and men who do not engage in anal sex as well as, therefore suggesting that HPV is not only acquired by anal sex (Nguyen et al., 2010). Therefore, HPV is not the only risk factor contributing to the high incidence of anal cancer among MSM (Nguyen et al., 2010).

Liver Cancer. Hepatocellular cancer (HCC), or liver cancer, is the third leading cause of death from cancer, following lung and stomach cancers, worldwide (Nguyen et al., 2010). Most cases of HCC are associated with HCV or hepatitis B virus (HBV) infection, with cirrhosis being essential for the development of HCC in both infections (Nguyen et al., 2010). Other risks that may contribute to HCC in those individuals who are infected with HCV or HBV include toxins (alcohol, aflatoxin), metabolic disturbances (diabetes, nonalcoholic fatty liver disease, and hereditary hemochromatosis), and immunomediated dysfunction (primary biliary cirrhosis and autoimmune hepatitis) (Nguyen et al., 2010).

Because HCV and HBV have similar routes of transmission, they are found to be in 33% and 10% (respectively) of HIV-infected individuals worldwide (Nguyen et al., 2010). Therefore, high-risk individuals, those patients HIV/HBV-coinfected or cirrhotic patients with HIV/HCV, should have HCC surveillance annually or biannually (Nguyen et al., 2010). Detecting HCC early can increase the chances for successful hepatic resection or liver transplantation, and potentially curing the infection (Nguyen et al., 2010).

Reinfection/Superinfection (Mutations)

In 1986, HIV-2, a second type of HIV, was isolated from a West African AIDS patient (CDC, 2011a). Although HIV-2 is relatively similar to HIV-1 in mode of transmission and opportunistic infections, persons infected with HIV-2 seem to develop immunodeficiency slower and milder, also displaying less infectiousness early in the course of infection (CDC, 2011a). However, as the disease advances, HIV-2 seems to increase in infectiousness, yet the duration of the HIV-2 virus is shorter when compared to HIV-1 (CDC, 2011a).

Although HIV-2 is predominantly found in Africa, the first case in the US was diagnosed in 1987. The CDC began working with state and local health departments to collect demographic, clinical, and laboratory data on HIV-2 infection in order to learn more and distinguish the differences between and HIV-1 and HIV-2 infection (CDC, 2011a). The two types of HIV are closely related and share a common cellular receptor and risk determinants for infection, however both viruses have distinct epidemiologic and biologic properties (Sarr et al., 1998). Because HIV-2 is significantly slower in rate of disease progression as compared to HIV-1 and is known to be less transmissible, it is educated conjecture that HIV-2 viral infection would mostly likely be at a replicative disadvantage in dual infection (Sarr et al., 1998). Due to the fact that some immunosuppressed individuals lack or have lost the HIV-2 provirus suggests that over time the dual-infected individual may only sustain the HIV-1 virus capable of transmission and pathogenesis (Sarr et al., 1998). In 1998, Sarr et al. found that the potential for dual infection with HIV-1 and HIV-2 was considered, though not yet confirmed (Sarr et al., 1998).

However, in 2002, a worldwide report noted 16 cases of HIV-1 superinfection, or the reinfection of an individual who already has an established infection with a heterologous HIV strain (Smith, Richman, & Little, 2005). A superinfection is an infection with a second strain after an immune response has already been established to the initial infection (Smith et al., 2005). Due to the magnitude and diversity of HIV globally, largely driven by recombination, circumstantial yet substantial evidence shows that dual infection is widespread, whether it be coinfection or superinfection (Smith et al., 2005).

The term *superinfection* is used interchangeably with *reinfection* in some literature, with some feeling that “super” implies a stronger second infection, which is not always the case (Smith et al., 2005). *Reinfection* might also imply that the first virus has been cleared before the second infection, such as is seen with influenza (Smith et al., 2005). It is hypothesized that individuals with an early HIV infection, thus an immature HIV-specific immune response, may be the most likely candidates for acquiring the second strain of the virus, as compared to chronically infected individuals (Smith et al., 2005). This risk is influenced by the intrahost viral dynamics, type of exposure, and treatment regimens (Smith et al., 2005). If an HIV infected individual is undergoing regimented antiretroviral therapy they may be protected from superinfection (Smith et al., 2005). Conversely, superinfection has been reported to complicate antiretroviral therapy and possibly drug resistance testing (Smith et al., 2005).

HAART & Side Effects of Medications

Between 1990 and 1999, people living with HIV in the US increased 400%, to 312,804 (Hergenrather et al., 2004). The advent of health-enhancing protease inhibitors and highly active antiretroviral therapy (HAART) in 1995 not only contributed to the enhanced longevity of persons diagnosed with AIDS (Hergenrather et al., 2004) but also contributed to a decline in HIV-associated morbidity and mortality (Vincent et al., 2004), categorizing HIV/AIDS as a chronic illness instead of an immediate death sentence (Pines et al., 2011). Those individuals within the HIV-positive community capable of accessing HAART are not only living longer, they are also beginning to see comparable numbers of morbidity and mortality as those of individuals without HIV infection (Pines et al., 2011).

Although HAART has enhanced the lives of many people living with HIV, it has also resulted in an increase in unprotected sexual behaviors due to a lessened concern about HIV transmission (Vincent et al., 2004). People living with HIV receiving HAART are at a higher risk for contracting sexually transmitted diseases (STDs) than other people living with HIV who are not receiving HAART. Since HAART adherence reduces HIV transmission risk, persons who are HIV-positive, including persons who inject drugs, are more likely to have unprotected sex with their partners (Vincent et al., 2004).

Side-effects and drug-related symptoms associated with HAART play a huge role in the adherence to treatment and quality of life of people living with HIV (Vincent et al., 2004). Even the mere perception of perceived side effects has had a negative impact on antiretroviral treatment, leading to inappropriate health behaviors (Vincent et al., 2004). The subjective perception of HAART-related side effects, as reported by people living with HIV undergoing treatment, may induce psychological distress, leading to riskier sexual behaviors (Vincent et al., 2004).

Lipodystrophy is a disturbance in the way a human body produces, uses, and stores fat, and at this time there is no known effective treatment (AIDSinfo - HIV/AIDS Information, 2005). Lipodeposition is the distribution of the disrupted body fat, causing the appearance-related side effects brought on by HAART and other HIV-related drug treatments (Rao et al., 2008). Of the reported side effects from HAART, lipodystrophy and lipodeposition were reported with the most frequency as contributing to poor HAART adherence, which in turn encourages the development of treatment resistant strains of HIV while also hindering the reduction of viral loads (Rao et al., 2008).

Aging

Since the advent of drugs to treat HIV/AIDS, HIV-positive persons are living longer; however they are having major health problems associated with aging and perceive less treatment options and greater mental health concerns (Pitts et al., 2005). As prevalence rates continue to increase, older people living with HIV are rating their health as being worse than younger people living with HIV and are significantly less likely to rate their well-being as excellent (Pitts et al., 2005). This could be linked to the fact that older people living with HIV were distinctly less likely to be in contact with services, HIV-related or not, with personal support that would normally be found through a regular sexual relationship being significantly less than younger people living with HIV (Pitts et al., 2005).

Older people living with HIV report higher levels of hepatitis A and B than younger people living with HIV yet lower levels of vaccination (Pitts et al., 2005). Conversely, older people living with HIV report fewer cases of hepatitis C than younger people living with HIV (Pitts et al., 2005). Pitts et al. also found that the financial circumstances of older people living with HIV were worse when compared to younger people living with HIV (Pitts et al., 2005). These discrepancies highlight the increasing concern for the enhancement of clinical and community needs for older people living with HIV (Pitts et al., 2005).

Although it was found that older people living with HIV (80.7%) were notably more likely to be using antiretroviral therapy as compared to younger people living with HIV (69.1%), older people living with HIV were significantly less likely to make use of services than younger people living with HIV and were less likely to user services at non-

HIV related organizations (Pitts et al., 2005). These challenges are associated with the consequences of long-term therapy effects and the natural aging process (Pitts et al., 2005).

Quality of Life Issues for People Living with HIV

The CDC defines quality of life as "a broad multidimensional concept that usually includes subjective evaluations of both positive and negative aspects of life," (CDC, 2011b). Therefore, quality of life includes the effects of jobs, housing, schools, the surrounding social structure, culture, values, spirituality, and health. The effects of HIV/AIDS have a direct effect on quality of life.

Although HIV affects the quality of life of both men and women, in Montana, men represent the majority of people living with HIV. Not all men who are HIV-positive identify as gay; however, the CDC reported that in 2007, MSM were 44 to 86 times as likely to be diagnosed with HIV compared with other men, and 40 to 77 times as likely as women (CDC, 2010b). The CDC reports that since the beginning of the HIV epidemic, MSM have continued to consistently represent the largest portion of persons diagnosed with AIDS as well as persons with an AIDS diagnosis who have died (CDC, 2010b). Regardless of sexual orientation, there are multiple factors that affect the quality of life of people living with HIV. Some of the most salient factors discussed in the literature are negative stigmas associated with people living with HIV, social and psychological effects associated with an HIV diagnosis, and employment issues connected to HIV status.

Negative Stigma and HIV

In 1963, sociologist Erving Goffman defined stigma as "the situation of the individual who is disqualified from full social acceptance" (Rao, Pryor, Gaddist, &

Mayer, 2008). This definition is still pertinent and relevant in the HIV-positive community today. People living with HIV are scrutinized for their HIV-positive status, but they aren't the only ones affected by this disqualification from social acceptance. Wolitski, Pals, Kidder, Courtenary-Quirk, and Holtgrave (2009) showed that "HIV stigma affects not only people who have been diagnosed with HIV, but also has negative effects on those with undiagnosed HIV infection, those who are at-risk for HIV or are members of groups at increased risk, and the friends and family members of people living with HIV" (Wolitski et al., 2009, p.1230). Research has also shown that the stigmas surrounding HIV status have a greater negative impact on people living with HIV than the impact of HIV-related mental illness or physical health problems (Rao et al., 2008). The intersection of this disqualification is seen manifested by public-stigma and self-stigma, both of which effect people living with HIV.

Public-stigma, or external stigma, is the social reaction or reactions that people have based on the stigmatizing characteristics that they perceive in others, whereas self-stigma, or internal stigma, is the internalized cognitive, emotional and behavioral impact that those stigmatizing characteristics have on people living with HIV (Rao et al., 2008). External stigma can cause people living with HIV to feel guilt or disgust about their HIV status, causing an internalization of that stigma and those negative emotions, which can inhibit their ability to cope with the stresses of HIV/AIDS as well as the stigma attached to their HIV status (Wolitski et al., 2009). These external stigmas can be internalized, creating lowered self-esteem and self-efficacy and an increased incidence of depression, anxiety, and hopelessness (Rao et al., 2008).

Rao et al. reports that one-third of American adults nationwide have negative attitudes toward people living with HIV (Rao et al., 2008). Some of the negative external stigmas associated with these attitudes are blaming people living with HIV for their illness, misperceptions about HIV route of transmission, unfounded fears of casual contagiousness, and negative attitudes toward persons associated with people living with HIV who are also affected by HIV (Wolitski et al., 2009). Disclosure of HIV status, which was found to be associated with HIV stigma, has not been shown to lead to a consistent reduction in sexual risk-taking behaviors (Wolitski et al., 2009).

Research has consistently shown that women, homeless people living with HIV, people living with HIV who have a high school education or less, and those recently diagnosed with HIV experience the highest levels of HIV stigma (Wolitski et al., 2009). Although stigma seems to have some effect on all people living with HIV, MSM living with HIV/AIDS may experience less stigmatization within the gay community because of their experience with HIV/AIDS, creating more positive attitudes toward homosexuality (Wolitski et al., 2009).

Because external stigma can become internalized, it is important to combat societal stigmas surrounding HIV/AIDS and strengthen the support services for people living with HIV and their support networks. Increasing information and positive representations of people living with HIV via mass media and other intervention strategies can help in reducing these negative HIV stigmas (Wolitski et al., 2009).

Social and/or Psychological Issues Related to HIV Infection

Stigma and other negative attitudes toward people living with HIV can affect social and psychological capabilities in such a way as to necessitate support services.

Bravo, Edwards, Rollnick, and Elwyn (2010) found HIV-related discrimination to be one of the most significant barriers to decreasing the spread of HIV, preventative initiatives, and diagnostic process complications (Bravo et al., 2010). Internalized feelings of shame, guilt, disgust, and/or humiliation are other issues surrounding people living with HIV as they progress through their disease and the stressors that come along with an HIV diagnosis. An example of a social stressor can be seen in critical attitudes within ethnic/racial minority communities toward homosexuality, which have led gay men to feel disengaged from the support networks around them, increasing levels of psychological distress (Rao et al., 2008). Also, in a comprehensive review of literature, Bravo et al. (2010) found that an HIV diagnosis can cause avoidance of social contact with family, friends, the healthcare systems, and public services due to a fear of stigmatization and discrimination, leading directly to lowered self-esteem and self-isolation. It was also found that isolation and subsequent loneliness are some of the most salient emotional problems associated with an HIV diagnosis (Bravo et al., 2010).

Pitts, Grierson, and Misson (2005) did a study on older and younger people living with HIV to decipher the differences between the age groups in mental health condition diagnoses. The study found that a comparable number of younger and older people living with HIV had been diagnosed with a mental health condition (23.4% and 27.2 % respectively) (Pitts et al., 2005). Diagnoses represented in the study were depression and anxiety/panic disorders, with no significant differences between older or younger people living with HIV for medications (Pitts et al., 2005). Despite the lack of significant differences, the older people living with HIV did note their quality of life as being lower than the reported levels by the younger people living with HIV.

According to a study done by Nam et al., a key predictor of high adherence to treatment regimens is a general acceptance of an HIV diagnosis and the belief that the treatment is beneficial. Bravo et al. (2010) also found that positive interpersonal relationships play an important role to treatment adherence. One study found that social support related directly to a higher level of treatment adherence, psychosocial and physical adaptation – while social isolation had the opposite effect. The time period immediately following diagnosis was reported to be the time of greatest personal confusion, distress, suicidal ideation, and disruption. (Bravo et al., 2010).

It would seem safe to conjecture that as drugs to treat HIV continue to extend the life expectancy of people living with HIV, that the need for continued and extended social and psychological support, both from personal relationships and connections to healthcare services, should be investigated in order to keep this population mentally and physically healthy as they battle this chronic disease.

Basic Survival Needs and HIV

Another issue affecting the quality of life of people living with HIV is their ability or inability to maintain a job. Federal legislation makes it illegal to discriminate when hiring based on HIV status (ACLU, 2011), however, people living with HIV still face issues which inhibit their job-seeking potential or capabilities. People living with HIV report that having a job is one of the most significant contributions to successfully living with and through their illness and keeping their emotional health positive (Hergenrather, Clark, & Rhodes, 2004). People living with HIV reported the importance of increasing their self-esteem via work, which they in turn correlate with a respected adult status in American culture (Hergenrather et al., 2004).

However, there are several factors that correlate with the lack of employment-seeking behavior. These factors include negative self-perceptions about their HIV status, a limited or no-work history, perception of the lack of friendly workplace environments toward HIV-positive persons, and how work will impact medical treatment adherence (Hergenrather et al., 2004).

The Bureau of Labor Statistics (BLS) showed in June 2011 the employment rate for adult men (89.9%), adult women (92%), teenagers (76.5%), whites (91.9%), blacks (84.8%), Hispanics (88.4%), and Asians (93.2%) (BLS, 2011). Comparably, Pitts et al. found in a 2005 study that only 14.9% of older people living with HIV and 29.2% of younger people living with HIV were full-time employed, 18.1% of older people living with HIV and 21.8% of younger people living with HIV were part-time employed, and 15.6% of younger and 47.9% of older people living with HIV were not working or retired (Pitts et al., 2005). Despite these low numbers in comparison to the national employment rate averages, people living with HIV perceive the consequences of employment as contributing to an increase in their self-esteem, thereby improving their mental health and physical well-being (Hergenrather et al., 2004).

Another issue surrounding basic survival needs for people living with HIV is whether or not they have a stable housing environment. Kalichman et al. (2011) found that over half the men in their study population investigating people living with HIV in Atlanta, Georgia were concerned they would have no place to stay as compared to 41% of women in the study (Kalichman et al., 2011). Wohl et al. (2011) also found that unstable housing for people living with HIV has been associated with difficulties remaining linked to consistent and appropriate HIV care and poor physical health status

(Wohl et al., 2011). Although all populations can be effected by the health threats associated with homelessness and hunger, people living with HIV are more vulnerable to unstable housing and food insufficiency due to the direct link to HIV-related health outcomes, decreasing health status and quality of life (Wohl et al., 2011).

Although there are funding sources in place across the country to aid in seeking basic survival needs as well as receiving quality care and other services, in 2009 45% of HIV programs across the nation experienced decreased funding, with 64% of states expected a continued decline (Kalichman et al., 2011). Although Montana does receive grant money from the U.S. Department of Housing and Urban Development on a yearly basis, no grant money is allocated to the state of Montana on behalf of the Housing Opportunities for Persons with AIDS (HOPWA) (U.S. Department of Housing, 2011). Therefore, it is imperative that these issues continued to be taken into consideration and investigated in order to continue to address more effective and efficient access to housing, employment, food and any other necessary basic survival needs.

Risk Behaviors of People Living with HIV

Sexual Risk-Taking Behaviors

It is important to understand the impetuses behind sexual abstinence as well as sexual risk-taking behaviors within HIV-positive communities in order to better address the needs and issues in a targeted manner that supports not only risk reduction, but also the sexual health of people living with HIV (Courtenay-Quirk, Zhang, & Wolitski, 2009). Risk taking behavior(s) are evaluated in all communities in order to fully comprehend the needed information in order to reduced risk. A national survey conducted on teens by The Kaiser Family Foundation found that 26% of sexually active 15-to-17 year-olds believe that HIV infection cannot happen from unprotected oral sex, with 15% being unaware of whether or not they could even be infected in that manner (CDC, 2009). Although the risk of HIV transmission via oral sex is much less than the risk from anal or vaginal sex (CDC, 2009), these are examples of knowledge issues and information needs that should be addressed in order to educate everyone, whether HIV-positive or HIV-negative, of the importance of reducing sexual risk-taking behavior and evaluating abstinence as a choice.

Studies have shown that within the HIV-positive community, regardless of HIV status, sexual abstinence is more prevalent among women as compared to men, among older persons, and among those who do not have a regular sexual partner or spouse (Courtenay-Quirk et al., 2009). The top noted reasons for being abstinent were lack of interest in sex, lack of a partner to engage in sex with, and concerns about protecting one's own health and the potential health of their partners (Courtenay-Quirk et al., 2009). A higher level of education and a previous experience with housing problems were found to be factors associated with abstinence among heterosexual men living with HIV (Courtenay-Quirk et al., 2009).

When unprotected sex does occur among HIV-positive persons it is usually associated with substance abuse, psychosocial factors, and other demographic characteristics (Courtenay-Quirk et al., 2009). There is also evidence to suggest that low or non-adherence to HIV medications and treatment and/or a history of sexual abuse are associated with sexual risk behavior (Courtenay-Quirk et al., 2009).

In a study done to evaluate the prevalence of unprotected sex among people living with HIV who were aware or unaware of their infection status, it was found that those who were aware of their status reduced their unprotected sex behavior(s) an average of

53%, and with partners of HIV-negative or unknown serostatus, there was a 68% reduction seen in unprotected sex behavior(s) (Courtenay-Quirk et al., 2009). In 1998, Kilmarx et al. found that 67% of people who are HIV-positive and had been diagnosed with the previous two years had reduced the frequency of sexual activity, with a pre-diagnosis median of 10 act per month to a self-reported post-diagnosed median of once per month (Courtenay-Quirk et al., 2009). There has also been an increase in STDs via high-risk sex practices, prompting initiatives that hope to implement routine STD screenings and risk reduction counseling for people living with HIV (Kim et al., 2003).

Injection Drug Use Behaviors

Injection drug use is a behavior that puts people at an increased risk for the likelihood of acquiring HIV and/or HCV. In a study by Pilon et al. (2011) in Canada, it was found that risk behaviors associated with injection drug use accounted for 17% of all new HIV diagnoses (Pilon et al., 2011). Schwarz et al. (2011) also found that substance abuse was a reported factor in delays to HIV testing (Schwarz et al., 2011). In 2009 there were 122 known living cases of HIV related to injection drug use in Montana, with 40 of those cases residing in Yellowstone County (Speaker, 2010). Although there are measures to ensure safe and sterile use when injecting drugs, there are still incidences where resources for injection are pooled, increasing the likelihood of sharing injecting equipment and increasing the risk of HIV transmission (Speaker, 2010).

Barriers to Testing, Treatment and Other Services

Although there are publically funded programs to improve access to HIV care, there is still a gap between those receiving care and those not linked into care services. A population-based system that can be used to estimate the number of people who have never received HIV care of that have delayed care would be useful to program planners when determining resources needed to provide services and in designing strategies to overcome barriers to testing, treatment, and other care-related services (Fagan, Bertolli, & McNaghten, 2010).

Some barriers to HIV support services are language difficulties, active drug use, health beliefs, lack of case management, diminished mental status, inadequate housing, stigma, fear, and lack of disclosure of HIV status to social networks and support systems (Wohl et al., 2011). It is important to identify and address these barriers as they can delay or prevent individuals from a timely entrance into, or continuation of, core medical or support services, therefore reducing the success of care (*Ryan White CARE Act – Implementation of the New Minority AIDS Initiative Provisions,* 2009). Therefore, it is imperative to decrease barriers to care in order to deliver the most comprehensive, integrated, and quality HIV prevention and treatment care to all those who are in need.

Bravo et al. (2010) found that an HIV diagnosis can lead to psychological pain, work and social discrimination, distress, and isolation (Bravo et al., 2010). These issues were enough to keep people living with HIV from disclosing their status to others, including possible support services where they might begin receiving treatment and care. The most commonly cited reason for delayed testing in a study done by Schwarz et al. (2011) was fear. When participants identified previous injection drug use or sex between men, they were more likely to be fearful of testing and the consequential effects on their health and livelihood (Schwarz et al., 2011).

Table 1. Ten Barriers to Minorities in Obtaining HIV/AIDS Services Most Frequently Identified by Ryan White CARE Act Part A and B Minority AIDS Initiative Grantees Nationwide (*Ryan White CARE Act – Implementation of the New Minority AIDS Initiative Provisions*, 2009).

Barrier	**Number of Part A grantees reporting this barrier (of 56)**	**Number of Part B grantees reporting this barrier (of 30)**	**Total number of grantees reporting this barrier (of 86)**
Co-morbidities	56	23	**79**
Housing issues	55	21	**76**
Poverty	54	19	**73**
Lack of insurance	56	12	**68**
Substance abuse	47	20	**67**
Lack of transportation	51	14	**65**
Language issues	42	18	**60**
Prison population issues	45	15	**60**
Stigma/fear	45	14	**59**
Lack of health information	41	12	**53**

Schwarz et al. (2011) and Wohl et al. (2011) found that a lack of health insurance and low education were contributing factors to an utilization of HIV care services or a lack of getting tested despite awareness of risk factors (Schwarz et al., 2011; Wohl et al., (2011). The fear of not being able to pay for health care or an inability to receive health insurance due to a preexisting condition, sometimes unrelated to HIV, were also issues hindering persons at risk for infection from getting tested or receiving treatment following a positive HIV diagnosis. Substance use and/or mental illnesses also contributed to a delay in testing or treatment sometimes related to a lack of knowledge about the tolerability and efficacy of drug treatments and funded testing services (Schwarz et al., 2011). Wohl et al. (2011) also found that a lack of knowledge about eligibility for services or an inability to navigate the large and complex care delivery system were barriers to testing and treatment (Wohl et al., 2011).

Identifying and understanding the barriers that effect persons at risk for HIV and people living with HIV from getting tested or accessing treatment services is necessary in order to perpetuate the continued aim of unfettered access to high quality, life-extending care, free from stigma and discrimination (*National HIV/AIDS* Strategy, 2010).

Prevention/Treatment Efforts

Prevention programs to reduce the behavioral risks for HIV transmission have historically been focused on decreasing unsafe sex practices and associated drug use that put as many as five million people at risk for HIV transmission (Janssen et al., 2001). Most of these programs have been theory-driven and have put emphasis on the development of cognitive, social, and technical competencies and skills that are associated with lower-risk sex and drug use practices (Kim et al., 2003). However, specific primary prevention efforts focused on decreasing HIV transmission from individuals with HIV infection to those who are uninfected have been limited (Janssen et al., 2001).

In 2003, the CDC released another program to help continue in the reduction of HIV infection incidence, Advancing HIV Prevention (AHP) (CDC, 2007). This initiative has four strategies: (1) Make HIV testing a routine part of medical care; (2) Implement new models for diagnosing HIV infections outside medical settings; (3) Prevent new infection by working with people with HIV infection and their partners; and (4) Decrease further perinatal HIV transmission (CDC, 2007).

In order to create the most effective prevention programs as well as enhance and prolong effective treatment, focus has shifted to highlight “treatment as prevention”. This strategy for HIV prevention is called the Serostatus Approach to Fighting the Epidemic

(SAFE). The CDC launched this strategy intending to focus on those individuals who are infected with HIV, also including those who are unaware of their serostatus, as well as those individuals who has been tested and found to be uninfected, yet are continuing high risk behaviors for transmission (Janssen et al., 2001). There are five steps to SAFE: (1) Increase the number of persons with HIV infection who know about their serostatus; (2) Increase the use of preventative and health care services; (3) Increase high-quality care and treatment; (4) Increase adherence to therapy by individuals with HIV infection; and (5) Increase the numbers of individuals with HIV infection who adopt and sustain HIV-STD risk reduction behavior (Janssen et al., 2001). It is also the aim of SAFE to help develop new partnerships for people living with HIV with organizations that have historically been uninvolved with HIV prevention as well as expanding traditional public health partners (Janssen et al., 2001).

In order to continue the positive impact of SAFE, it is critical to increase, by 30,000 each year, the number of people living with HIV who become aware of their serostatus and then become appropriately linked to the available and accessible care and prevention services (Janssen et al., 2001). By increasing the number of people living with HIV who are aware of their serostatus, it is hopeful that public funding for care through Medicaid and the Ryan White CARE Act will increase, making more services available and accessible (Janssen et al., 2001). Because the effectiveness of behavioral interventions has shown positive results, it is suggested that, when implemented properly, SAFE programs might actually avert approximately 20% of HIV infections, averaging 8,000 cases per year (Janssen et al., 2001). Therefore, it is important to maintain current prevention programs for high-risk uninfected persons while also implementing the SAFE initiative in order to reduce HIV incidence and increase the number of people living with HIV who are aware of their serostatus (Janssen et al., 2001).

While focusing on the continued prevention of HIV infection, maintaining accessible and available treatment services is also important to the survival, quality of life, health status, sense of well-being, and energy of people living with HIV (Kim et al., 2003). People living with HIV who begin medical treatment early and remain in care have the best chance for long-term suppression of the HIV virus as well as an increased survival and quality of life (Gardner et al., 2009). However, studies have shown that people living with HIV are less likely to utilize health care services than drug users, persons with unstable housing, persons with depression, and those persons who are not psychologically ready to enter care (Gardner et al., 2009).

As the prevalence of HIV continues to rise, there is continued focus on the prevention of new HIV infections and HIV incidence. Because the clinical care setting is an ideal place for the implementation of prevention practices, this is recognized as a key element in the future of prevention activities. The clinical setting is the best place to identify patient serostatus and address their risk behaviors, while also working to decrease the spread of a drug-susceptible and drug-resistant virus (Schreibman & Friedland, 2003).

As HIV prevalence continues to rise, there must be more attention directed toward treatment and prevention efforts, as well as risk reduction, possibly in the form of counseling in the HIV medical care settings, with the hopes of improving access and maintaining linkage to necessary care (Kim et al., 2003). There must be continued risk reduction education for people living with HIV in medical care settings, with priority on enhancing access to HIV testing as well as the medical care offered in such settings (Kim et al., 2003). Accessing care in a clinic or office visit, not necessarily a Ryan White CARE Act funded setting, may be the only exposure people living with HIV may have to someone they trust who can also provide education about HIV transmission prevention and risk reduction behaviors (Kim et al., 2003). Prevention and treatment measures are of high importance whether it is a general practitioner delivering information or a case manger overseeing particular persons. All of these health care providers and workers should be able to aid in the identification of barriers to prevention and treatment.

Conclusion

With more than 40 million people living with HIV worldwide (*Positive Prevention: Prevention Strategies for people with HIV/AIDS,* 2003), prevention efforts and continued treatment services are necessary. Despite the increasing number of people living with HIV, there is still a negative stigma associated with an HIV diagnosis, which can directly affect people living with HIV as well as those persons in their lives who are HIV-negative. People living with HIV can also suffer from a variety of accessory health problems aside from their HIV status, which can contribute to a decreased quality of life. Therefore, it is imperative to link people living with HIV and those at high-risk for HIV transmission to health care settings where they can learn about risk reduction behaviors and continue to seek care should they need those services.

Although it may seem that focusing prevention on those individuals with HIV is victimizing or stigmatizing, it is the right of every person living with HIV to live well, and in order to do so, HIV prevention, treatment, care, and support should be viewed as the interrelated pieces they are (*Positive Prevention: Prevention Strategies for people* *with HIV/AIDS*, 2003). The best way to assess the needs and perceptions of people living with HIV in Montana is to gain information from those Montana residents living with HIV.

CHAPTER THREE

Methodology

The purpose of this study was to assess the HIV testing, prevention, and treatment needs of people living in Montana who are infected with HIV. Specifically, information from this study was used to describe the demographic characteristics of people living with HIV; the behaviors that contribute to reinfection and/or transmission of the virus to others; barriers to accessing HIV testing, prevention and/or treatment services; and barriers to maintaining treatment and/or services.

Description of Target Population

The population assessed in this study included people over the age of 18, who are infected with HIV and who currently reside in Montana. CDC defines the human immune deficiency virus (HIV) as a virus that can damage a person's body by destroying specific blood cells ($CD4^+$ T cells), which are crucial to helping the body fight disease (CDC, 2011a). People living with HIV include those diagnosed with any of several retroviruses that infect and destroy helper T cells (CD4) of the immune system, thereby causing a stark reduction in their numbers.

Protection of Human Subjects

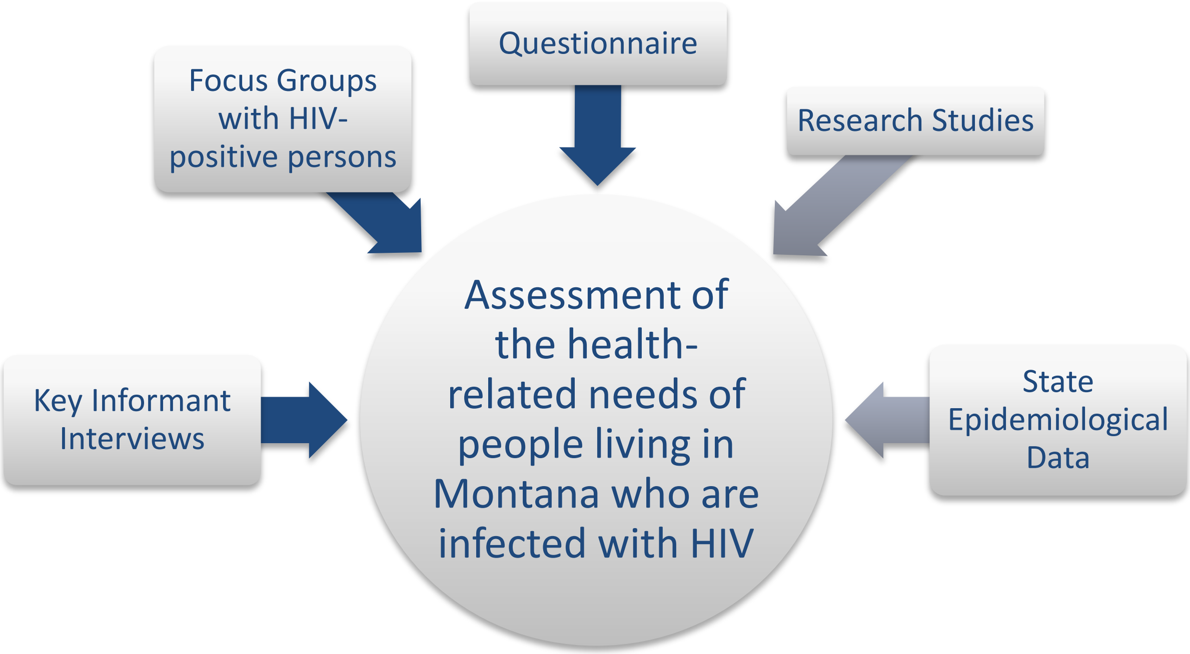
The human subject application material and consent forms were completed in accordance with the University of Montana Institutional Review Board (IRB) (see Appendix A).

Research Design

This research used a case study mixed methods design, combining qualitative and quantitative data. A case study design is ideal when looking at research that evaluates present-day issues surrounding behavior that cannot be manipulated or examined in a controlled setting. Yin (2003) states that when investigating a phenomenon, "the case study method allows investigators to retain the holistic and meaningful characteristics of real-life events" (Yin, 2003, p. 1).

Because of the complexity of studying present-day, real life situations, evidence in a case study design was gathered from multiple sources in order to complement each other (Yin, 2003). The figure below helps to illustrate data triangulation using various collection methods under the case study design for this research:

Figure 3. Data Collection Methods



Procedures

Both primary and secondary data was utilized in this study. The sources of primary data were a questionnaire, available in paper copy or online, key informant interviews, and focus group interviews. The secondary data sources were previous research studies and state epidemiological data related to HIV/AIDS.

Instrumentation, Sample Selection, Data Collection, and Data Analysis

Primary Data Sources

Questionnaire

Instrumentation. The questionnaire for this study, available in paper copy and online, (see Appendix K) was developed based on a review of recent literature, the 2005 Montana HIV-positive needs assessment questionnaire, and other established needs assessment questionnaires used throughout the country. This instrument gathered information that described the demographics of the target population, HIV/AIDS status, behaviors since becoming HIV-positive, assistance and/or prevention and/or treatment service use, and barriers to assistance and/or prevention and/or treatment services. The questionnaire was predominantly formatted with close-ended qutesions, however most questions offered the opportunity to add additional information for a more open-ended collection of information. The questionnaire was reviewed and revised by an expert panel consisting of case managers from the Ryan White Care ACT Program, The University of Montana faculty, and key informants in the HIV-positive community. Following the review and revisions, the questionnaire was pilot tested with five HIV-positive members of Montana's HIV Prevention Community Planning Group (CPG).

Sample selection. The questionnaire was distributed to people living with HIV who are 18 years of age or older and live in Montana. Questionnaire participants were recruited using two different methods. First, Ryan White Title II case managers throughout Montana's five planning regions were asked to offer the questionnaire to clients that were accessing services on their caseload. Case managers from each region were asked to mail the questionnaires to these clients during the six week data collection period. Paper copies of the questionnaires were mailed in packets that included an informed consent, a $10 incentive, a self-addressed stamped envelope, as well as a link to the online version of the questionnaire. Persons receiving the packet could choose to take the questionnaire on-line or complete the paper copy and mail it directly to the researchers in the enclosed envelope.

Second, the snowball technique was used to access people living with HIV who were not currently enrolled in prevention and/or treatment services with a Ryan White case manager for inclusion in the sample. The snowball technique is appropriate in rural states such as Montana because access to high-risk groups can pose a challenge. For this research project, the technique involved asking key informants in the HIV-positive community (i.e. support group facilitators and/or staff at community based organizations (CBO) that offer HIV services) to offer questionnaire packets to individuals living with HIV who were not currently accessing services through a Ryan White case manager.

Data collection. Questionnaire packets were prepared, including a cover letter explaining the purpose and importance of completing the questionnaire (see Appendix K), a consent form (see Appendix I), instructions on how to access the online version of the questionnaire if this was the preferred method, a self-addressed stamped envelope and a questionnaire that was color-coded according to the case manager or key informant who was mailing them out. Researchers described the purpose of the project and the procedures involved in the distribution of the questionnaire packets to case managers and key informants who agreed to assist with the project and packet dissemination.

Each questionnaire participant was given a packet and asked to read the cover letter and consent form. Participants who received a packet in person from their case manager or from a key informant were given the option of completing either the paper or online version in a place that was convenient for them. Participants who received the packet in the mail were also given the option of completing the paper copy or an online version at a time and place that was convenient for them. Participants were asked to only answer questions they felt comfortable responding to. Therefore, it was not necessary for every question to be filled out in order to return it to the researchers.

Volunteers who were recruited for participation via the snowball technique were given the link to an online version of the questionnaire. Upon completion of the questionnaire, participants were prompted to use a hyperlink to access another webpage where they were asked for an address to which the $10 incentive could be mailed. The name and address given by the volunteer were stored in the secure website on SurveyMonkey, to which only the researcher had the passcode and access. The name and address were then recorded on a plain envelope that contained only a $10 bill. Once this information was transferred it was erased from the SurveyMonkey secure site. The envelope was placed in the mail immediately following the reception of the information so no record of the volunteer's name remained. Information obtained from the questionnaire was not associated or linked with any identifying information.

*Data analysis***.** Responses collected from the questionnaire were statistically analyzed using the computer program SPSS 20.0. Questionnaire analysis included descriptive statistics to report the demographics, risk behaviors associated with HIV transmission, perceived barriers to accessing and maintaining linkage to prevention and/or treatment services for HIV among people living with HIV in Montana. Trustworthiness was established though interrater reliability. Two researchers reviewed each transcript and discussed major themes that came out of this data analysis process. Response data was compared to available data from previous studies so as to triangulate the data in order to verify similarities and identify differences. Frequencies were reported by actual count and sample sizes. Tables and graphs were used to illustrate the frequencies and relationships when appropriate.

Focus Groups

Instrumentation. The focus group questions (see Appendix B) for this study were developed based on a review of recent literature and past rural and urban HIV needs assessment focus group questions. The focus group interview schedule included a group of predetermined questions that were aimed at the following issues: quality of life issues, health problems, behavioral risk factors related to health problems, barriers to accessing prevention and/or treatment services and any other thoughts related to the needs of people living with HIV. This interview schedule provided a basic structure for the presentation of the aforementioned topics; however, if other issues that were relevant arose during discussion, those issues were discussed as well. The focus group questions were reviewed and revised by the expert review panel.

Sample selection. Focus group participants consisted of people living with HIV who are 18 years of age or older and live in Montana. Both Ryan White and non-Ryan White clients were invited to be involved in the group interviews. The focus groups were conducted in separate locations throughout the state based on the availability of individuals conducting the focus group and the participants' availability.

Volunteer participants were recruited by case managers and key informants who were known to the researchers. It was possible that focus group volunteers also completed the questionnaire. The information accessed in both is similar, however, the focus groups gathered more detailed information that the questionnaire format did not address. Key informants who were currently facilitating support groups solicited volunteer participants from their groups. Key informants also invited HIV-positive persons who were not currently in a support group to volunteer. Verbal invitations took place during case management/client meetings, during support group meetings or via telephone contact. HIV-positive persons who agreed to participate were informed about the scheduled time and place for the focus group, and were provided with the researchers' and group facilitators' contact information if questions or concerns arose prior to the focus group meeting.

*Data collection***.** Four focus groups consisting of 22 individuals were conducted. HIV-positive persons who are over 18 years of age and expressed an interest in participating were provided with information about the time and location of the group. Upon arriving for the focus group, the participants were given a copy of the informed consent (see Appendix G), and provided with the opportunity to ask questions. Participants were asked to read the informed consent and provide verbal consent rather than written consent. In this way, group participants' names were not connected to the study. Participants were reminded that the names of individuals and information shared within the group were confidential and should not be shared outside the group meeting.

The researcher and research assistant conducted the Missoula County focus group. The other three focus groups in the remaining counties were conducted by gatekeepers of the HIV-positive community. These gatekeepers agreed to conduct focus groups and were then provided a digital recorder, informed consent forms for each participant, focus group questions, a focus group contact summary sheet (see Appendix E), a small stipend for organizing and facilitating the focus group, and incentives for each participant. The focus groups were audio recorded. Following the completion of the focus group, the gatekeepers mailed the digital recorder and focus group contact summary sheet back to the researchers. Participants received a $25 incentive at the beginning of the focus group and were offered snacks and non-alcoholic beverages during the group. Immediately following the focus group the audio files were transcribed. No identifying information was included in the transcription. Immediately following the transcription the files were destroyed. Contact summary sheets were completed after each focus group to help the researcher organize immediate thoughts on the themes and issues, impressions, questions, speculations, and any information to be included in future focus groups.

During the focus group, the researcher solicited information regarding participants' perceptions of their HIV prevention needs and of the needs of other people living with HIV. Specifically, information about risk behaviors, barriers to HIV testing, treatment and prevention services were solicited. This information was elicited using open-ended questions (see Appendix B). Focus groups lasted from 1 to 2 hours.

Key Informant Interviews

Instrumentation. Interview questions for this study were developed based on a review of recent literature and past rural and urban HIV needs assessment interview questions. The interview schedule includes questions that were aimed at the following issues: quality of life issues, health problems, behaviors related to health problems, barriers to accessing prevention and/or treatment services, and any other thoughts related to the needs of people living with HIV (see Appendix B). This interview schedule provided a basic structure for the presentation of the aforementioned topics; however, if other issues that were relevant arose during discussion, those issues were discussed as well. The questions were evaluated and revised by the expert review panel prior to finalizing the interview schedule.

Sample selection. A convenience sample of 10 individuals were recruited to participate in face-to-face, phone, or email interviews regarding HIV prevention needs. The snowball sampling technique was used whereby one or two leaders in the HIV-positive community (referred to as key informants) who were known to the researchers were contacted by phone and asked to volunteer for an interview (see Appendix C).

Following the interview, the key informant was asked to recommend other key informants or professionals who work primarily with people living with HIV who might have been interested in volunteering for an interview. Potential interviewees were contacted by the researcher who explained the study and asked if they were interested in participating in an interview.

*Data collection***.** A private, convenient meeting time and place was arranged with key informants who were interested in volunteering for the study via face-to-face or phone interview. Prior to the interview the key informant was given a verbal description of the study and was asked to read and provide verbal consent (see Appendix D). Key informants who preferred to answer interview questions via email were sent a description of the study, consent form, and the interview questions. Interviews were audio recorded and lasted approximately one-half to two hours. Immediately upon transcription of the interview the files were destroyed. Names of interviewees were not connected to the data. Following the interview, the key informant was asked to recommend other key informants or professionals who work primarily with people living with HIV who might have been interested in volunteering for an interview. Potential interviewees were contacted by the researcher who explained the study and asked if they are interested in participating in an interview.

During the interview, the researcher solicited information regarding the interviewees' perceptions of the HIV prevention needs of people living with HIV with whom they have come in contact. Specifically, information regarding factors that influence HIV risk behaviors and barriers to accessing services were solicited. Following the interview, contact summary sheets were completed to notate general information about the key informant including location and date of interview, age, self-identified sexual orientation and ethnicity (see Appendix E).

*Data analysis***.** Primary data was analyzed qualitatively and took place in a five step process as outlined by Ulin, Robinson, and Tolley (2005). Immediately after each focus group and key informant interview took place, the research assistant reviewed all notes and audio recordings. Each focus group and key informant interview was transcribed in its entirety. After transcription, all audio files were destroyed.

The first step of the qualitative data analysis process was reading, which is described as "developing an intimate relationship with data" (Ulin et al., 2005, p. 145). This is a process that fully immerses the research assistant in the data in order to become well-versed and more familiar with its content. This process took place gradually as each interview and focus group was conducted. Becoming familiar with the data as it was collected allowed the research assistant to identify gaps in the questions or other areas that might have needed improvement. This also allowed the research assistant to begin to identify tentative themes in the data.

The second step in the process described by Ulin et al. (2005) was coding, described as "identifying the emerging themes" (Ulin et al., 2005, p. 146). Once transcriptions were complete they were read through to identify the emerging themes. These potential themes were complied in a list that was collapsed in order to reduce the number of themes and to develop themes that were not detail-specific. The research assistant then used Microsoft Word and printed transcriptions to identify multiple segments of data that were related to specific themes and to identify multiple themes in individual segments.

The third step in the data analysis process as defined by Ulin et al. (2005) was "displaying data" as "distinguishing nuances of a topic" (Ulin et al., 2005, p. 157). This is explained as "laying out or taking an inventory of what you know related to a theme; capturing the variation or richness, of each theme; separating qualitative and quantitative aspects; and noting differences between individuals or among subgroups" (Ulin et al., 2005, p. 157). During this step the research assistant explored the themes and data further and in more depth to identify subthemes that were present but previously overlooked.

The fourth step, data reduction, was described as "getting the big picture" (Ulin et al., 2005, p. 160), or "the process of distilling the information to make visible the most essential concepts and relationships" (Ulin et al., 2005, p. 160). This step took place once all data had been collected and the research assistant had become intimately familiar with the data and recurrent themes and subthemes. The researcher also reviewed themes and subthemes for internal validity, with the hopes of further condensing the themes.

The fifth and final step in the qualitative data analysis process was interpretation. Ulin et al. (2005) describes this step as "the act of identifying and explaining the data's core meaning. . . It is to identify ways that the many different pieces of the research puzzle (emerging themes and subthemes, connections and contradictions) fit and what it all means" (Ulin et al., 2005, p. 162). During this step the primary data collected from the key informant interviews and focus groups was analyzed and the secondary data was used to support, fill in gaps, and further explain results.

Secondary Data Sources

Literature Review

A comprehensive review of recent literature was conducted to identify the behaviors that contribute to HIV reinfection and/or transmission of the virus to others; barriers to accessing HIV testing, prevention and/or treatment services; and barriers to maintaining treatment and/or services. Current literature demonstrates that factors such as the effects of negative stigma, mental health concerns, employment, other health related issues aside from HIV, and lack of effective social support systems are some of the barriers seen in other HIV-positive populations.

Epidemiological Data

State epidemiologic data specific to people living with HIV was examined by the researchers. The state epidemiologist worked with the researchers to determine what segments of the population (e.g., age, sex, ethnic group, race) were infected with HIV. Furthermore, epidemiologic data also provided information about changes or variations in the incidence and prevalence over time and in different geographic locations, and helped establish associations between HIV and a variety of known risk factors.

CHAPTER FOUR

Results

The purpose of this study was to assess the HIV testing, prevention, and treatment needs of people living in Montana who are infected with HIV. The needs assessment included primary and secondary data sources. The results of this assessment are discussed below, beginning with the primary data, consisting of key informant interviews, focus group interviews, and Montana 2012 HIV-positive questionnaire.

Key Informant Interviews

From November 2011 to February 2012, eight phone interviews and two email interviews with key informants helped to inform the needs assessment. Individuals involved in the interviews included Ryan White case managers, members of the Montana HIV Prevention Community Planning Group (CPG), community based organization (CBO) staff members, community health clinic staff members, mental health professionals, outreach workers, and other leaders in the HIV-positive community. These individuals were from the following counties: Missoula, Gallatin, Hill, Yellowstone, Lewis and Clark, and Flathead, representing a wide range of communities in the state.

The key informant interviews ranged in duration from thirty minutes to slightly over one hour. Interviewees ranged from young outreach workers to experienced leaders in the HIV-positive community. Six of the interviews were conducted face-to-face, two were conducted over the phone, and two were completed via email. All of the interviews were conducted by the research assistant. Because themes from the key informant interviews were analyzed in conjunction with the focus group interview themes, they will be discussed following the description of the focus group interviews.

Focus Group Interviews

Focus groups were conducted in Missoula County, Gallatin County, Yellowstone County, and Silver Bow County.

Table 2. Focus Group Interview Counties & Participants

Missoula County Focus Group: 4 participants	**Gallatin County Focus Group:** 5 participants
Yellowstone County Focus Group: 6 participants	**Silver Bow County Focus Group:** 7 participants

A total of 22 people living with HIV were involved in the focus groups. One was a self-identified heterosexual woman and the remaining 21 self-identified as gay men. Participants were between 25 and 58 years old, two self-identified as Hispanic and 20 self-identified as White. The participants were residents of the counties in which the focus group took place – Missoula, Gallatin, Yellowstone, and Silver Bow, with one participant residing in Custer County. The focus group interviews ranged in duration from slightly over a half an hour to two hours in length.

Themes

A number of themes related to the needs of people living with HIV in Montana were identified in the key informant and focus group interviews. There were six main categories with themes for each. Categories and themes were identified through qualitative data analysis using the five step process set forth by Ulin et al. (2005). These steps were used to best decrease researcher bias during the analysis and identification of key categories and themes. These categories and themes were initially identified by the research assistant and validated by the researcher. The six categories were organized as follows: 1) Quality of Life Issues; 2) Health Problems; 3) Risky Behaviors;

4) Successful Assistance/Prevention/Treatment Services/Experiences; 5) Assistance/Prevention/Treatment Needs, and 6) Barriers to Accessing Assistance/Prevention/Treatment Services. Each theme includes quotes from either the key informant or focus group interviews; quotes provided offer the best representation of the theme. Quotes from key informant interviews are denoted as “KI” and quotes from the focus group interviews are denoted as “FG” to best differentiate between the two. During transcription, if an interviewee used unnecessary words such as “like”, “um”, “you know” or other words that affected the flow and context of the quote, they were removed to enhance reading ease.

Category 1: Quality of Life Issues

Theme 1: Stigma/Discrimination/Fear

Every key informant and focus group interview identified stigma, discrimination, and fear as major contributors to the detriment of quality of life for people living with HIV in Montana. These issues were perceived to effect relationships, employment, accessing services, and overall health and well-being.

> *“So I think there’s a dilemma for people in this region where if they want to live out with their HIV in an open way, it’ll have sometimes really high consequences for their social and vocational worlds.” –KI*
>
> *“I think in some ways even though we’re an open-minded place in a very conservative zone, sometimes there’s a real fear that there’ll be kind of dramatic forms of backlash and, you know, even violence or risk-to-life that happen occasionally and so I think it creates an environment of fear even though there’s sort of a quality of openness in the local community, I think it creates tension for people, being able to resolve those two.” –KI*

Theme 2: Loss of Personal Relationships/Isolation

The lack of or collapse of personal relationships affects overall quality of life. Because people who are not HIV-positive often are ignorant or misinformed about HIV, out of fear, they tend to avoid family and friends who have become infected.

> *"I get shunned, I get shunned from family get-togethers, birthdays, anniversaries, nobody comes to visit me." –FG*

> *"I had rejection from a number of family members just out and out, I mean it's better now, but it was just out and out and when I was going to see my dear cousins, she had just given delivery to twin boys. My cousin-in-law called crying saying that they had to disinvite me because her pediatrician had told her that I, would not allow me in the home, would not allow my presence in the home and you think that people wouldn't be thinking that way, but they do." –FG*

> *"I think the majority of us with HIV go to just not having sex at all… Not that we don't want to have sex, it's just not something that people are easy about doing with us. It's very difficult." –FG*

The effects of isolation not only effect personal relationships, but also the ability to access services. This affects overall health and well-being as well as the emotional and social support that might otherwise be available for people living with HIV in Montana.

> *"To go along with stigma, I'll also add isolation. Isolation is a huge problem for people with HIV." –FG*

> *"I have to second the isolation because I wasn't sure if that was me or if it was really something that everybody did and I am terrible at it. This is actually the 4th time in two months that I have been out of my house. Isolation is huge for me." –FG*

> *"So many clients do not have any other person in their life that they feel they can talk openly to, except their case manager." –KI*

Theme 3: The Impact of HIV as a Chronic Rather Than Acute Illness

In the beginning of the HIV/AIDS epidemic, multiple services were offered to make dying more comfortable for those persons who were infected with HIV. Now that people are in need of more long-term services, shifts have occurred in the allocation of funding, the availability of services, and the knowledge of the disease as it has progressed from acute to chronic status.

> *"There was a time when we had state money to help people with rent and security deposits and my God there were times we helped people with pet food because they were their companion and they were ill and we could do short-term homecare services and utility bills and so there's this whole culture of support around the positive person that's gone away. You could argue that it's time for it to go away, but it doesn't mean that it's not a huge culture shock to the positive person. Many people said to me that the hardest thing that happened to them, around '91, '92, is that they didn't die. They had made a lot of decisions, to sell life insurance, to go through their savings, stop going to school, with the sense being they were going to be on disability forever." –KI*
>
> *"I don't believe that our housing program was designed to sustain people for a lifetime... It was designed to stabilize people who had a shortened life expectancy when it was originally designed." –KI*
>
> *"One thing I would say is that people living with HIV in Montana aren't being treated as people with chronic illness and a lot of things that accompany chronic illness like depression and fatigue and simple quality of life." –FG*
>
> *"There was a time when I had a drawer filled with gas cards and everybody that came got a gas card and that money went away." –KI*

Theme 4: Poverty

Living with HIV not only poses social and professional barriers, but also poses financial stress. This was noted to be due to an inability to hold employment because of health status, an inability to maintain a house due to the exhaustion of keeping it up while dealing with the disease, and the cost of all the medication and other medical treatment associated with HIV care. Financial stress was also seen in the sheer presence of poverty. Living in poverty can create issues with accessing HIV-related services and care.

> *"Housing and healthcare's paid for, but what about all the other stuff. What about just being normal? What about not having to constantly worry about having no money?" –KI*
>
> *"Many of the clients are unemployed and living in poverty." –KI*
>
> *"Anyone living in extreme poverty is probably not caring for themselves the way that you would really hope they would be." –KI*
>
> *"I think it could also be a result of living on the edge of extreme poverty for so long, that economic stress, I think, takes a huge toll on people." –KI*
>
> *"So many of our clients along with their diagnosis, they face poverty which really limits their ability to get the medications they need, to get the resources they need, transportation, so many other things come out of that poverty issue." –KI*

Category 2: Health Problems

Theme 1: Mental Health

Mental health is a health problem that came up multiple times in both key informant and focus groups interviews. The most prevalent mental health disorder mentioned was depression, but seasonal affective disorder, bipolar disorder, and anxiety were also mentioned. Although infection with HIV can contribute to depressive symptoms, it was also mentioned that depression prior to infection could have predisposed individuals to participate in risky behaviors that exposed them to the virus in the first place.

> *"My problem was not just stigma because I had my own sense of, well I don't want to deal with this and I don't want people to know about it, but it was just that I move in a world of depression so in a way I don't see things sometimes as clearly as other people do." –FG*

> *"The depression one is a big one because when you are first diagnosed you have depression along with probably 100 other things that weren't quite right in your life; none of us were probably doing the healthy and positive things." –FG*

> *"Mental health in a way, or emotional, I think, at least for me that's one, I mean depression has always been a part of my life and it's so, it's not because I'm HIV positive, it's one complicated thing or the other." –FG*

> *"As far as depression goes, we have a double-edge sword because most of our population are MSM and gay men on the whole, gay-bi men are four times more likely to be depressed than the general population." –KI*

Theme 2: Drug Side-Effects

One of the most prevalent health problems noted by key informants and people living with HIV in Montana is the side-effects associated with taking drugs as part of an HIV treatment regimen. These side-effects seem to amplify some of the aforementioned mental health concerns, which in turn can lead to problems with personal relationships and other quality of life issues. Some people even mentioned discontinuing or deregulating their HIV treatment drug regimen in order to cope with the side effects.

> *"I spent the last 3 years trying to straighten-out my anxiety and depression and it's just now gotten to the point where I feel like a normal person and I totally agree with <FG participant> that I believe it's been because of the meds that I've been taking for the last 28 years and trying to deal with the isolation." –FG*

> *"I'm convinced that the meds are causing my depression." –FG*

> *"It would be the mental health, and I think it's some of the long-term effects of these meds on your brain, because I've noticed an amplification of my anxiety." –FG*

> *"On the medications there's also this metabolic syndrome that people suffer from and it's part of that thing of people having fat distribution in different places, like lipoatrophy in their limbs and lipodystrophy in their bellies and, we do see higher lipid numbers in people who are on medications." –KI*

Category 3: Risky Behaviors

Theme 1: Substance Use

Use and abuse of drugs and alcohol was mentioned in every interview, showcasing the relationship between substance use and mechanisms used to cope with stigma, fear of disclosure, denial, mental health concerns, and drug side-effects. The outcome of substance use varied, but an overall sense of lack of judgment and the inability to make smart decisions about sex related to HIV transmission was discussed.

> *"It's because it's huge, it's just absolutely huge, crystal meth, especially with gay men, absolutely ridiculous. And it doesn't even matter, young to seventy years old, for the sexual heightening it's just amazing." –FG*
>
> *"A lot of our positive patients smoke and drink alcohol and do all sorts of things to cope with the trauma of being stigmatized in this society." –KI*

Theme 2: Unprotected Sex

Most of the focus group participants noted that once someone knows their HIV-positive status, they are more likely to take necessary precautions to decrease their risk for transmission or reinfection. Unsafe or unprotected sex still occurs, however, often in conjunction with the use of substances, the presence of mental health concerns, and the overall feeling of stigmatization and discrimination within the HIV-positive population. It was also identified that this risky behavior is prevalent for persons who do not know their current HIV status.

> *"Nonetheless, safe sex is still not practiced enough within our own community and within any community. With HIV positive people especially." –FG*
>
> *"I think when you talk to people about unprotected sex there's a sense of, this is my liberty and I fought for this sexual freedom and you don't need to control me*

> *and my partner doesn't care that I have HIV, but I think whenever you have that behavior you potentially introduce other co-infections." –KI*

> *"The reality is fucking is fun. And people do it. And sex is fun. If it didn't feel good, we wouldn't do it and we have to get to that point of recognizing the excitement of it all and we have to get to the point of recognizing that we sometimes make really stupid decisions when we're sexually excited." –KI*

The use of drugs such as Viagra and Cialis to address erectile dysfunction was also noted to be prevalent among the aging HIV-positive population. Although this was identified as a positive contribution to their personal relationships, it was also identified that the use of these drugs could lead to prolonged sexual activity that is not always protected or safe. This puts HIV-positive people at risk for HIV co-infection as well as at risk for transmission of STDs.

> *"People then are more sexually active [when taking drugs like Viagra or Cialis] so they are putting themselves at risk for sexually transmitted diseases, which then they in turn, if they're not treated for those infections, can then go on and pass them on and infect other people."-KI*

> *"You're putting yourself more at risk by having those extended periods of sexual activity or now that you can have sex with three or four different guys in one weekend. That might not be the case if you didn't have a drug like Viagra or Cialis." –KI*

Category 4: Successful Assistance/Prevention/Treatment Services/Experiences

Theme 1: Importance of Case Managers

Many participants expressed their appreciation for the assistance, prevention, and treatment services that are currently provided for people living with HIV in Montana. Although barriers do exist that hinder access for some services, case managers were commended for their hard work and continued diligence in offering services that meet the needs of people living with HIV.

> *"We really have a good relationship with <local clinic>, so if somebody tests positive here they go there for the confirmation test and that's where they get access and they meet the case manager and it is positive and they get enrolled into care right away." –KI*

> *"So for me what helped was actually having that one doctor who made a statement to me that stuck in my head even though I didn't want to listen to it and having <local case manager> sorta put me back on earth, you know you need help." –FG*

> *"I think that there's this sense with case managers at <local clinic>, that people are listened to and they seem to have a positive connection with their case managers. And I think that there's an openness to feel tension or difficulty, people seem like they can go back to their providers when there's problems or questions and they can feel heard, that's really good. That's really great, I think there's just a real strong willingness in this community to meet peoples' needs, like within the social service and mental health and medical community, I think when people come up positive there's a desire to move towards and be open, which I think is valuable." –KI*

> *"Some of us are fortunate enough to have a case manager who does keep up on her patients." –FG*

> *"I feel I am fortunate to have a case worker who does care and who does ask those questions." –FG*

Theme 2: Importance of Health Care Providers

Appreciation was expressed for the relationships created and fostered with doctors, nurses, physician assistants (PA), and other health care providers. The quality of the relationship between the health care providers and the person living with HIV was integral to maintaining access to services.

> *"I've had really good services with the doctors, they all take lots of time with you and any questions that you have they want to give you answers, so at least I want to say that the services I've had here are really good." –FG*

> *"Sometimes I think that my best healthcare provider was not a doctor my best healthcare provider were physician assistants and licensed practical nurses because they took the time they understood my knowledge and my health and my own body in a way that we have some doctor culture that is hard to get through." –FG*
>
> *"We talk to the nurses at <local clinic> almost daily on how they can better service the needs of the clients that come here or go to them." –KI*
>
> *"I think too that we see more and more doctors and physicians, at <local clinic>, you don't find any discrimination there. I've never felt it. Nobody who's ever been over there has felt it." –FG*

Theme 3: The Multiple Benefits of HIV-Positive Retreats

One of the best opportunities for people living with HIV in Montana to learn skills that empower them to deal with their HIV-positive status was identified as the retreats that are offered by different organizations across the state. For men and women alike the retreats create a sense of community, especially for those persons who feel isolated and discriminated against due to their HIV-positive status.

> *"I have my one female, one year she went to the women's retreat and it was the first time she'd ever gone, and I asked her about it afterward and she said that she didn't feel so alone, she is not the only one." –KI*
>
> *"The good thing about treatment and prevention services that we've received is the fall retreat up at <Montana retreat location>. Not only does it help with the treatment and prevention, but also helps us with our isolation and all that." –FG*
>
> *"We are seeing a lot more young people that are HIV positive coming to the retreats and that's good and heartbreaking at the same time." –KI*

Participants that attended the retreats reported feeling empowered by their exposure to national experts, alternative knowledge about treatment options, and hearing from other HIV-positive individuals about their struggles and accomplishments.

> *"We're really fortunate in our retreats that we tend to bring in national experts on treatment issues and so because I've always really felt that that's really, HIV positive individuals really want to make sure that they have the most up to date education on treatment because we know that single-handedly has made the biggest difference in quality of life issues, for people are the new treatments." –KI*
>
> *"I learned more about my meds and how they interact and stuff like that. He just brought up things I never even thought to ask about." –FG*
>
> *"I know that every time I ever have a retreat with a group of people that I'm working with I leave it feeling repurposed and reenergized and appreciated." –KI*
>
> *"The information is just great. This year was my first one and all the information I took was excellent. I learned more about my meds from one guy." –FG*

Category 5: Assistance/Prevention/Treatment Needs

Theme 1: Heighten Awareness of the Existence of HIV in Montana

This need was found to be associated with almost every quality of life issue, health problem, and risky behavior. Key informants and focus group participants identified the need for comprehensive HIV education for the general public as well as people at risk for HIV. Because HIV infection has come to be seen as a chronic illness due to advances in treatment and care over the last twenty years, public awareness of the disease has dramatically declined. People living with HIV in Montana desire to have more visibility without the fear of stigma or discrimination.

> *"It's still a contagious disease and it's transmitted, it's even more important to have the visibility and awareness especially in university towns." –FG*
>
> *"I think in places like Montana and smaller populated states it's even more important to have that visibility because it's going to keep creeping. That's all there is to it." –FG*
>
> *"To keep it out there and aware, it helps the young people, it helps the people who don't know much about the disease, especially those in a rural area like Montana." –FG*

> *"I do think that visibility will diminish stigma. The more familiar with something the less frightening something is." –FG*

An important vehicle for increasing awareness of HIV and sexuality issues in general is the implementation of comprehensive sex education. A more open and comprehensive approach to sex education in public and private schools, as well as in the home and with peers, was identified as being just as important if not more so than HIV education. Many participants believed that a lack of this type of honest and open education has led to an inability to discuss sexual issues and/or concerns beginning at a young age.

> *"I just want to solve it all by making comprehensive sex ed mandatory from a young age and letting that be our guide, knowing and trusting that once people have this comprehensive sex ed and aren't stigmatized by their bodies or their sexuality or it might be their curiosity, it wouldn't be so hard for folks to access those services." –KI*
>
> *"I think we have to talk about it, we just have to keep talking about it, the soundbyte has to stay in the consciousness of the public all the time. And we have to keep moving, I can't say that sticking a message out for a month and then going away for eleven months is very effective. I think we have to have a very consistent constant message that HIV is treatable, it's preventable, and in fact it's more preventable if people are on treatment. There are so many misconceptions and people, they are very ignorant about certain aspects of the disease, which we need to start treating it as a disease and not a moral issue. Because the moral issue is what's getting us into trouble, people don't wanna talk about sex. And that's too bad because almost everybody I've ever heard of has it, or the potential for it, we need to talk about it more." –KI*
>
> *"I think it's so important that safe sex be an educational topic for the younger people who are engaging in sex and for the LBGT community, or for any community for that matter, because you just don't know, it only takes once." –FG*

Theme 2: Knowing How to Navigate HIV Services

Although most of the focus group participants were linked into Ryan White case management care, increased knowledge and skills related to navigating HIV-related services was identified as an assistance, prevention, and treatment service need. Mental health concerns, such as depression, were identified as barriers to gaining the knowledge necessary to navigate the complex system and services that provide assistance and care for people living with HIV.

> *"That's where it kind of becomes important to have a good case manager that can actually help a person get through those systems because they're not necessarily easy to navigate if you're not familiar with them." –KI*
>
> *"Other than that word of mouth, I think is huge, and in most situations in poor communities, I would say, or uninsured communities, your folks understand how to survive and they share that information." –KI*
>
> *"Treatment services, I mean like getting some of the lab work done or assistance with dental or helping guide them through the services especially someone who is recently diagnosed." –KI*

In relation to an increased visibility of services available for people living with HIV in Montana, focus group participants identified the need for more advertisement of HIV-related functions with flyers, monthly newsletters, and banners. These forms of marketing were thought to be positive for participation rates and also for increasing the normalization of the disease in communities in Montana.

> *"Getting out the word that if a positive comes up, the person who is with you to give you those results needs to have better information of exactly who to see then." –FG*
>
> *"I would say flyers would be better. And not ones you have to go pick up, ones that would be sent." –FG*
>
> *"Getting more information out, like monthly newsletters." –FG*

Theme 3: Empower People Living with HIV to Advocate for Themselves

The need for empowerment and personal advocacy were identified in key informant and focus groups interview. People living with HIV in Montana voiced their desire to education themselves and to be advocates for themselves in regard to their HIV related needs. They express a desire to take more responsibility for their well-being and ultimately gain more control of their assistance, prevention, and treatment services through increased knowledge and greater visibility.

> *"I'm just saying that I think as clients, we need to be diligent, we need to be our own advocates and we need to know that the physician is our employee, whether they're bring paid from our donations that went into disability, they're being paid, we're paying them" –FG*
>
> *"We still need to remain vigilant. And we are the experts, we know what's going on with our bodies, we feel them. Be proactive." –FG*
>
> *"As well as like the client community involvement. It's up to us, we can't just stand by and expect to be taken care of, but it's hard, that's a big challenge, I'm sure for being noticed, and this is probably the biggest that I have been to, as far as involvement, since I have been here, and people have spread out in this state and that makes it really hard I'm sure." –FG*
>
> *"As far as the needs I think that we're coming to a point where I believe that we're gonna need more people with HIV to actually stand up and speak up for what their needs are and what they need to have happen." –KI*
>
> *"Definitely working on the mental health and empowerment of the individual cause I think people who feel good about themselves make better decisions for themselves and are willing to set those boundaries." –KI*
>
> *"I think it is our duty to start helping our clients look towards health sufficiency." –KI*
>
> *"I'm a big proponent and have been for the last thirty years of telling people educate yourselves, don't rely on the doctor to do that for you because they're busy, they don't have the time, so it's up to you to, this is your life, you educate yourself and make sure that you don't just take what they say as, okay, the voice of God." –KI*

Theme 4: Provide Peer Advocates who can Assist in Overcoming Barriers to Accessing Services

People living with HIV in Montana also identified the need for advocates to help them counter barriers that exist when accessing assistance, prevention, and treatment services. These advocates could be other people living with HIV in Montana or volunteers willing to aid in the navigation of the system when someone is in need of assistance to take that first step toward services.

> *"What about advocates for people… What if I'm really ill and I don't feel like my doctor is hearing me, what about a person who is available to call them up and say I need you to go to the doctor with me, this person is just not hearing me, you know?" –FG*
>
> *"It's how can we pass on as individuals a prevention message. I mean who better to pass on a prevention message than someone who is already positive, I mean you don't get any better." –FG*
>
> *"I would like to see HIV positive people given the tools to help advocate for HIV positive folks." –KI*
>
> *"Well you kinda are in shock for weeks maybe months and just having somebody again just take your hand and say its going to be ok here's what you need to do next and here's what you need to do next cause it's a shitload of things to do there is a lot to pay attention to, and even in the right frame of mind it's a lot to pay attention to and in a state of shock." –FG*

Theme 5: Improve Physicians Expertise in Treating People with HIV

Having more competent, knowledgeable, holistic HIV health care providers was identified as one of the greatest needs to enhance assistance, prevention, and treatment services for people living with HIV in Montana. This was mentioned in every focus group and by some of the key informants.

"I just would love to have a mobile medical unit where we could go into communities; I don't even know if it would be effective. But I think the fact that people in the outlying areas are so dependent on trying to get somewhere else rather than having some way to bring that environment to them." –KI

"To have a doctor or a nurse practitioner or a PA be the state HIV medical specialist and they would handle calls or questions from other doctors in the state, or they would handle calls or questions from patients. Or just general HIV medical questions from maybe pharmacists or something like that, like somebody who could be on call for that purpose, that express purpose." –KI

"There are a lot of great big heavy docs not in this state and maybe we need to see what it would take to get them here, not to talk to us, but to talk to our doctors and put together a comprehensive, if the state wants to spend some money then go and get a couple doctors to update a form yearly that this is the latest and greatest thing that every doctor should be doing, give it out to every person who has HIV to give it to their doctor." –FG

"Even if there was a mobile health provider that could drive around and get everybody up to date on their appointments, or their meds or whatever it was that they needed, their check-ups and stuff, that would be cool." –KI

"I would've just loved to have seen an HIV care specialist who is a circuit rider who went and had a clinic once a week in every town, like in five major towns in Montana, and that's what they did." –KI

"Having good education for healthcare providers about the issue and having it mandatory, because I know sometimes they have options to do or not do some of these workshops, and most of them choose not to because they're busy, and I understand that, but it's something that's really important." –KI

"I think we're doing the best we can in terms of provision in medical care, but I think it does seem like there's been a loss in terms of turning the HIV treatment into sort of this clinic model, cause I noticed back in the mid-90's people tended to have a much more profound relationship with their physician, and it seems like now many people like their physicians, but there's this sort of random quality, they might have a doctor for ten or eleven months and then it shifts to another one, there's just lots of changes with the way the medical care's provided. So I think that's had some negative impact on people." –KI

"More relevant training for the physicians, more access to better case management, just continuing to improve it, that would be great." –KI

"More physicians that are aware of HIV and able to work with them, the secondary infections and different things." –KI

> *"Really knowing a physician that knows the different medications and a pharmacist that knows the medications and basically it's just a matter of, okay, what do you want to have to deal with, do you want to deal with fatigue, do you wanna deal with diarrhea." –KI*

Theme 6: Addressing Mental and Emotional as well as Physical Needs

The need for more comprehensive and holistic treatment of HIV and its effects was identified in every key informant and focus group interview. Without addressing the mental and emotional needs in conjunction with physical needs, the likelihood of improved quality of life while living with HIV is slight.

> *"I think that people kind of get their mental health needs met on a sort of individual basis, where there's a need for that, but I'm talking about more of an integration of mental health and prevention efforts and also treatment would be great." –KI*
>
> *"So really being aware of the emotional component that's impacting all the different stages in different ways." –KI*
>
> *"Being able to get treatment for those in a holistic way, you know, like that whole complex of things." –KI*
>
> *"I think just removing the anxiety for people when they're addressing issues with their medication and with the pharmacy, I think sometimes that's very stressful." –KI*

Category 6: Barriers to Accessing Assistance/Prevention/Treatment Services

Theme 1: Lack of Transportation

Transportation to and from assistance, prevention, and treatment services was identified as a barrier to accessing these services.

> *"I had to drive 150 miles one morning for an appointment, the doctor was late, and then she kicked me out in about ten minutes time." –FG*

> *"I have two clients enrolled and both of them probably live, I'd say probably 100 miles from me." –KI*
>
> *"Many live in rural areas that do not have access to providers and transportation is expensive to get to the nearest community with HIV care." –KI*
>
> *"In a rural state like Montana transportation is a big issue for a lot of our clients, even our clients who live in town." –KI*
>
> *"I think transportation is huge… I think when the whole price of gas thing went up, we saw people across the board just not come for appointments, or come for the medical appointment but not come for the mental health appointment, so I think that co-occurring thing around the cost of mental health and adding into that the possibility that you need it weekly, you have to drive from <Montana city>." –KI*

Theme 2: Fear of a Lack of Confidentiality/Anonymity and Stigma

Fear surrounding the lack of confidentiality, loss of anonymity, and stigma when accessing assistance, prevention, and treatment services was identified by key informant and focus group interviewees as a negative influence to seeking or maintaining a link to services. Some of the fears identified focused on the lack of confidentiality in small communities in Montana, decreasing the likelihood of anonymity and increasing the risk for discrimination in rural communities.

> *"I always feel that I'm walking to the doctor's office, they've got the camera, I sign my name, okay it's recorded somewhere, ya know? So I mean it's kind of a joke on some of the confidentiality." –FG*
>
> *"Even if we don't tell anybody, the whole world finds out anyway." –FG*
>
> *"Stigma. Walking into the office, making that call, asking the questions, revealing whatever needs to be revealed about behavior or experience or exposures." –FG*
>
> *"The stigma comes up again, where people, it's just hard to call a doctor to get a mammogram much less an HIV test. It's just hard to do." –FG*

> *"You have times that people are concerned about confidentially because it's such a small town and they're afraid they'll know people if they go to the clinic or that sort of thing." –KI*

> *"Another one would be how am I going to access this care, what can folks really do, are people going to know, are they going to find out, is someone I know going to be working there, or confidentially, scares folks." –KI*

> *"I think people know [about the CAB meetings] but I think it's another issues of anonymity, I think it's pretty challenging to show up in a room and see people in the community that you didn't know were positive are positive and deal with all that." –KI*

Theme 3: Lack of Experienced and Knowledgeable Health Care Providers

Every focus group and a few key informant interviews identified the lack of experienced and knowledgeable health care providers as a barrier to accessing assistance, prevention, or treatment services. People living with HIV in Montana still feel a burden to educate their physicians about the medical issues they are having that are either related to or not related to their HIV status.

> *"The local care providers either don't know enough about HIV to do it or just don't even want to deal." –KI*

> *"I don't feel like I'm not being listened to, just not quite current and up-to-date about stuff, he's got to refer to someone else when I only go in once every four months. So, it may be four months before I've got some little problem, it'll be four months before I find anything out about it." –FG*

> *"They want to treat the HIV virus and nothing else. Nothing that comes along with it, nothing that is caused by it, nothing that could be contributing to it, we are going to give you a pill to treat the virus now go away." –FG*

> *"Lack of medical knowledge and I'm not talking just in care of the HIV, but our everyday healthcare in which the people don't have a clue about anything to do with HIV. So, you get a cold and they flip out about the HIV or you go to a dentist and they don't know anything about HIV and every single aspect of medical care, there's a lack of medical knowledge." –FG*

> *"They might be frustrated with the level of care here when it comes to more complex issues, they might feel like, God, if I was in LA or Seattle and this guy was looking out for me, medically, they would have caught that, when a provider here, it might be a more generalized response." –KI*

Theme 4: Struggle to Pay for Medical Treatment

The cost associated with treatment services was identified as a barrier in terms of accessing services. The cost of HIV-related treatment services, including medication for accessory health problems, leaves people living with HIV in Montana in a financial struggle when trying to meet all their other financial responsibilities.

> *"I'm far more anxious then I used to be and then the cost of those anxiety meds, $230 a month for just a month's supply of anxiety pills." –FG*
>
> *"This is the last month I'm being covered. So at the end of this month, we're gonna have to try to, and they already told me I don't qualify for ADAP because I'm working, that I don't qualify for some other program because I make too much money, I make $950/month, I don't really see how that's too much money. My medication is twice that." –FG*
>
> *"I would say all of our folks are either on Medicaid or are receiving care through Ryan White, meds through ADAP, the traditional medical care is being taken care of. Anything outside of that, though, there's no funding for. So I think that means that anything not HIV-related is not covered unless they have Medicaid." –KI*
>
> *"Well I know for me I quit using services because I got into a financial place in my life where I didn't need to use state money or other people's money to take care of myself but I tell you what when you have to go back into it, it sure is a pain in the ass." –FG*
>
> *"I don't get travel anymore and I didn't get a raise and I don't know what happened there but they all of a sudden decided I make too much money to get paid travel anymore and my copay for a specialist visit is $50 and I have to drive 225 miles one way to get there and then my copay for an office visit is $20 but I have to drive 60 miles one way, to get there 70, and between the copays and the mileage and everything all of it together it mounts up." –FG*

Theme 5: Uncertainty about how to pay for HIV Medications

HIV-positive individuals reported a sense of fear and uncertainty about where continued funding for their medication would come from. Key informants felt like the push toward treatment is vitally important for the overall health of people living with HIV in Montana and should continue, however without the funding to sufficiently support all the people seeking these services, access will continue to decrease.

> *"They [CDC] want 100% of people that know that they're HIV positive to access care. Which is great, again, but it does no good when you're not putting the dollars there to have those services and pay for those services. You can talk about getting people in treatment all you want but if all you're gonna be able to tell them is, well great, now we have your name and we can do some blood work but we really can't give you the medications because there's this waiting list and you're 27th on the list, so in the meantime let's go through the drug company and we'll see if we can get you the drug that way, which most of the drug companies will provide a drug for a year, but then there's no guarantee that after a year that you still won't be on that waiting list." –KI*
>
> *"I would still like to have a little bit of information, more information from my case worker. I have no idea where I'm getting my next months' worth of medication from at this point." –FG*
>
> *"We always have more people needing medication assistance than we have ADAP spots." –KI*
>
> *"We just don't have enough resources to cover everybody. So even though there are resources available, there's not enough for all the clients to get what they need." –KI*

Funding constraints continue to impose upon the overall effectiveness of treatment that is secondary to HIV-specific needs. This diminishes the time case managers have available to viably work with the clients on their caseloads.

> *"Then we have to be putting more and more money into the treatment side and we have to then cut on case management, we have to cut on dental care, we have to cut on all these other health services because more and more money is going to the drugs, which tend to be, are still very, very, very expensive." –KI*

> *“I have 22 individuals in our community who are signed up to receive Ryan White case management with me. I am "budgeted" to provide 2 hours per week for all of these clients. This is very difficult, as most clients tend to have extremely complicated lives.” –KI*

> *“I know <local case manager> in <Montana city> has two hours a week to work for HIV. Two hours, and she’s the HIV client person. And she works more than that, she stays late, she does stuff, and I know that that’s all the financing they have. Two hours a week, not two hours a day, it’s really low.” –KI*

Theme 6: Inconvenient Times and Location of Services/Events

Another barrier to accessing assistance, prevention, and treatment services was identified as the scheduled time and place of services and/or events. Most organized events interfered with work schedules or were not accessible due to a lack of transportation due to location.

> *“We have to send people a long ways sometimes to see their HIV doctor. And in that way it’s sort of divorced from their medical care.” –KI*

> *“Well, any of the meetings [social] they might have are during the day. So for anyone who works and has a job, you miss them.” –FG*

> *“When you’re a professional, you can’t just take off that amount of time and then leave your office closed and expect them to cover that, so some of the mental health stuff that I think does exist, isn’t accessible.” –FG*

> *“We advertise for retreats but a lot of people can’t get to it so it doesn’t do that much good.” –KI*

> *“All functions here are through the <local CBO> and they’re all in the afternoon. I go to work at 2 and I don’t get off until 2 o’clock in the morning, they’re not on weekends, so unless I want to get up at 6am to get there at 9am, that’s about the only time I can see them.” –FG*

> *“Extending the hours, doing some of the functions on weekends, would be nice. All the group meeting and stuff are all Monday-Friday.” –FG*

> *“There has to be, there was so much in the Portland area, every week they had meetings and they were after 6-7pm, so there was just so much to partake in that*

> *if you wanted to you could. Here, there is nothing, it's during the week and I honestly don't choose to do that. Because when I have my day off, it's a Monday or a Thursday, I'm not going down there, I'm just not, cause here's what's exciting about it, there will be two people, cause I've been to those meetings and it's me and somebody else and <local case manager>, I love her but that doesn't do me good. Bigger cities have bigger opportunities than smaller cities." –FG*

Theme 7: Distrust/Dislike of Health Care Providers/Organizations

The lack of positive relationships with health care providers and organizations providing HIV-related services was identified as a barrier to accessing or continuing to seek assistance, prevention, or treatment services.

> *"Here I was, I spent two hours' time on the road and she kicked me out without listening to me and I've found that with doctors around here a lot, especially around here with modern health care is that they are pushed so, to get so many patients through in a day that healthcare, all healthcare is suffering from it, not just HIV. I think for us, again, when you have to wait several weeks for an appointment and they don't listen to you, I think it's a really bad thing." –FG*
>
> *"Probably one of the reasons [people with HIV in Montana discontinue services] would be because they received bad service or they felt that they were judged by the provider, which I do know that does happen, whether it's intentional or not, probably most of the time it's not intentional." –KI*
>
> *"There's big issues around traditional healers maybe having a different opinion about treatment and some suspicion around what I would call more conventional medication and so I think that's a thing – does the environment make you feel at home in whatever is unique to your experience." –KI*
>
> *"I think relationships are a big part of it [continuing or disconnecting from services]. That for whatever reason sometimes the client feels that relationship has been damaged and they don't trust the person as much anymore, that sort of thing, whether it's legitimate or not, they have that perception." –KI*

Focus group participants also identified the need for options outside of the state-funded health care providers and the opportunity of choice when beginning a relationship with a health care provider.

> *"A long time ago I went and talked with someone that got so weird with the personal dynamic… I never went back, but that was the only option I was given. And I just don't think that's right, if you are going to go see a doctor you should be able to go see a doctor that you are comfortable with." –FG*
>
> *"Well and not just the person that the state is willing to pay for either I feel like that is not necessarily the best doctor that is out there either." –FG*
>
> *"Some of those people become disconnected from care, maybe they have hostility about how they were treated by a physician, or hostility about how they felt they were funded by, reduction in funding for certain kind of services or those kinds of things." –KI*

Questionnaire

Demographics

Three hundred and forty-six questionnaires were disseminated across the state by Ryan White case managers and key informants. One hundred and sixty nine questionnaires were returned, with 150 completed and returned via post mail and 19 completed on-line via SurveyMonkey, for a 49% response rate. The majority of questionnaire respondents were men (84.0%).

The table below shows the age breakdown of the questionnaire respondents; the majority of respondents (41.9%) were in the 42 to 51 age range.

Table 3. Age of Questionnaire Respondents (n=167)

22-31	7.8% (n=13)
32-41	12.6% (n=21)
42-51	41.9% (n=70)
52-61	29.9% (n=50)
62-71	7.2% (n=12)
72-81	.6% (n=1)

Ethnicity of the respondents closely mirrored the ethnicities of individuals in Montana who are infected with HIV. Some respondents identified with and answered more than one ethnicity, therefore the total percentages was more than 100%. The table below illustrates identified ethnicities.

Table 4. Ethnicity of Questionnaire Respondents (n=169)

Native American/Alaska Native	5.9% (n=10)
Asian/Pacific Islander	--
African American	1.2% (n=2)
White (non-Hispanic)	92.3% (n=156)
Hispanic	1.8% (n=3)
Other	.6% (n=1)

The majority of questionnaire respondents had completed some college, but did not graduate (30.8%) with those having completed high school/GED (27.2%) following. The table below illustrates highest level of education completed.

Table 5. Highest Level of Education Completed by Questionnaire Respondents (n=169)

Less than high school	3.6% (n=6)
Some high school, but did not graduate	3.6% (n=6)
High school/GED	27.2% (n=46)
Trade or Vocational School	8.3% (n=14)
Community College Graduate	5.9% (n=10)
Some college, but did not graduate	30.8% (n=52)
College Graduate	16.0% (n=27)
Graduate or Professional School	4.7% (n=8)

The majority of questionnaire respondents identified their gross annual individual income as being between $10,001 and $20,000 (27.4%). Nearly 66% of respondents earned $20,000 or less per year. The table below illustrates gross annual individual income.

Table 6. Gross Annual Individual Income of Questionnaire Respondents (n=164)

$100,000+	.6% (n=1)
$75,001-$100,000	1.2% (n=2)
$50,001-$75,000	3.7% (n=6)
$35,001-$50,000	7.9% (n=13)
$20,001-$35,000	20.7% (n=34)
$10,001-$20,000	27.4% (n=45)
$6,000-$10,000	17.7% (n=29)
Less than $6,000	20.7% (n=34)

The majority of questionnaire respondents identified as gay (59.9%) with 31.7% of respondents identifying as heterosexual/straight. The table below illustrates sexual orientation.

Table 7. Sexual Orientation/Preference of Questionnaire Respondents (n=167)

Heterosexual/Straight	31.7% (n=53)
Gay	59.9% (n=100)
Lesbian	--
Bisexual	6.0% (n=10)
Other	2.4% (n=4)

Most questionnaire respondents were single (58.9%), with those in a committed monogamous relationship with a man (25.6%) following. Respondents were asked to choose all relationship statuses that applied to them, therefore the total percentage was more than 100%. The table below breaks down the relationship status categories.

Table 8. Current Relationship Status of Questionnaire Respondents (n=168)

Single	58.9% (n=99)
In a committed monogamous relationship with a man	25.6% (n=43)
In a committed monogamous relationship with a woman	8.9% (n=15)
In a non-monogamous (open) relationship with a man	4.2% (n=7)
In a non-monogamous (open) relationship with a woman	--
Married to a man, but in a non-monogamous (open) relationship	2.4% (n=4)
Married to a woman, but in a non-monogamous (open) relationship	.6% (n=1)

Most questionnaire respondents were on disability (37.8%) with those working full-time (21.6%) positions following. A number of respondents identified with more than one current employment status, therefore the total percentage was more than 100%. The table below breaks down the categories for current employment status.

Table 9. Current Employment Status of Questionnaire Respondents (n=168)

Employed full time	23.8% (n=40)
Employed part time	11.3% (n=19)
Not employed	19.0% (n=32)
Self employed	7.1% (n=12)
On disability	41.7% (n=70)
Student	1.8% (n=3)
Other	5.4% (n=9)

Questionnaire respondents were asked to identify their living situation; if they were living in their own home or apartment (renter or owner) they were asked if they were receiving housing assistance. Of the 163 individuals who responded to this question, 44 (26.0%) identified as receiving housing assistance, however the majority of respondents are not receiving housing assistance (53.4%). The table below demonstrates current housing assistance status.

Table 10. Current Housing Assistance Status of Questionnaire Respondents (n=163)

No	53.4% (n=87)
Yes	27.0% (n=44)
I'm not sure	1.8% (n=3)
Does not apply to me	17.8% (n=29)

Respondents were asked to identify whether they do or do not have health insurance and what type of coverage they are receiving. The majority of respondents were covered by Medicare (40.3%) and Ryan White/AIDS Drug Assistance Program (40.3%). Some respondents identified as receiving more than one form of coverage, therefore the total percentage was more than 100%. The table below breaks down the various forms of health insurance.

Table 11. Current Health Insurance Coverage of Questionnaire Respondents (n=144)

Medicaid	30.6% (n=44)
Medicare	40.3% (n=58)
Private Insurance	23.6% (n=34)
Ryan White/AIDS Drug Assistance Program	40.3% (n=58)
Veteran's Benefits	3.5% (n=5)
Indian Health Service or Tribal Health	.7% (n=1)
Other	6.3% (n=9)

The majority of questionnaire respondents reside in planning region five (35.4%). The map below breaks down region of residence.

Figure 4. Questionnaire Respondents per Planning Region

HIV/AIDS Status

This section of the questionnaire asked respondents about their perception of overall health, suspected route of infection, years since learning of positive diagnosis, time between diagnosis and seeking treatment, AIDS status at time of initial HIV-positive diagnosis, and barriers to initial testing. The majority of questionnaire respondents identified as having good or very good overall health (66.3%). The table below breaks down overall health.

Table 12. Overall Health Status of Questionnaire Respondents (n=166)

Very good	23.5% (n=39)
Good	42.8% (n=71)
Fair	27.1% (n=45)
Poor	6.0% (n=10)
Very poor	.6% (n=1)

Questionnaire respondents were most likely to report becoming infected with HIV via having had sex with a man (77.9%). Some respondents identified more than one possible route of infection; therefore the total percentage was more than 100%. The table below breaks down reported route of infection.

Table 13. Reported Route of Infection of Questionnaire Respondents (n=167)

Sex with a man	77.9% (n=130)
Sex with a woman	7.2% (n=12)
Sex with an injection drug user	4.2% (n=7)
Injecting drug use	6.6% (n=11)
Blood transfusion	1.2% (n=2)
Don’t know	4.8% (n=8)
Other	6.0% (n=10)

There was a large range in the number of years since learning of a positive HIV diagnosis. The distribution of individuals in each category was fairly consistent with the exception of the category, 26 to 30 years, where 7.8% of respondents indicated knowing their diagnosis for that length of time. Nearly 50% of respondents reported being diagnosed with HIV 10 years or longer. The table below demonstrates this data.

Table 14. Years since HIV Diagnosis of Questionnaire Respondents (n=165)

1-5 years	18.8% (n=31)
6-10 years	19.4% (n=32)
11-15 years	17.0% (n=28)
16-20 years	21.2% (n=35)
21-25 years	15.8% (n=26)
26-30 years	7.8% (n=13)

Although the majority of questionnaire respondents sought HIV treatment less than one week following their positive diagnosis (40.4%), nearly one-fourth (24.7%) waited more than one year to seek HIV treatment (24.7%). The table below breaks down length of time between a positive HIV diagnosis and initially seeking treatment.

Table 15. Time Between HIV Diagnosis & Seeking Treatment of Questionnaire Respondents (n=166)

Less than one week	40.4% (n=67)
1 week to 3 months	19.9% (n=33)
3 to 6 months	8.4% (n=14)
6 months to 1 year	6.6% (n=11)
More than 1 year	24.7% (n=41)

Thirty-four respondents were diagnosed with AIDS at the same time they received their HIV-positive diagnosis, however 50 respondents addressed the question referring to the reasons they had not tested sooner. Respondents were asked to check all applicable reasons; therefore the total percentage was more than 100%. The five most prevalent responses are shown in the table below.

Table 16. Barriers to Testing for HIV Overall and by Gender of Questionnaire Respondents (n=50)

	Percent Overall	Percent Male	Percent Female
I thought I was at low or no risk	32.0% (n=16)	28.9% (n=13)	60.0% (n=3)
I was in a monogamous relationship	16.0% (n=8)	13.3% (n=6)	40.0% (n=2)
I was afraid of being discriminated against if I was HIV+	20.0% (n=10)	20.0% (n=9)	20.0% (n=1)
I was too scared to get the test done	16.0% (n=8)	17.8% (n=8)	--
Too scared to find out the results of the test	24.0% (n=12)	26.7% (n=12)	--

Fifty-three (31.5%) of questionnaire respondents identified as currently being diagnosed with AIDS and 164 (98.2%) of respondents identified as having had their CD4 count or viral load checked in the last 12 months.

Linkage to Treatment or Related Services

The most important aspect to accessing services after initial HIV diagnosis is being linked to the proper services. The majority of respondents (36.4%) identified their doctor or health care provider as the person who initially connected them to HIV treatment or related services. The table below describes how HIV-positive people were initially linked to services.

Table 17. Linkage to Treatment or Related Services of Questionnaire Respondents (n=165)

I have never been linked to treatment services for HIV	.6% (n=1)
My personal doctor/health care provider connected me with treatment and services	36.4% (n=60)
I have an HIV positive friend/acquaintance who helped me find services	7.9% (n=13)
The person who did my HIV test referred me to a Ryan White case manager	16.4% (n=27)
The person who did my HIV test linked me to treatment services	20.6% (n=34)
I looked on the internet to find out where to get treatment and services	3.0% (n=5)
Other	15.1% (n=25)

Case Managers

As an integral part of assistance, prevention, and treatment services, the questionnaire sought information related to knowledge about the availability of case managers across the state, whether the person currently had or in the past had a case manager, and what the reasons were as to why they did not currently have a case manager. One hundred and fifty-eight (94.0%) of the respondents were aware that case managers are available in Billings, Missoula, Great Falls, Helena, Havre, Kalispell, Butt, and Bozeman who can help people living with HIV in Montana obtain treatment and other services. The majority of respondents were currently enrolled with a case manager (91.6%). The table below breaks down this data.

Table 18. Current Case Manager Status of Questionnaire Respondents (n=167)

I have one now	91.6% (n=153)
I no longer have one	5.4% (n=9)
I have never had one	3.0% (n=5)

Although only 14 respondents identified as never had or no longer have a case manager, 23 respondents answered the question pertaining to the reason why they are no longer or have never been connected to a case manager. Respondents were asked to identify all reasons that applied to their neglecting to connect to a case manager or discontinuing the relationship with their case manager, therefore the total percentage was more than 100%. The table below demonstrates the top four reasons for no longer or never having been connected to a case manager.

Table 19. Reasons for Discontinuing/Neglecting to Connect to a Case Manager (n=23)

I live too far away	21.7% (n=5)
I don't know how a case manager could help me	17.4% (n=4)
I don't need services	17.4% (n=4)
I can get services myself	30.4% (n=7)

Risky Behaviors

In an effort to understand behaviors that put people who are living with HIV at risk for transmitting the virus, questions were asked in relation to sexual activity, STDs, medical illness, and substance use. Over one-third of questionnaire respondents reported that they have stopped sexual relations since becoming HIV-positive. The table below illustrates this data.

Table 20. Sexual Activity since HIV Diagnosis of Questionnaire Respondents (n=164)

Stopped sexual relations	37.8% (n=62)
Never use condoms	3.0% (n=5)
Sometimes use condoms	27.4% (n=45)
Always use condoms	31.7% (n=52)

Respondents were also asked how often they ask for the HIV status of their sexual partners, if their current sex partner has been tested for HIV, and how often they reveal their status to their partners. Nearly 40% of the respondents reported not being sexually active; therefore there was no need to inquire about the HIV status of a partner. The majority of respondents who did have a current sex partner(s) said that their partner had been tested for HIV and that their partner(s) were aware of their HIV status. The tables below illustrate this data related to sexual activity and sexual partners.

Table 21. Know the HIV Status of Partner(s) (n=156)

No	10.3% (n=16)
Yes	38.5% (n=60)
Sometimes	8.3% (n=13)
Not sexually active	42.9% (n=67)

Table 22. Know Current Sex Partner(s') Testing History (n=104)

No	6.7% (n=7)
Yes	74.0% (n=77)
Don’t know	19.2% (n=20)

Table 23. Share HIV Status with Partner(s) (n=115)

No	5.2% (n=6)
Yes	82.6% (n=95)
Sometimes	12.2% (n=14)

Thirty-four respondents reported having been diagnosed with an STD since receiving their HIV diagnosis. Respondents were asked to identify all diagnosed STDs; therefore the total percentage was more than 100%. The table below breaks down STD diagnoses.

Table 24. STDs since HIV Diagnosis of Questionnaire Respondents (n=34)

Syphilis	26.5% (n=9)
Genital warts	32.4% (n=11)
Gonorrhea	20.6% (n=7)
Herpes	44.1% (n=15)
Chlamydia	26.5% (n=9)
Other	11.8% (n=4)

One hundred and one respondents reported having other medical illness besides HIV/AIDS, with the most prevalent being mental illness. Respondents were asked to identify all other medical illnesses; therefore the total percentage was more than 100%. The table below demonstrates this data.

Table 25. Other Medical Illness(es) of Questionnaire Respondents (n=101)

Hepatitis C/Hepatitis B	28.7% (n=29)
Diabetes	7.9% (n=8)
Alcoholism	15.8% (n=16)
Heart disease	20.8% (n=21)
Drug dependency	6.9% (n=7)
Mental illness	32.7% (n=33)
Opportunistic infections	8.9% (n=9)
Other	42.6% (n=43)

Many respondents marked “other” in addition to one or more of the listed medical illness. A review of the other medical illness revealed no common themes. Illnesses ranged from asthma, COPD, cancer, anal warts, etc.

One hundred and twenty-four respondents reported having used substances in the past, with the majority of respondents having used alcohol (82.3%) with marijuana following (73.4%). Respondents were asked to identify all past substances that had been used, therefore the total percentage was more than 100%. The table below demonstrates past substance use.

Table 26. Past Substance Use of Questionnaire Respondents (n=124)

Alcohol	82.3% (n=102)
Marijuana	73.4% (n=91)
Crack	15.3% (n=19)
Cocaine	38.7% (n=48)
Heroin	8.9% (n=11)
Meth/Crystal	38.7% (n=48)
Downers	12.9% (n=16)
Other	16.9% (n=21)

Only seven respondents had injected drugs in the past year and of those seven only two had shared needles. One hundred and seven respondents reported that their drug/alcohol use was not a problem. The table below demonstrates the data related to drug/alcohol use.

Table 27. Problem Use of Drugs/Alcohol of Questionnaire Respondents (n=164)

None, I don't have a problem	65.2% (n=107)
Small problem – doesn't negatively affect my family, social, or work life	18.9% (n=31)
Somewhat of a problem – occasionally has a negative effect on my family, social, or work life	7.3% (n=12)
Big problem – negatively affects my family, social, or work life	2.4% (n=4)
Don't know	1.2% (n=2)
In recovery/Sober	4.9% (n=8)

Mental Health & Close Relationships

Ninety-eight respondents reported having emotional concerns, with stress and depression being reported by over three-quarters of respondents. The table below breaks down of these emotional concerns.

Table 28. Emotional Concerns of Questionnaire Respondents (n=98)

Stress	78.6% (n=77)
Depression	74.5% (n=73)
Guilt	17.3% (n=17)
Suicidal tendencies	19.4% (n=19)
Anger/resentment	39.8% (n=39)
Worry/fear (concern about the future)	64.3% (n=63)
Loneliness (isolating yourself)	57.1% (n=56)
Other	13.3% (n=13)

Seventy respondents reported the use of some form of treatment to counter emotional or stress-related problems. The majority of respondents were using some form of prescription medication. The table below demonstrates these forms of treatment.

Table 29. Forms of Treatment for Emotional Concerns of Questionnaire Respondents (n=70)

Prescription medicine	82.9% (n=58)
Alternative therapies	5.7% (n=4)
Counseling	42.9% (n=30)
Other	10.0% (n=7)

Sixty respondents identified problems that have been caused in their close relationships due to their HIV status, with stress or isolation in relationships with family being the more prevalent. The table below shows the breakdown of problems.

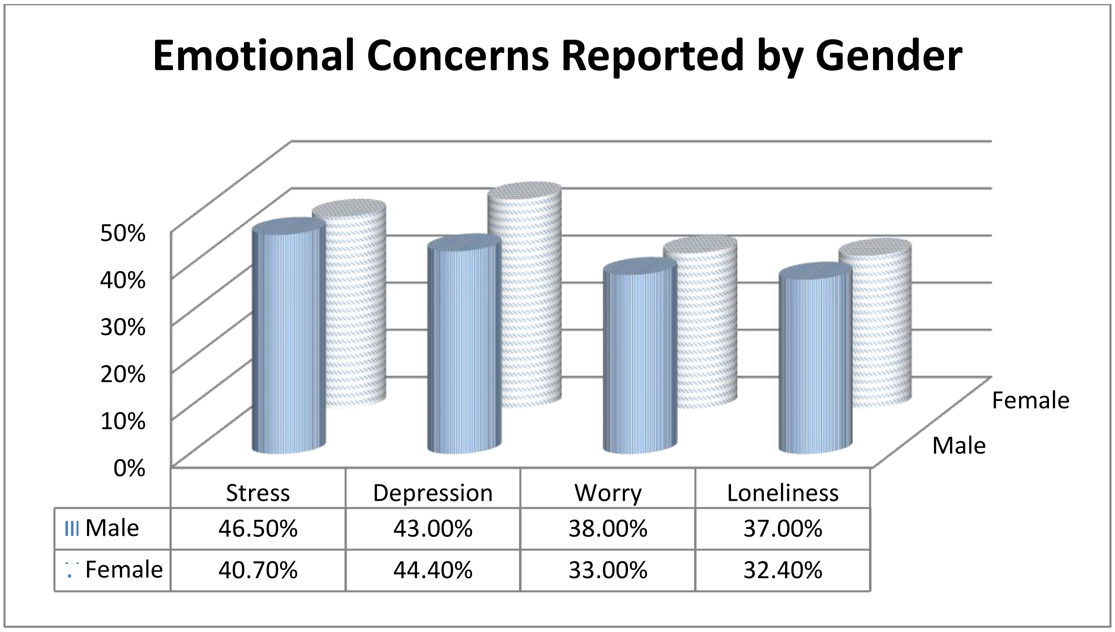
Table 30. Problems in Close Relationships of Questionnaire Respondents (n=60)

Stress or isolation in relationships with your family	58.3% (n=35)
Difficulties in relationship with your spouse/partner	46.7% (n=28)
Difficulties in relationship(s) with children	13.3% (n=8)
Other	26.7% (n=16)

Emotional Concerns Reported by Gender

The most noted emotional concerns were stress, depression, worry, and loneliness. The graph below demonstrates this information.

Figure 5. Emotional Concerns Reported by Gender



	Stress	Depression	Worry	Loneliness
Male	46.50%	43.00%	38.00%	37.00%
Female	40.70%	44.40%	33.00%	32.40%

Preferred Service Needs

Respondents were asked to identify prevention or education services that they would prefer; the majority of respondents identified the need for more HIV-positive weekend retreats. The table below demonstrates the breakdown of other prevention and education services that would be preferred.

Table 31. Preferred Services of Questionnaire Respondents (n=162)

I don’t need any services	29.6% (n=48)
HIV+ weekend retreats	34.0% (n=55)
Group counseling (with other HIV+ people)	19.8% (n=32)
Group education workshops	14.2% (n=23)
Peer counseling (by other HIV+ people)	14.2% (n=23)
Counselor led HIV+ support group	16.7% (n=27)
Education offered by your primary care provider	16.9% (n=27)
Individual counseling	27.8% (n=45)
Other	7.4% (n=12)

Preferred Services Reported by Gender

The only distinct differences in preferred services between genders were females’ identification of the need for more group education workshops while males identified the need for more group counseling with other HIV-positive people. The percentages were calculated using the overall number of males and females as identified in the demographic questions and the number of individuals who identified each preferred service. The table below demonstrates this data.

Table 32. Preferred Services Reported by Gender (n=162)

	Male (n=136)	Female (n=26)
I don't need any services	28.2%	29.6%
HIV+ weekend retreats	32.4%	33.3%
Group counseling	21.1%	7.4%
Group education workshops	12.0%	22.2%
Peer counseling	14.1%	11.1%
Counselor led HIV+ support groups	16.2%	14.8%
Education offered by your primary care provider	16.2%	14.8%
Individual counseling	27.5%	22.2%

Preferred Services Reported by Gross Annual Individual Income

Also associated with selected preferred services was gross annual individual income. Again it was found that persons who identified as making at or below $35,000 gross annual individual income were more likely to identify the need for services than those individual making above $35,000 gross annual individual income. The percentages were calculated using the overall number of respondents identifying with the specific gross annual individual income grouping and the number of individuals who identified each preferred service. The table below demonstrates this data.

Table 33. Preferred Services Reported by Income (n=154)

	$35,001-$50,000 (n=12)	$20,001-$35,000 (n=34)	$10,001-$20,000 (n=45)	$6,000-$10,000 (n=29)	Less than $6,000 (n=34)
I don't need any services	25.0%	20.5%	31.1%	48.2%	14.7%
HIV+ weekend retreats	25.0%	44.1%	31.1%	20.6%	38.2%
Group counseling	16.6%	23.5%	11.1%	17.2%	11.7%
Group education workshops	25.0%	17.6%	11.1%	6.8%	17.6%
Peer counseling	16.6%	14.7%	15.5%	6.8%	17.6%
Counselor led HIV+ support groups	16.6%	17.6%	15.5%	20.6%	11.7%
Education offered by your primary care provider	16.6%	11.7%	13.3%	17.2%	26.4%
Individual counseling	--	26.4%	28.8%	10.3%	52.9%

Preferred Services Reported by Region

Not all reported preferred services were similar between the different planning regions. The table below illustrates the variation in preferred services as reported by the different planning regions.

Table 34. Preferred Services Reported by Region

	Region 1 (n=5)	Region 2 (n=6)	Region 3 (n=50)	Region 4 (n=41)	Region 5 (n=56)
I don't need any services	60.0%	33.3%	32.0%	24.4%	25.0%
HIV+ weekend retreats	40.0%	16.7%	26.0%	46.3%	30.4%
Group counseling	20.0%	33.3%	6.0%	34.1%	17.9%
Group education workshops	20.0%	16.7%	6.0%	19.5%	12.5%
Peer counseling	--	--	14.0%	19.5%	12.5%
Counselor led HIV+ support groups	--	--	12.0%	22.0%	19.6%
Education offered by your primary care provider	--	--	24.0%	14.6%	10.7%
Individual counseling	20.0%	33.3%	28.0%	24.4%	28.6%

Preferred Services Reported by Years since HIV Diagnosis

The table below illustrates preferred services as reported by the number of years respondents identified since their HIV diagnosis.

Table 35. Preferred Services Reported by Years since HIV Diagnosis

	1-5 yrs (n=31)	6-10 yrs (n=32)	11-15 yrs (n=28)	16-20 yrs (n=35)	21-25 yrs (n=26)	26-30 yrs (n=13)
I don't need any services	16.1%	25.0%	39.3%	37.1%	30.8%	15.4%
HIV+ weekend retreats	35.5%	25.0%	17.9%	25.7%	50.0%	53.8%
Group counseling	29.0%	21.9%	7.1%	20.0%	19.2%	15.4%
Group education workshops	29.0%	15.6%	10.7%	8.6%	7.7%	--
Peer counseling	22.6%	12.5%	7.1%	11.4%	11.5%	23.1%
Counselor led HIV+ support groups	19.4%	21.9%	10.7%	14.3%	11.5%	15.4%
Education offered by your primary care provider	22.6%	21.9%	10.7%	11.4%	15.4%	15.4%
Individual counseling	38.7%	15.6%	21.4%	25.7%	23.1%	46.2%

Barriers to Accessing Prevention & Treatment Services

Questionnaire respondents were asked to identify barriers that inhibit them from accessing prevention and/or treatment services. The table below demonstrates the barriers to accessing prevention and/or treatment services ranked by big barrier.

Table 36. Barriers to Accessing HIV and AIDS Services

	Big Barrier	*Small Barrier*	*Not a Barrier*
Not having enough insurance coverage	n=51	n=42	n=68
The cost of assistance or treatment	n=37	n=46	n=78
Fear/Stigma	n=30	n=48	n=85
Burnout from dealing with/talking about HIV	n=25	n=46	n=92
My state of mind or mental ability to deal with the treatment	n=22	n=35	n=107
My concern that other people may see me when I go to get care or learn about my HIV infection (lack of confidentiality/stigma)	n=22	n=48	n=96
Not knowing what service or treatment is available to me/lack of services	n=21	n=38	n=103
The location of the organization providing services	n=17	n=31	n=112
Not having transportation	n=17	n=20	n=121
Anonymity/confidentiality	n=16	n=45	n=99
Other	n=15	n=2	n=4
Lack of experience of the person providing services to me	n=13	n=34	n=112
My physical health	n=12	n=39	n=111
The quality of assistance or treatment	n=12	n=35	n=111
Not knowing what medical assistance or treatment I need to treat my HIV or AIDS infection	n=11	n=21	n=127
Discrimination I experience by the persons or organizations providing the service	n=7	n=31	n=124
The amount of time I had to wait to get an appointment	n=7	n=18	n=137

Barriers to Accessing HIV and AIDS Services Reported by Planning Region

Since Montana is a rural state, it was important to identify the barriers to accessing HIV and AIDS services based on geographic location. The map below demonstrates the number of questionnaire respondents broken down by region of residence.

Figure 6. Questionnaire Respondents per Planning Region

In the table below, percentages are used to give a more accurate representation of the burden of these barriers on the different planning regions. These percentages were calculated using the number of responses per big barrier and the number of respondents identified from that region.

In Region 1 the lack of experience of the person providing services was noted as the greatest barrier. In Region 2 the cost of assistance or treatment and not having enough insurance coverage were identified as the greatest barriers. In Region 3 not having enough insurance coverage was identified as the greatest barrier. In Region 4 discrimination experienced by the persons or organizations providing services was identified as the greatest barrier. In Region 5 not having enough insurance coverage and fear/stigma were identified as the greatest barriers.

Table 37. Barriers to Accessing Services Reported by Region (n=50)

	Region 1 (n=5)	Region 2 (n=6)	Region 3 (n=50)	Region 4 (n=44)	Region 5 (n=56)
Wait time for appointment	--	--	2.0%	2.4%	8.9%
State of mind	--	33.3%	6.0%	17.1%	17.9%
Quality of treatment	--	--	2.0%	12.2%	10.7%
Physical health	--	--	--	9.8%	12.5%
Not knowing treatment options	20.0%	--	--	7.3%	12.5%
Location of services	20.0%	--	2.0%	14.6%	16.1%
Lack of transportation	--	16.7%	4.0%	14.6%	14.3%
Lack of services	20.0%	33.3%	2.0%	14.6%	17.9%
Lack of provider experience	40.0%	16.7%	4.0%	9.8%	7.1%
Lack of insurance coverage	20.0%	66.7%	32.0%	24.4%	28.6%
Lack of confidentiality	20.0%	16.7%	6.0%	9.8%	17.9%
Fear/Stigma	--	16.7%	16.0%	17.1%	23.2%
Discrimination	--	--	2.0%	48.8%	5.4%
Cost	20.0%	66.7%	18.0%	24.4%	21.4%
Burnout	--	--	16.0%	12.2%	19.6%
Anonymity	--	--	8.0%	12.2%	10.7%

Barriers to Accessing HIV and AIDS Services Reported by Gross Annual Individual Income

Some important relationships were noted within the data collected via the questionnaire. When level of income was compared to selected big barriers to accessing HIV and AIDS services it was found that as income levels decreased, the number of reported big barriers increased. Those persons identified as making more than $35,000 gross annual individual income did note some big barriers, but the graph below shows the greatest burden of big barriers when accessing HIV and AIDS services for those persons making at or below $35,000 gross annual individual income.

Table 38. Barriers Reported by Gross Annual Individual Income (n=154)

	$35,001-$50,000 (n=12)	$20,001-$35,000 (n=34)	$10,001-$20,000 (n=45)	$6,000-$10,000 (n=27)	Less than $6,000 (n=32)
Lack of services	16.6%	5.9%	8.9%	11.1%	21.8%
Location of services	0.08%	2.9%	6.7%	14.8%	18.7%
Physical health	0.08%	--	8.9%	7.4%	9.3%
Quality of treatment	--	2.9%	8.9%	11.1%	6.2%
Not knowing treatment options	--	--	2.2%	11.1%	15.6%
State of mind	0.08%	2.9%	8.9%	11.1%	32.0%
Lack of transportation	16.6%	--	8.9%	14.8%	18.7%
Lack of confidentiality	0.08%	5.9%	6.7%	18.5%	25.0%
Discrimination	0.08%	2.9%	4.4%	--	9.3%
Fear/Stigma	25.0%	11.8%	15.6%	29.6%	21.8%
Anonymity	16.6%	8.8%	6.7%	18.5%	6.2%
Lack of provider experience	16.6%	5.9%	6.7%	7.4%	9.3%
Wait time for appointment	0.08%	--	2.2%	--	12.5%
Cost	41.6%	17.6%	22.2%	14.8%	28.1%
Lack of insurance coverage	41.6%	23.5%	26.7%	22.2%	50.0%
Burnout	16.6%	8.8%	11.1%	29.6%	12.5%

Barriers to Accessing HIV and AIDS Services Reported by Gender

The majority of people living with HIV in Montana as represented in the questionnaire data identify as gay males (71.4%). All female respondents living with HIV in Montana identified as heterosexual. Not having enough insurance coverage was identified as the greatest barriers to accessing HIV and AIDS services by both males and females. Males also identified the cost of assistance and treatment as a consistent barrier. Females identified fear/stigma, concern that other people may see them when they get care or learn about their HIV infection (lack of confidentiality/stigma), their state of mind or mental ability to deal with the treatment as their greatest and most consistent barriers. Therefore, the difference in barriers between males and females was of interest. The graph below demonstrates big barriers based on gender. The percentages were calculated using the overall number of males and females as identified in the demographic questions and the number of individuals who identified each barrier.

Table 39. Barriers Reported by Gender (n=169)

	Male (n=142)	Female (n=27)
Lack of services	12.0%	14.8%
Location of services	8.5%	18.5%
Physical health	8.5%	--
Quality of treatment	7.0%	7.4%
Not knowing treatment options	6.3%	7.4%
State of mind	11.3%	22.2%
Lack of transportation	9.9%	11.1%
Lack of confidentiality	11.3%	22.2%
Discrimination	2.8%	11.1%
Fear/Stigma	16.9%	22.2%
Anonymity	9.2%	11.1%
Lack of provider experience	6.3%	14.8%
Wait time for appointment	4.2%	3.7%
Cost	22.5%	18.5%
Lack of insurance coverage	28.9%	37.0%
Burnout	15.5%	11.1%

CHAPTER FIVE

Key Discussion Issues from the Study

This assessment utilized a mixed methods design to examine the prevention needs of people who are living with HIV in Montana. Ten interviews with key informants and four focus group interviews with individuals living with HIV were conducted across the state. A total of 32 individuals were involved in the interviews. In addition, a questionnaire was distributed to 346 individuals who are living with HIV. Approximately half of the questionnaires were returned.

While the demographic characteristics of the individuals represented in this assessment varied broadly, there were significant similarities among individuals living with HIV who agreed to participate in a focus group or respond to a questionnaire. The vast majority of participants in this assessment were white males who identified themselves as gay. While there was a broad range of socio-economic and education levels, over half of the individuals earned under $20,000 per year, and most had not graduated from college. A majority of questionnaire respondents reported being unemployed or on disability and approximately a third were receiving housing assistance. Nearly all of the assessment participants (92%) had a case manager, and therefore were connected to HIV-related services.

The following discussion represents a synthesis of data collected, both qualitatively through interviews, and quantitatively through a statewide questionnaire. The researchers explored quality of life issues, behaviors that put individuals at risk for reinfection or transmission of the virus to others, physical and mental health issues, prevention and treatment needs, and barriers to accessing or continuing treatment.

Quality of Life Issues and Health Problems

People living with HIV suffer from a number of quality of life and health issues that previously have been well documented in the literature. Participants in this assessment identified stigma, fear of discrimination, loss of personal relationships, and poverty as issues that affect the quality of their lives. Similar quality of life issues were identified by Bravo et al. in 2010 who found that an HIV diagnosis can cause avoidance of previously established social contracts with family, friends, health care systems, and public services due to a fear of stigmatization and discrimination, leading directly to lowered self-esteem, and increased social isolation (Bravo et al., 2010). One key informant summed up the experience of many people living with HIV when she said, “So many clients do not have any other person in their life that they feel they can talk openly to, except their case manager.”

As might be expected, nearly half the individuals who completed the questionnaire identified depression and stress as major health issues. It seems plausible that a diagnosis of HIV infection may propel an otherwise mentally healthy person into depression. Qualitative interview data, however, shed light on the fact that HIV infection may have simply exacerbated a pre-existing condition of depression and not necessarily caused it. One focus group member summed up the feelings of many participants when he said, “I mean depression has always been a part of my life and it’s so not because I am HIV-positive. It’s one complicated thing or the other.” A second focus group participant related a similar message when he said, “The depression one is a big one, because when you are first diagnosed you have depression along with probably 100 other things that weren't quite right in your life. None of us were probably doing the healthy and positive things [prior to diagnosis]."

In addition to depression, over half of the questionnaire respondents reported having at least one medical issue aside from HIV infection. The list of medical issues ranged from bronchitis to seizures to cancer. No one illness was reported by more than a fifth of the survey respondents and thus, no illness stood out as being particularly prevalent. HCV, however, was the most commonly reported medical condition aside from HIV. While nationwide, approximately 35% of people living with HIV are co-infected with HCV (Proeschold-Bell et al., 2010), the number of individuals reporting co-infection was substantially lower (17%) in this assessment.

Risky Behaviors

As has been frequently noted in the literature, the use of drugs and alcohol as a mechanism for coping with low self-esteem and depression can lead to unsafe sexual practices and contribute to mental health issues. Studies have found that although individuals are aware of the consequences of their risky sexual behaviors, and fear the effects of those behaviors on their health, depression and hopelessness may lead them to cope in unhealthy ways (Rao et al., 2008, Schwarz et al., 2011). As one key informant stated, "A lot of our positive patients smoke and drink alcohol and do all sorts of things to cope with the trauma of being stigmatized in this society."

While alcohol and other drug use may have contributed to risky behaviors prior to infection with HIV, it is important to note that less than 10% of participants in this assessment reported alcoholism and less than five percent reported addiction to other drugs. Indeed, when asked if drug and alcohol use was a problem, over 80% of questionnaire respondents reported that they did not perceive to have problems associated with drugs and/or alcohol. In regard to sexual risky behaviors, almost two-thirds of the participants in this assessment appear to have stopped sexual relations or report always using condoms.

Unfortunately however, nearly a third of individuals reported "sometimes" or "never" using condoms. One focus group participant summed up many individuals' feelings about condom use when he said, "Nonetheless, safe sex is still not practiced enough within our own community and within any community; with HIV-positive people especially." Courtenay-Quirk et al. (2009) found 30% of people living with HIV who were also unstably housed or homeless reported some or no condom use during sexual activity. While the rationale for not using condoms is not known, one key informant described it this way, "The reality is fucking is fun. And people do it. And sex is fun. If it didn't feel good, we wouldn't do it and we have to get to that point of recognizing the excitement of it all and we have to get to the point of recognizing that we sometimes make really stupid decisions when we're sexually excited."

Prevention and Treatment Services

A key purpose of this study was to identify prevention and treatment services that people living with HIV found most helpful. Not surprisingly, interview participants as well as questionnaire participants identified case managers and health care providers as key elements to maintaining both their physical and mental health. One participant summed up many individuals' feelings about case management by saying, "I think that there's this sense with case managers at <local clinic>, that people are listened to and they seem to have a positive connection with their case managers. And I think that there's an openness to feel tension or difficulty, people seem like they can go back to their providers when there's problems or questions and they can feel heard, that's really good." This emphasis on providers who are caring, take time to answer questions, and do not stigmatize their HIV-positive patients are integral to keeping their patients connected to care and treatment. This concept was reinforced by a second focus group participant who said, "Sometimes I think that my best healthcare provider was not a doctor; my best healthcare providers were physician assistants and licensed practical nurses because they took the time. They understood my knowledge and my health and my own body in a way that we have some doctor culture that is hard to get through."

A third important existing service identified by many individuals was the HIV-positive retreats. In regard to all current prevention interventions, including support groups, individual counseling, peer counseling, and education, retreats were by far the most popular with nearly two-thirds of survey respondents affirming their importance. One focus group participant stated, "The good thing about treatment and prevention services that we've received is the fall retreat up at <Montana retreat location>. Not only does it help with the treatment and prevention, but also helps us with our isolation and all that." The retreats were identified as opportunities to enhance social interactions with other people living with HIV as well as a means to increase their knowledge base about other issues related to HIV that might not always be accessible during routine visits to their health care provider. As mentioned by one focus group participant, "I learned more about my meds and how they interact and stuff like that [while attending the retreat]. He just brought up things I never even thought to ask about."

Prevention and Treatment Unmet Needs

A second key purpose of the assessment was to identify important prevention and treatment services that were needed, but not necessarily available. Unmet needs that were identified by focus group and key informant interviewees revealed three main areas of focus. First, was the recognition that people living with HIV should be empowered to advocate for themselves. As one focus group member said, “We still need to remain vigilant. And we are the experts, we know what’s going on with our bodies, we feel them. Be proactive.” This issue arose, in part, because of the recognition of HIV a chronic illness. As HIV has transitioned from an acute and deadly disease to one that is chronic and not immediately life threatening, the resources and services designed to assist people living with the infection have both declined and been stretched to their limits as people require services for the long-term. Participants suggested that empowerment can come from case managers assisting their clients in learning to navigate the HIV-related services. As one key informant stated, “That’s where it kind of becomes important to have a good case manager that can actually help a person get through those systems because they’re not necessarily easy to navigate if you’re not familiar with them.” In addition, peer advocates could provide people living with HIV the confidence they need to advocate for themselves. One focus group participant identified this need by stating, “What about advocates for people… What if I’m really ill and I don’t feel like my doctor is hearing me, what about a person who is available to call them up and say I need you to go to the doctor with me, this person is just not hearing me, you know?” Participants honed in on the importance of peer support, as seen in the form of advocates and other people living with HIV, as a means toward empowerment.

The second important prevention and treatment service need that arose from the interviews was a strong belief that HIV needs to be destigmatized within communities, across the state, and at a national level. Assessment participants believed that increased public education through comprehensive sex education in public schools and increasing visibility would contribute greatly to reducing the stigma that currently surrounds HIV. In regards to sex education, one key informant had this to say, "I just want to solve it all by making comprehensive sex ed mandatory from a young age and letting that be our guide, knowing and trusting that once people have this comprehensive sex ed and aren't stigmatized by their bodies or their sexuality or it might be their curiosity, it wouldn't be so hard for folks to access those services." Comprehensive sex education was viewed as a way to reduce risky sexual behavior and increase the visibility of HIV leading to a decreased stigma associated with HIV. The idea of increased visibility was explained by this focus group participant, "I think in places like Montana and smaller populated states it's even more important to have that visibility because it's going to keep creeping. That's all there is to it."

The third important need was to improve physicians' expertise in treating people with HIV and to treat them more holistically. Suggestions for improving health care providers' expertise ranged from mandatory HIV trainings, to bringing in expert speakers, to employing an HIV care specialist who is a "circuit rider" and whose job it is to visit each major city in Montana every week. One key informant spoke to the importance of expert speakers, which are currently used at some HIV-positive retreats, "We're really fortunate in our retreats that we tend to bring in national experts on treatment issues… HIV-positive individuals really want to make sure that they have the most up to date education on treatment because we know that single-handedly has made the biggest difference in quality of life issues, for people are the new treatments.”

Physicians’ expertise was described not only in regard to HIV, but also in regard to a need for comprehensive holistic treatment of HIV including mental and emotional, as well as physical needs. Rao et al. (2008), Bravo et al. (2010), and Hergenrather et al. (2005) also found that the relationship between mental, emotional, and physical health are interrelated and as such should be treated as integral parts of each other when accessing health care services. One key informant spoke to this idea of holistic care by stating, “I think that people kind of get their mental health needs met on a sort of individual basis, where there’s a need for that, but I’m talking about more of an integration of mental health and prevention efforts and also treatment would be great.”

Barriers to Testing and Accessing Services

A third key purpose of this assessment was to identify barriers to testing, barriers to accessing treatment and barriers to continuing treatment. Only 21% of respondents were diagnosed with AIDS at the same time they discovered they were infected with HIV. When asked about their barriers to being tested earlier, the most frequent responses were that they thought they were at low or no risk for infection and they were in a monogamous relationship at the time. Fear also played a role in postponing an HIV test – fear of the test itself and fear of the discrimination that could accompany a positive diagnosis. One key informant spoke to this fear, stating, “I think in some ways even though we’re an open-minded place in a very conservative zone, sometimes there’s a real fear that there’ll be kind of dramatic forms of backlash and, you know, even violence or risk-to-life that happen occasionally and so I think it creates an environment of fear even though there’s sort of a quality of openness in the local community, I think it creates tension for people, being able to resolve those two.”

These barriers to testing are similar to barriers associated with accessing prevention and treatment services. A study done in Montana in 2006 identified a lack of knowledge of resources and fear associated with accessing treatment as major barriers to accessing the available prevention and/or treatment services necessary to effectively treat HIV (Towner, 2006). Also noteworthy was Bravo et al.’s finding that fear of discrimination was found to be a major barrier to initial testing for HIV infection as well as initial and continued treatment for HIV (Bravo et. al, 2010).

Other barriers to treatment and services appear to be tied in with the poor economic status of the people living in Montana with HIV. Lack of transportation is a particularly salient barrier because of the sheer size of the state and the sparse population. Although persons living in small isolated towns have the greatest barriers related to transportation, one key informant stated, “In a rural state like Montana transportation is a big issue for a lot of our clients, even our clients who live in town.” Many focus group participants spoke to the combined effect of financial stress and a lack of transportation, one participant stated, “I don’t get travel [travel money from state-funded agencies] anymore and I didn’t get a raise and I don’t know what happened there but they all of a sudden decided I make too much money to get paid travel anymore.”

Poor economic status is directly related to uncertainty about how to pay for treatment services and how to pay for medications. One focus group participant said, “This is the last month I’m being covered [by private insurance]. So at the end of this month, we’re gonna have to try to, and they already told me I don’t qualify for ADAP because I’m working, that I don’t qualify for some other program because I make too much money, I make $950/month, I don’t really see how that’s too much money. My medication is twice that.” These barriers mirror those found by previous studies, showing that a lack of health insurance and lack of money to pay for services create barriers that hinder access of services and continued linkage to services (Schwarz et al., 2011; Wohl et al., 2011).

And finally, as in many rural areas, fear of lack of confidentiality and the lack of experience of the local health care providers in treating people infected with HIV were cited as barriers to accessing services. The lack of anonymity in small communities in Montana was perceived to decrease the likelihood of confidentiality and increase the risk for discrimination in rural communities. This was highlighted by one focus group participant who stated, “I always feel that I’m walking to the doctor’s office, they’ve got the camera, I sign my name, okay it’s recorded somewhere, ya know? So I mean it’s kind of a joke on some of the confidentiality.” Also, improving the knowledge and expertise of health care providers was a prominent focus for key informants and focus group participants alike; one key informant acknowledged this issue by stating, “Having good education for healthcare providers about the issue and having it mandatory, because I know sometimes they have options to do or not do some of these workshops, and most of them choose not to because they’re busy, and I understand that, but it’s something that’s really important.”

Limitations

A number of limitations exist in this research as were highlighted in Chapter one. The information included in this assessment was limited to the specific experiences of the individuals who participated in the focus groups, key informant interviews, and questionnaire. Many of the participants in this assessment identified as currently being linked to a case manager and therefore linked to prevention and treatment services. As such, the information in this assessment does not fully represent those people living with HIV in Montana who are not currently enrolled with a case manager or who are actively accessing HIV-related services offered by state-funded agencies. Furthermore, while Native Americans and women living with HIV were represented in the survey in proportion to their numbers statewide, they were not represented in the focus groups or interviews. The data was also limited to the interviewers' abilities and biases; additionally, key informants who conducted the focus group interview did not receive training prior to conducting the focus groups and therefore may have been limited in their understanding of the research questions.

Conclusions

Currently the goal of the National HIV/AIDS Strategy (2010) is to offer every person, regardless of age, gender, race/ethnicity, sexual orientation, gender identity or socioeconomic circumstance, unfettered access to high quality, life-extending care, free from stigma and discrimination (National HIV/AIDS Strategy, 2010). However, as HIV has shifted from an acute death sentence to a chronic, yet treatable disease, external stigmas and discriminatory presuppositions continue to create barriers that hinder proper care and treatment for people living with HIV in Montana.

This assessment was an attempt to explore quality of life issues and examine the barriers that inhibit HIV-related treatment and care for people living with HIV in Montana. Approximately 190 HIV-positive individuals took part in focus group interviews and/or completed a questionnaire, with 10 key informants participating in one-on-one interviews. HIV-positive individuals who participated in this assessment were, for the most part, living with few financial resources and had limited education and employment opportunities. Although 92% of HIV-positive participants identified as having a current case manager, and therefore are currently connected to prevention and treatment services, there continues to be many salient and vital needs to be met and barriers to be overcome.

Foremost among the needs uncovered in this assessment was the need to increase the general public's awareness of HIV; the need to have access to health care providers who are holistic, caring and current in their knowledge about treating HIV; and finally, the need to maintain or increase the availability of existing case management services, HIV-positive retreats and support groups. All of the needs identified in the assessment point to the necessity of continued diligence toward decreasing cultural stigma, discrimination, and fear surrounding HIV. Many participants in this assessment believed that reducing stigma will contribute to the empowerment of people living with HIV and will give them the confidence they need to seek out the knowledge and skills that are necessary for them to advocate for their own needs. This persistent movement to involve all people in a greater understanding of HIV is important for improving the overall health outcomes and quality of life for people living with HIV in Montana.

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APPENDIX A: The University of Montana Institutional Review Board Approval

The University of
Montana

INSTITUTIONAL REVIEW BOARD
for the Protection of Human Subjects
FWA 00000078

Research & Development
University Hall 116
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Missoula MT 59812
Phone 406-243-6670 | Fax 406-243-6330

Date: November 17, 2011

To: K. Ann Sondag, Health and Human Performance

From: **Dan Corti**, IRB Chair

RE: IRB 195-11: "A Needs Assessment of People Living with HIV in Montana"

Your IRB proposal cited above has been **APPROVED** under **expedited review** by the Institutional Review Board in accordance with the Code of Federal Regulations, Part 46, section 110. Expedited approval refers to research activities that (1) present no more than minimal risk to human subjects, and (2) fit within the following category for expedited review as authorized by 45 CFR 46.110 and 21 CFR 56.110:

7. Research on individual or group characteristics or behavior (including, but not limited to, research on perception, cognition, motivation, identity, language, communication, cultural beliefs or practices, and social behavior) or research employing survey, interview, oral history, focus group, program evaluation, human factors evaluation, or quality assurance methodologies. (NOTE: Some research in this category may be exempt from the HHS regulations for the protection of human subjects. 45 CFR 46.101(b)(2) and (b)(3). This listing refers only to research that is not exempt.)

University of Montana IRB policy requires you to file an annual Continuation Report (Form RA-109) for expedited studies. However, you are required to timely notify the IRB if there are any significant changes or if unanticipated or adverse events occur during the study, if you experience an increased risk to the participants, or if you have participants withdraw from the study or register complaints about the study.

APPENDIX B: Focus Group & Key Informant Interview Questions

FOCUS GROUP/KEY INFORMANT INTERVIEW QUESTIONS

People Living with HIV in Montana

Focus group will begin with an ICEBREAKER:

1. ***Quality of Life Issues:***
    - **a.** What do you believe to be the three greatest problems for people living with HIV in Montana?
        - **i.** i.e. poverty, social isolation, geographic isolation, unemployment, and/or social stigma
    - **b.** What would be the single most important change you would suggest to improve the lives of people living with HIV in Montana?

2. ***Health Problems:***
    - **a.** What do you believe to be the three greatest health problems for people living with HIV in Montana?
        - **i.** i.e. compromised immune systems, reinfection, co-infection transmission to uninfected individuals and/or depression or other mental health concerns

3. ***Behaviors Related to the Health Problems:***
    - **a.** What risky behaviors do you believe people living with HIV engage in that might be detrimental to their health?
    - **b.** What risky behaviors do you believe people living with HIV engage in that might put other people's health at risk?
    - **c.** What are the greatest assistance and/or treatment needs of people living with HIV in Montana that are not currently being met?
        - i. How can services be improved to better meet the needs of people living with HIV in Montana?
        - ii. What are the good things about the prevention and treatment services that you or those you know have received?

4. ***Barriers to Accessing Prevention and/or Treatment Services***
    - **a.** What are barriers to accessing prevention and treatment services immediately after HIV diagnosis?
    - **b.** What are the reasons that individuals who previously used services discontinue those services?
    - **c.** What types of prevention and treatment services do people living with HIV in Montana need but can't get?
    - **d.** What barriers do you see people living with HIV facing in regards to obtaining assistance and/or services?
        - i. Example: lack of knowledge about services, mental health issues like depression, problems with transportation, ability to pay for services, etc.
    - **e.** What are the best ways to reach people living with HIV in Montana who are not currently being served?

- **f.** What are the best ways to maintain individuals' participation in prevention and treatment services?
- **g.** What services are provided that client use most frequently?
- **h.** What services are provided that aren't being used?
  - **i.** What factors contribute to this lack of use?
    - **1.** i.e., lack of knowledge of services, lack of education, lack of transportation, etc.

5. ***<u>Are you aware of ways that people with HIV can reduce the chances of infecting others?</u>***

- a. What are some of those ways?
- b. Who educated you about the ways in which people living with HIV can reduce the chances of infecting others?
  - **i.** What do you think are the most effective ways to educate people living with HIV about reducing risk behaviors?

6. ***<u>What other thoughts do you have regarding the needs of people living with HIV in Montana?</u>***

APPENDIX C: Key Informant Interview Recruitment Script

Verbal Instructions for Recruiting Volunteers for the Interview

Provide each potential volunteer with an explanation of the interview; and a brief explanation of the procedures for the interview.

Purpose: The purpose of this study is to assess the HIV prevention needs of people living in Montana who are infected with HIV. By participating in this interview you will help provide valuable information that will be used to develop better HIV prevention services for people living with HIV in Montana. The interview is designed to help gather information for this study to further develop and potentially improve the effectiveness of HIV prevention interventions offered in Montana.

Please remind them:

- The study is completely voluntary and confidential and they may choose not to answer any of the questions posed at the interview.
- If they volunteer they will be asked to meet with the researcher who will ask them questions about HIV prevention needs.
- The interview will be audio recorded, but no identifying information will be transcribed from the interview and the tapes will be erased at a later date.
- By participating they are helping fight the spread of HIV in Montana. The information gathered by the interview will be used to improve HIV prevention programs for men who have sex with men in Montana.

If individuals are willing to participate, give them a copy of the interview questions, the researchers' contact information, and ask them if it is okay for the researcher to contact them to set up a time and place for the interview.

Allow a few minutes for potential participants to ask any question or talk it over.

- Ask them to fill out a card with contact information if they think they are interested and turn them back in to you.

APPENDIX D: Key Informant Interview Consent Form

KEY INFORMANT INTERVIEW PARTICIPANT CONSENT FORM

TITLE
A Needs Assessment of People Living with HIV in Montana

SPONSOR
The Montana Department of Public Health and Human Services – HIV/STD Section

PROJECT DIRECTOR:
Dr. Annie Sondag
The University of Montana
Department of Health & Human Performance
Missoula, MT 59812
(406) 243-5215
annie.sondag@mso.umt.edu

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

PURPOSE
The purpose of this study is to assess the HIV prevention needs of people living in Montana who are infected with HIV. By participating in this interview you will help provide valuable information that will be used to develop better HIV prevention services for people living with HIV in Montana.

PROCEDURES
Interview participation for this study 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 people living with HIV in Montana. The interview will take approximately one hour. The session will be audio recorded and transcribed for accuracy of responses.

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. 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 the Montana Department of Public Health and Human Services. By participating in this study, your answers will help staff offer services and develop programs to meet the HIV prevention needs of people living with HIV in Montana.

CONFIDENTIATLIY

All information collected during your interview will be ***confidential***. Interviewers will avoid identifying any of the participants. Interviewers 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 interview participants will remain confidential and will not be associated with research findings in any way.
- At the conclusion of the study, any and all data containing information about participants will be destroyed.
- 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, Emily Epperson,* at (770) 316-6719.

If you have any questions about your rights as a research subject you may contact the Chair of the Institutional Review Board in the Research Office at The University of Montana – Phone (406) 243-6670.

CONSENT

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 of this consent to keep.

APPENDIX E: Key Informant & Focus Group Interview Contact Summary Sheet

Key Informant & Focus Group Interview Contact Summary Sheet

Interview Date:________________ Interview Length: ________________

Interview No.: ________________ Interview Location: ________________

1. Physical description/impressions:

2. Main themes and issues:

3. Research question most directly addressed:

4. New working hypothesis or speculations:

5. Problems or questions:

6. Direction of information needed for next interview:

APPENDIX F: Focus Group Recruitment Script

Verbal Instructions for Recruiting Volunteers for the Focus Group

Provide each potential volunteer with an explanation of the focus group; and a brief explanation of the procedures for the focus group.

Purpose: The purpose of this study is to assess the HIV prevention needs of people living in Montana who are infected with HIV. By participating in this interview you will help provide valuable information that will be used to develop better HIV prevention services for people living with HIV in Montana. The focus group is designed to help gather information for this study to further develop and potentially improve the effectiveness of HIV prevention interventions offered in Montana.

Please remind them:

- The study is completely voluntary and confidential and they may choose not to answer any of the questions posed at the focus group.

- If they volunteer, they will be asked to attend a focus group. They will receive $25 for participation that they are free to keep should they decide to leave the focus group early.

- The focus group will be audio recorded, but no identifying information will be transcribed from the focus group and the tapes will be erased at a later date.

- By participating they are helping fight the spread of HIV/STDs in Montana. The information gathered by the focus group will be used to improve HIV prevention and/or treatment services for people living with HIV in Montana.

If individuals are willing to participate, give them a copy of the focus group questions, the researchers' contact information, and information about the time and place the focus group will occur.

- Allow a few minutes for potential participants to ask any question or talk it over.
- Remind the potential participants that if they have any questions they can contact the researchers.

APPENDIX G: Focus Group Consent Form

FOCUS GROUP PARTICIPANT INFORMED CONSENT

TITLE
A Needs Assessment of People Living with HIV in Montana

SPONSOR
The Montana Department of Public Health and Human Services – HIV/STD Section

PROJECT DIRECTOR:
Dr. Annie Sondag
The University of Montana
Department of Health & Human Performance
Missoula, MT 59812
(406) 243-5215
annie.sondag@mso.umt.edu

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

PURPOSE
The purpose of this study is to assess the HIV prevention needs of people living in Montana who are infected with HIV. By participating in this interview you will help provide valuable information that will be used to develop better HIV prevention services for people living with HIV in Montana. Ultimately, this information will be used to develop programs to prevent the spread of HIV.

PROCEDURES
Participation in this focus group is ***voluntary***. You are asked to read this consent form. If you agree to participate you will be asked a number of questions regarding your perceptions of the needs of people living with HIV in Montana. The focus group interview may take approximately one hour. The session will be audio recorded and transcribed for accuracy of responses.

PAYMENT FOR PARTICIPATION
You will receive $25.00 cash for participating in this focus group.

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. You are welcome to refrain from answering any question for any reason or to discontinue your participation at any time. Contact information for organizations where you can receive confidential answers to your questions or receive more information and/or support are listed at the end of this consent form.

BENEFITS
Your help with this study will provide valuable information to the Montana Department of Public Health and Human Services. By participating in this study, your answers will help staff offer services and develop programs to meet the HIV prevention needs of people living with HIV in Montana.

CONFIDENTIALITY

All information collected during this focus group interview will be ***confidential***. Researchers and interviewers will avoid recording any identifying information. 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 interview 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 without loss of the incentive money or any other benefits to which you are normally entitled.

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, Emily Epperson,* at (770) 316-6719.

If you have any questions about your rights as a research subject you may contact the Chair of the Institutional Review Board in the Research Office at The University of Montana – Phone (406) 243-6670.

CONSENT

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.

APPENDIX H: Resource Contact Sheet

HIV Testing Services in Montana

BILLINGS and EASTERN MONTANA		
***RiverStone Health**	Billings	406-651-6416
***Yellowstone AIDS Project**	Billings	406-245-2029
Montana Migrant Council** (Full time locations in Billings, Fairview & Dillon; Mobile unit in Flathead and Lake Co.) ***Toll free # for referrals to any Mt. Migrant sites	Billings Fairview Dillon ***Billings***	406-248-3149 406-742-5201 406-683-5570 ***800-813-4492***
Custer County Health Department	Miles City	406-874-3377
Dawson County Health Department	Glendive	406-377-5213
Roosevelt County Health Department	Wolf Point	406-653-6223
BOZEMAN		
***Bridger Clinic**	Bozeman	406-587-0681
***Connections**	Bozeman	406-451-9995
***AIDS Outreach**	Bozeman	406-451-5718
GREAT FALLS and CENTRAL MONTANA		
***Cascade City-County Health Dept.**	Great Falls	406-454-6950
***Hill County Health Department**	Havre	406-265-5481
***Central Montana Family Planning**	Lewistown	406-535-8811
HELENA, BUTTE and SOUTHWEST MONTANA		
***Lewis and Clark City-County Health Dept.**	Helena	406-443-2584
Leo Pocha Memorial Clinic	Helena	406-449-5796
***B.A.S.S.**	Butte	406-491-1378
Butte Family Planning	Butte	406-497-5080
***Butte Silver Bow City-County Health Dept.**	Butte	406-497-5016
***MCDC – Montana Chemical Dependency Ctr.**	Butte	406-496-5430
Beaverhead Family Planning	Dillon	406-683-3183
***Montana Migrant Council – Dillon site**	Dillon	406-683-5570
MISSOULA and NORTHWEST MONTANA		
***Partnership Health Center**	Missoula	406-258-4165
***Missoula City-County Health Department**	Missoula	406-258-3881
***FDH and Associates**	Missoula	406-829-8075
***Missoula AIDS Council**	Missoula	406-543-4770
***Salish Kootenai College**	Pablo	406-275-4926
Lake County Health Department	Polson	406-883-7314
***Flathead City-County Health Department**	Kalispell	406-751-8150

***Receives funding from Montana DPHHS for HIV Testing. Tests are offered at no charge. Additional HIV testing information is available at www.getcheckedmt.org.** HIV testing is also available at Family Planning entities as well as IHS and Tribal Health locations.

Various Montana Resources

BILLINGS	
Yellowstone AIDS Project	www.yapmt.org
TriState HELP Eastern Region	406-248-6600
AIDSpirit Montana	406-696-1164; info@aidspiritusa.org
BOZEMAN	
Gallatin Valley Human Rights Task Force	Bozeman - www.embracediversity.org
AIDS Outreach	406-451-5718; info@aidsoutreachmt.org
Bozeman GLBTIQ Resource Center	406-600-3608
Connections	caseyconnections@msn.com
BUTTE	
Butte AIDS Support Services	BASSinMT@aol.com
Helena	
L&C AIDS Project	457-8952; RPIERSON@co.lewis-clark.mt.us
KALISPELL	
Flathead AIDS Council	406-261-4334
MISSOULA	
Missoula AIDS Council	www.missoulaaidscouncil.org
TriState HELP Western Region	406-543-4775
FDH & Associates	outinmt@aol.com
OTHER	
Montana Department of Public Health and Human Services	www.dphhs.mt.gov/PHSD/index.shtml/Helena
LGBT Statewide Events	QNews Montana
Missoula (Gay) Men's Chorus	www.gaymontana.org/community/gaychorus.html
The University of Montana Lambda Alliance	406-243-5922
Western Montana Community Center	Missoula – 406-543-2224
Gay Montana	Missoula – www.gaymontana.org
Montana PRIDE Network	Helena – www.montanapridenetwork.org
QSA	Bozeman – www.gsamsu.com
Imperial Sovereign Court of Montana	Missoula – www.geocities.com/iscsm

Gay-friendly health care providers listed at the following link:
http://www.mtgayhealth.org/medical/

APPENDIX I: Questionnaire Consent Form

QUESTIONNAIRE PARTICIPANT INFORMED CONSENT

TITLE
A Needs Assessment of People Living with HIV in Montana

SPONSOR
The Montana Department of Public Health and Human Services – HIV/STD Section

PROJECT DIRECTOR:
Dr. Annie Sondag
The University of Montana
Department of Health & Human Performance
Missoula, MT 59812
(406) 243-5215
annie.sondag@mso.umt.edu

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

PURPOSE
The purpose of this study is to assess the HIV prevention needs of people living in Montana who are infected with HIV. By participating in this interview you will help provide valuable information that will be used to develop better HIV prevention services for people living with HIV in Montana.

PROCEDURES
Interview participation for this study 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 people living with HIV in Montana. The questionnaire will take approximately 30-40 minutes to complete. All your answers will be anonymous.

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. You are welcome to refrain from answering any question for any reason or to discontinue your participation at any time.

PAYMENT FOR PARTICIPANTION
You will receive $10.00 cash for participating in this questionnaire.

BENEFITS
Your help with this study will provide valuable information to the Montana Department of Public Health and Human Services. By participating in this study, your answers will

help staff offer services and develop programs to meet the HIV prevention needs of people living with HIV in Montana.

CONFIDENTIATLIY

All information collected from the questionnaire will be ***confidential***. Questionnaires do not require any identifying information.

If you choose to access the online questionnaire, you will be asked to access a hyperlink following your completion of the questionnaire. This site will ask you to provide a mailing address where your $10 incentive can be mailed. This information will be stored in the Survey Monkey database and will only be accessed by the researcher. ***Your personal information will NOT be linked to your questionnaire answers.***

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

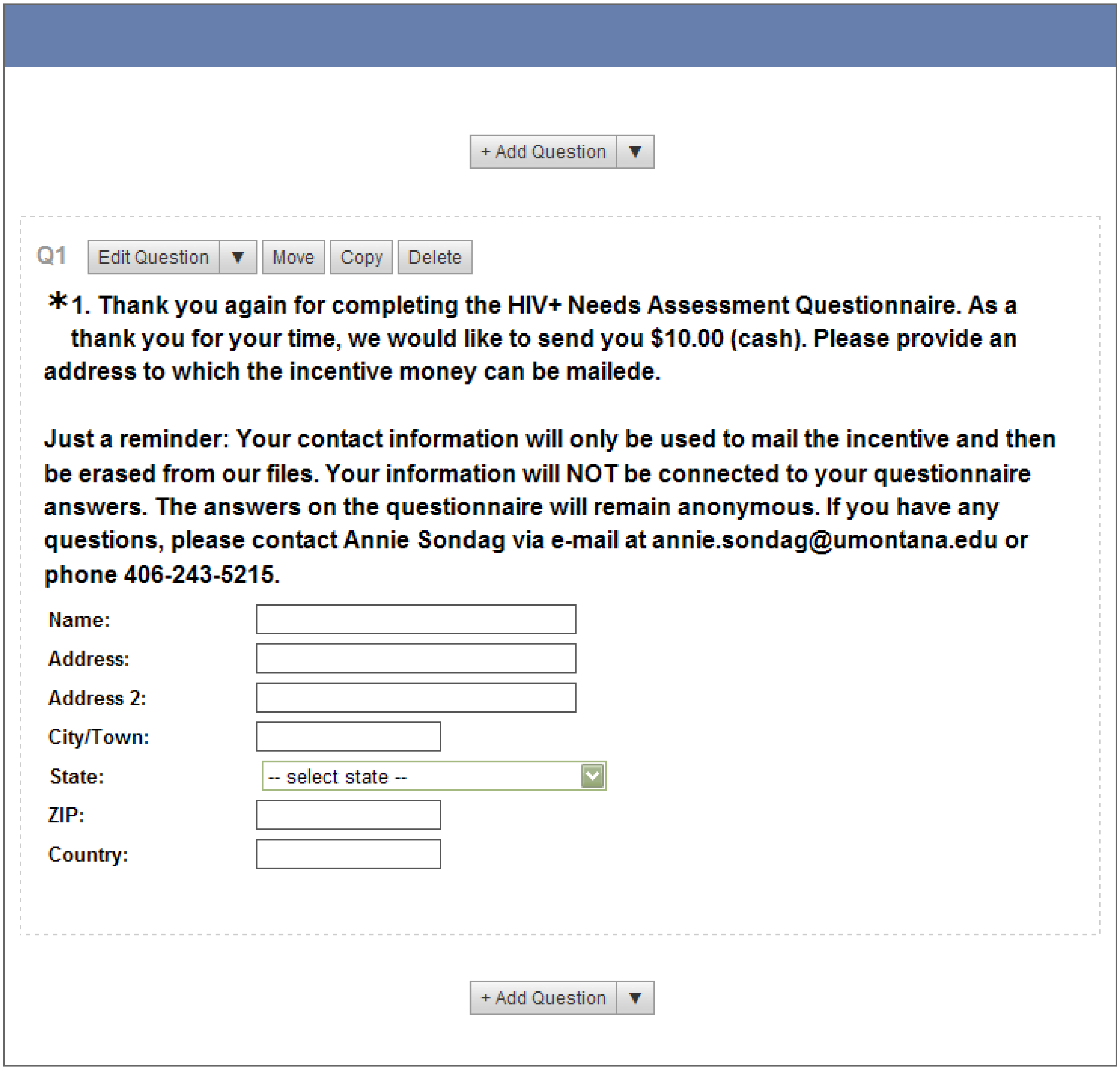
If you have any questions about the research now or later, you may contact *Dr. Annie Sondag* at (406) 243-5215 or *Annie's Research Assistant, Emily Epperson,* at (770) 316-6719.

If you have any questions about your rights as a research subject you may contact the Chair of the Institutional Review Board in the Research Office at The University of Montana – Phone (406) 243-6670.

CONSENT

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 of this consent to keep.

APPENDIX J: Questionnaire Incentive Page



*1. Thank you again for completing the HIV+ Needs Assessment Questionnaire. As a thank you for your time, we would like to send you $10.00 (cash). Please provide an address to which the incentive money can be mailede.

Just a reminder: Your contact information will only be used to mail the incentive and then be erased from our files. Your information will NOT be connected to your questionnaire answers. The answers on the questionnaire will remain anonymous. If you have any questions, please contact Annie Sondag via e-mail at annie.sondag@umontana.edu or phone 406-243-5215.

Name:
Address:
Address 2:
City/Town:
State: -- select state --
ZIP:
Country:

APPENDIX K: Questionnaire

Montana
2012 Consumer Questionnaire

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

- The purpose of this survey is to determine the health related needs of people who are living with HIV/AIDS in Montana.
- Your participation in this study will provide valuable information to public health and health care professionals who work with people 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__________.

THANK YOU VERY MUCH!

January 25, 2012

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 2012. This questionnaire is very important to YOU and *everyone* fighting the battle against HIV/AIDS. Information from the questionnaire will be used by the Department of Public Health and Human Services to find out the barriers people with HIV face when trying to access prevention and treatment services. The State of Montana will use the information from the questionnaire when it makes its funding request to the Centers for Disease Control and Prevention and for Ryan White HIV treatment funding requests. 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 complete the questionnaire on line, or complete the paper copy and return it in the enclosed self-addressed stamped envelope, or return it to your Ryan White case manager or to 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

2012 HIV Positive Survey
QUESTIONNAIRE PARTICIPANT CONSENT FORM

TITLE: A Needs Assessment of People Living with HIV in Montana

SPONSOR: The Montana Department of Public Health and Human Services – HIV/STD Section

PROJECT DIRECTOR: Dr. Annie Sondag, The University of Montana Department of Health & Human Performance Missoula, MT 59812 (406) 243-5215 annie.sondag@mso.umt.edu

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

PURPOSE: The purpose of this study is to assess the HIV prevention needs of people living in Montana who are infected with HIV. By participating in this interview you will help provide valuable information that will be used to develop better HIV prevention services for people living with HIV in Montana.

PROCEDURES: Interview participation for this study 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 people living with HIV in Montana. The questionnaire will take approximately 30-40 minutes to complete. All your answers will be anonymous.

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. You are welcome to refrain from answering any question for any reason or to discontinue your participation at any time.

PAYMENT FOR PARTICIPATION: You will receive $10.00 cash for participating in this questionnaire.

BENEFITS: Your help with this study will provide valuable information to the Montana Department of Public Health and Human Services. By participating in this study, your answers will help staff offer services and develop programs to meet the HIV prevention needs of people living with HIV in Montana.

CONFIDENTIALITY: All information collected from the questionnaire will be anonymous. Questionnaires do not require any identifying information. If you choose to access the online questionnaire, you will be asked to access a hyperlink following your completion of the questionnaire. This site will ask you to provide a mailing address where your $10 incentive can be mailed. This information will be stored in the Survey Monkey database and will only be accessed by the researcher. Your personal information will NOT be linked to your questionnaire answers.

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. 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, Emily Epperson, at (770) 316-6719.

PART 1:
Please tell us about yourself.
(Remember, your answers are strictly ANONYMOUS)

1. **What is your gender?**
   ○ Female ○ Male ○ Transgender ○ Other ____________________

2. **What is your race/ethnicity?**
   ○ Native American/Alaska Native ○ Asian/Pacific Islander ○ African American
   ○ White (non-Hispanic) ○ Hispanic ○ Other ________________________

3. **What is your age?** _______________

4. **What is the highest level of education you have completed?**
   ○ Less than high school ○ Some high school, but did not graduate ○ High school/GED
   ○ Trade or Vocational School ○ Community College Graduate
   ○ Some college, but didn't graduate ○ College Graduate ○ Graduate or Professional School

5. **Which of the following categories contains your Gross (the amount you would claim on your income tax form before taxes are taken out) individual yearly income?**
   ○ 100,000+ ○ 75,001-100,000 ○ 50,001-75,000 ○ 35,001-50,000 ○ 20,001-35,000
   ○ 10,001-20,000 ○ 6,000-10,000 ○ Less than 6,000

6. **How would you identify yourself?**
   ○ Heterosexual/Straight ○ Gay ○ Lesbian ○ Bisexual ○ Other ____________

7. **What is your current relationship status?** *(check all that apply)*
   ○ Single
   ○ In a committed monogamous relationship with a man
   ○ In a committed monogamous relationship with a woman
   ○ In a non-monogamous (open) relationship with a man
   ○ In a non-monogamous (open) relationship with a woman
   ○ Married to a man, but in a non-monogamous (open) relationship
   ○ Married to a woman, but in a non-monogamous (open) relationship

8. **What is your current employment status?**
   ○ Employed full time ○ Employed part time ○ Not employed ○ Self employed
   ○ On disability ○ Fulltime ○ Student ○ Other

9. **Where are you living right now?**
   ○ A house or apartment that I rent ○ A house or apartment that I own
   ○ In a friend or relative's house or apartment ○ Hospice or nursing facility
   ○ Live on the streets or in a shelter ○Jail or prison ○ Drug/alcohol treatment center
   ○ Living in public housing ○ Other ________________

10. **If you are living in your own house or apartment, are you receiving housing assistance?**
    ○ No ○ Yes ○ I'm not sure ○ Does not apply to me

11. Do you have any dependent children living with you?
○ No ○ Yes If yes, how many? ___________

12. Do you have health insurance?
○ No ○ Yes

13. If you answered yes to question 12, what kind of health insurance do you have?
○ Medicaid ○ Medicare ○ Private Insurance
○ Ryan White/AIDS Drug Assistance Program ○ Veteran's Benefits
○ Indian Health Service or Tribal Health ○ Other _________________________

PART 2:
Please Tell Us about Your HIV/AIDS Status

14. In general, how would you rate your overall health?

○ Very good ○ Good ○ Fair ○ Poor ○ Very poor

15. 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 _____________________

16. How many years ago did you learn you were HIV positive? _____________________________

17. How long after learning you were HIV positive did you seek treatment?
○ I have not yet sought treatment ○ Less than one week ○ 1 week to 3 months
○ 3 to 6 months ○ 6 months to 1 year ○ More than 1 year

18. When you found out you were HIV+, where you also diagnosed with AIDS?
○ No ○ Yes ○ Can't remember

19. If you were diagnosed with AIDS at the same time you tested positive for HIV, why didn't you test sooner? *(check all that apply)*
○ I thought I was at low or no risk
○ I didn't care if I was HIV+ or not
○ There was no cure, why bother
○ Too long to wait for results
○ Insurance reasons
○ Testing hours were inconvenient
○ Testing location was inconvenient
○ I always practiced safe sex
○ I was in a monogamous relationship
○ I was afraid of needles
○ I practiced only oral sex
○ I usually practiced safe sex
○ I didn't know about HIV
○ I was afraid of being discriminated against if I was HIV+
○ I was afraid of losing my partner
○ HIV test was too expensive
○ I didn't trust the health department/testing location
○ I wasn't sure where to get tested
○ I was afraid of losing my job if I was HIV+
○ I was afraid of being alienated from my family
○ I was too scared to get the test done
○ Too scared to find out the results of the test
○ I thought it was a gay disease
○ Other ____________________________________

20. When you did test, what prompted you to get tested? ________________________________

21. Are you currently diagnosed with AIDS?
○ No ○ Yes ○ Don't know

22. Have you had a CD4 count or viral load in the last 12 months?
○ No ○ Yes ○ Don't know

23. If you are receiving treatment, how did you get linked to treatment or related services?
○ I have never been linked to treatment or services for HIV
○ My personal doctor/health care provider connected me with treatment and services
○ I have an HIV positive friend/acquaintance who helped me find services
○ The person who did my HIV test referred me to a Ryan White case manager
○ The person who did my HIV test linked me to treatment services
○ I looked on the internet to find out where to get treatment and services
○ Other____

24. Are you aware that there are case managers available in Billings, Missoula, Great Falls, Helena, Havre, Kalispell, Butte, and Bozeman who can help you obtain treatment and other services?
○ No ○ Yes

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

26. If you currently have a case manager, who is your case manager?
○ Debbie Brown ○ Becky Taylor ○ Erin Chambers or Sasha Abrahamson
○ Kathy Mackey ○ Trisha Gardner ○ Shanda Smith
○ Robie Marcoux ○ Holly Jordt ○ Traci McArthur
○ Larisa Hammond ○ Karen Pelley ○ Rebecca Harvey
○ Other person ____

27. If you answered "no longer" or "never" to question 25, why not? *(check all that apply)*
○ I use alternative therapy because standard medicine is too harsh ○ I live too far away
○ I don't know how a case manager could help me ○ I don't need services
○ I don't trust health care providers to keep my condition confidential ○ I can get services myself
○ I'm worried people will find out I have HIV or AIDS ○ They don't understand my culture
○ A different service provider helped me get services ○ I can't afford treatment or other services
○ I feel too embarrassed to talk to a case manager about my HIV status
○ I didn't know one was available ○ Other ____________________________________

28. Using the map above, in which region do you reside?
○ Region 1 ○ Region 2 ○ Region 3 ○ Region 4 ○ Region 5

PART 3:
Please Tell Us about Your Behaviors Since Becoming HIV-Positive
(This is ANONOMOUS and you don't have to answer any questions that make you feel uncomfortable.)

29. Which best describes your sexual activity since becoming HIV positive?
○Stopped sexual relations ○Never use condoms ○Sometimes use condoms ○Always use condoms

30. Do you ask the HIV status of your partners?
○No ○Yes ○Sometimes ○Not sexually active

31. Has your current sex partner been tested for HIV?
○No ○Yes ○Don't know

32. Does your sex partner(s) know your HIV status?
○No ○Yes ○Sometimes

33. Have you been infected with a sexually transmitted disease (STD) since your diagnosis?
○No ○Yes ○I have not been tested for STDs since my diagnosis

34. If you answered yes to question 33, which STD have you been infected with (check all that apply)?
○Syphilis ○Genital warts ○Gonorrhea ○Herpes ○Chlamydia ○Other_______________

35. Do you have any other medical illnesses besides HIV/AIDS?
○No ○Yes

36. If you answered yes to question 35, what illnesses do you have?
○Hepatitis C / Hepatitis B ○Diabetes ○Alcoholism ○Heart disease
○Drug dependency ○Mental illness ○Opportunistic infections ○Other_______________

37. Have you used substances in the past?
○No ○Yes

38. If you answered yes to question 37, which substances have you used?
○Alcohol ○Marijuana ○Crack ○Cocaine ○Heroin ○Meth/Crystal
○Downers ○Other_______________________

39. Have you injected any drugs in the past year?
○No ○Yes

40. If you answered yes to question 39, have you shared needles while injecting drugs in the past year?
○No ○Yes

41. How much of a problem is your drug/alcohol use?
○ None, I don't have a problem
○ Small problem-doesn't negatively affect my family, social, or work life
○ Somewhat of a problem-occasionally has a negative effect on my family, social, or work life
○ Big problem-negatively affects my family, social, or work life
○ Don't know

42. Do you have emotional concerns, which have caused a problem for you in the past 6 months?
○No ○Yes

43. If you answered yes to question 42, what are you emotional concerns?
○Stress ○Depression ○Guilt ○Suicidal tendencies ○Anger/resentment
○Worry/fear (concern about the future) ○Loneliness (isolating yourself)
○Other____

44. Are you receiving any treatment for emotional or stress related problems (depression)?
○No ○Yes

45. If you answered yes to question 44, what treatment(s) are you using?
○Prescription medicine ○Alternative therapies ○Counseling ○Other____________________

46. Has becoming HIV+ caused problems in your close relationships?
○No ○Yes

47. If you answered yes to question 46, what problem(s) has it caused?
○Stress or isolation in relationships with your family
○Difficulties in relationship with your spouse/partner
○Difficulties in relationship(s) with children ○Other____________________________

48. What type of prevention or education services would you prefer?
○ I don't need any services
○ Group counseling (with other HIV+ people)
○ Peer counseling (by other HIV+ people)
○ Education offered by your primary care provider
○ Other__________________________________
○ HIV+ weekend retreats
○ Group education workshops
○ Counselor led HIV+ support group
○ Individual counseling

PART 4:
Please Tell us about your Barriers to Prevention and Treatment Services

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

Big barrier – stopped you from getting service(s) or caused you to discontinue service(s)
Small barrier – caused minor concern and/or delays in obtaining services(s)

	Big Barrier	Small Barrier	Not a Barrier
Not knowing what service or treatment is available to me/lack of services			
The location of the organization providing services			
My physical health			
The quality of assistance or treatment			
Not knowing what medical assistance or treatment I need to treat my HIV or AIDS infection			
My state of mind or mental ability to deal with the treatment			

Not having transportation			
	Big Barrier	Small Barrier	Not a Barrier
My concern that other people may see me when I go to get care or learn about my HIV infection (lack of confidentiality/stigma)			
Discrimination I experienced by the persons or organization providing the service			
Fear/Stigma			
Anonymity/confidentiality			
Lack of experience of the person providing services to me			
The amount of time I had to wait to get an appointment			
The cost of assistance or treatment			
Not having enough insurance coverage			
Burnout from dealing with/talking about HIV			
Other ______________________________			

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

1.____

2.____

51. Are there other forms of help that we have not mentioned that you would like to have access to, or are currently using? (Please specify below)

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

Thank You!