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# **ASSESSMENT OF THE NEEDS OF HIV POSITIVE PEOPLE IN MONTANA**

By  
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B.S., Northern Michigan University, 1999  
Marquette, Michigan

Presented in partial fulfillment of the requirements  
for the degree of  
Master of Science

Department of Health and Human Performance  
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Missoula, Montana  
July 2, 2001

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## **Thesis Abstract**

**Hackenbruch, Jennifer, M.S. 2001      Health and Human Performance**

**Assessment of the Needs of HIV Positive People in Montana**

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

The purpose of the study was to assess the needs of those people over the age of 18, living with HIV/AIDS in Montana. Data was collected from multiple sources. A survey instrument was developed, pilot tested, and implemented and used to gain insight in the following areas: living arrangements, demographics, HIV/AIDS status, behaviors, service needs, medical and health care needs, social support needs, and basic necessity needs. Five focus groups throughout the state and eight key informant interview with Ryan White Title II and Title III case managers were conducted.

Descriptive statistics and frequencies were reported by actual count and sample size. Alternative therapies were reported as the top medical and health care need, social/recreation activities were reported as the top social support need, and housing or rent assistance were reported as the top basic necessity needs.

Results of this study provided Montana's Department of Health and Human Services and Ryan White Consortia important needs assessment data to be used when planning HIV prevention strategies. The methodology developed for this study can be used for future needs assessments of this population.

## **Acknowledgments**

**“I must believe that whatever it is, I can handle it.”**

**~Iyanla Vanzant**

I would like to thank every one who supported me through the highs and lows of this adventure.

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## **CHAPTER I**

### **Introduction of the Study**

People living with Human Immunodeficiency Virus (HIV) have considerable need for a wide variety of services. These needs include medical, dental, social, psychological and mental, alternative therapies, drug treatment, basic necessity as in food, shelter, and transportation, and financial needs (Cunningham et al. 1999, Marx et al. 1997, Bunuck et al. 1996, Murphy et al. 1992). Those people living with HIV in rural areas may face many more challenges in meeting their needs than those in urban areas because rural health care facilities are far less adequate than those in urban areas (Lam & Liu, 1994).

Montana is considered a rural state with a population of approximately 900,000. Since 1985, there have been 431 AIDS cases in Montana. One hundred and ninety four of these cases are people living with AIDS (See appendix A) the remainder have either died of an AIDS related illness or moved out of the state. According to Jim Murphey, epidemiologist at the Montana Department of Public Health and Human Services (DPHHS), an estimated 500 to 600 people are living with HIV in the state. Because of the small population of the state, the prevalence of HIV/AIDS is relatively low when compared with other states. The federal government allocates HIV/AIDS funding based upon the number of AIDS cases diagnosed in each state. Therefore, in states like Montana, with a

low prevalence, the health care resources may not be adequate to meet the needs of people with HIV (Cohn et al. 1994).

Because many rural communities have not faced high prevalence of HIV/AIDS so fear, hostility, misunderstanding, and ignorance related to the disease exists (Smith et al. 1990). Montana is considered a rural state and because the HIV/AIDS health care system in small towns and rural communities differs from urban communities persons living with HIV/AIDS in Montana may have special needs and barriers in regard to maintaining a suitable quality of life. To determine needs, it is important to ask the people of this population what those needs are, including which are most important and which are more prevalent. Planning medical care and related services should be based on the analysis of the population to be served (Davis & Stapleton, 1991).

### **Purpose of the Study**

The purpose of this study was to assess the needs of people living with HIV/AIDS in Montana, including both those receiving, and those not receiving HIV related services. In addition, barriers to receiving HIV/AIDS related care was also be examined. DPHHS and Ryan White Title II Consortiums will use this information to identify the current resources available, and determine the gaps between needs and services.

## **Research Questions**

The research questions examined in this study will focus on persons living with HIV/AIDS in the state of Montana.

1. What are the needs of HIV positive people in Montana?
  - a. What are the health care needs?
  - b. What are the social support needs?
  - c. What are the housing needs?
  - d. What are the financial needs?
  - e. What are the basic needs?
2. What resources and services are being used by HIV positive people in Montana?
3. What are the barriers to receiving HIV prevention and health care services?
4. What are the identified gaps between needs and services?
5. What are the emerging needs of persons living with HIV in Montana?

## **Statement of the Problem**

The Montana Department of Public Health and Human Services (DPHHS) and the Ryan White CARE Act, Title II would like to improve the quality of services available to HIV positive people. The perceived need of this population in Montana was not known. Therefore, a statewide needs assessment was performed to determine the needs of the target

population. The results of this study will provide the DPHHS and Ryan White staff valuable insight concerning the needs of HIV positive people. Barriers to receiving care and meeting needs were identified. Available resources and services were noted, and the gaps between needs and services were identified. Determining the needs of HIV positive people in Montana, will ultimately improve the availability and quality of HIV related services.

### **Delimitations**

The delimitations of the study are as follows:

1. The study was delimited to HIV positive people in Montana.
2. Data was collected via surveys, focus groups, and key informant interviews.
3. Data was restricted to participants' self report on surveys, during focus groups and interviews.
4. Participants in the study were volunteers.

### **Limitations**

The limitations of the study are as follows:

1. Response was limited to the voluntary action of participants completing the survey.
2. Focus group and interview data was limited by what the participants were willing and able to share.

3. Data was limited to the honesty and accuracy of the participants when filling out the surveys, participating in the focus groups and interviews.
4. Data was limited to those individuals who were contacted by Ryan Whit case managers and indigenous leaders.

### **Definition of Terms**

**Gap analysis:** the difference between needs and the services available.

**HIV positive:** for the purpose of this study HIV positive includes those individuals diagnosed with HIV and/or AIDS.

**Need:** is the difference between the present situation and a more desirable one (Gilmore & Campbell, 1996, p. 4).

**Needs Assessment:** is a planned process that identifies the reported needs of an individual or group (Gilmore & Campbell, 1996, p. 5).

Identifying the health needs of the target population and deciding whether or not these needs are being met (McKenzie & Smeltzer, 1997, p. 39).

**Perceived needs:** are those needs envisioned and reported by the participants in a needs assessment process (Gilmore & Campbell, 1996, p. 5)

**Unmet needs:** refers to service needs of those individuals not currently in care as well as those in care whose needs are only partially met or not being met (HRSA, 11-5).

## **CHAPTER II**

### **Review of Literature**

As the HIV/AIDS epidemic moves into its third decade changes are occurring. The demographic information of the epidemic tells us that the incidence rate of HIV among the general heterosexual population, women and minorities is increasing more than with men who have sex with men (MSM) and injecting drug users (IDUs). The geographical scope of the disease is also changing. It is moving from concentrated urban areas to less populated rural areas.

#### **National AIDS Incidence**

According to the Centers for Disease Control and Prevention (CDC) in 1998 there were over 641,086 Americans with Acquired Immunodeficiency Syndrome (AIDS). Of that number, over half have died of an AIDS related illness. Of those people, almost 75% of them were between the ages of 25-44, 21% were over the age of 44, and less than 4% were under the age of 24. In 1996, estimated AIDS incidence and deaths among people with AIDS declined for the first time. New drug therapies are responsible for this decline. The extended lifespan of people living with AIDS has increased the prevalence of those living with the disease, which will increase the need for prevention and treatment services. The CDC estimates that 650,000 to 900,000 Americans are living with HIV, and at least 40,000 new infections occur each year (Trends in the HIV & AIDS Epidemic, CDC 1998).

At the beginning of the AIDS epidemic, the population with the highest incidence of the disease was MSM and IDUs. In the last ten years, national statistics have shown the prevalence of AIDS increasing most among the general heterosexual population, women and African Americans (Lam & Lui, 1994). According to the CDC, the incidence of AIDS in MSM began to decrease in 1993, while the incidence among IDUs and the heterosexual population continued to increase, increasing most with heterosexuals. This trend continued through 1995. In 1996, the incidence rates among IDUs decreased, and the incidence rates among heterosexuals began to level off (Trends in the HIV & AIDS Epidemic, CDC 1998).

From the beginning of the AIDS epidemic through 1994, showed incidence rates increased in all regions of the United States, increasing most in the Southern region. However, a major shift occurred in 1996 when AIDS incidence decreased in the Midwest by 10%, the West by 12%, in the Northeast by 8%, and neither decreased nor increased in the South (Trends in the HIV & AIDS Epidemic, CDC 1998). These statistics do not cover HIV incidence, and the decrease in AIDS incidence most likely due to successful drug treatments.

### Rural AIDS Incidence

As the demographics of the HIV/AIDS epidemic change, the geographical scope is expanding into rural areas of the United States.

The demographics of HIV/AIDS in rural America differ from the overall national demographics. Infected individuals in rural areas tend to be young, non-white, females who contracted the disease through heterosexual behavior (Sowell & Christensen 1996, Lam & Lui 1994).

By 1989 the number of reported AIDS cases showed a 37% increase in rural areas compared with a 5% increase in urban areas (Sowell & Christensen 1996, Cohn et al 1994). Between 1991 and 1995 AIDS cases increased by 80% in rural America. These numbers may be underestimated because in some rural communities the cases of HIV/AIDS may not be reported (Willard et al. 1999). According to the CDC there were 23,615 reported new cases of AIDS in non-metropolitan regions of the United States between March of 1994 and February of 1995 (Trends in the HIV & AIDS Epidemic, CDC 1998). Sowell & Christenson (1996) believe the increase in incidence and prevalence of HIV/AIDS in rural areas is related to both HIV transmission within these areas and migration of persons with HIV into these areas.

#### AIDS Incidence in Montana

According to the CDC, AIDS is the fourteenth most common disease reported in Montana. As of December 2000, there were 433 AIDS cases in Montana of those cases there have been 238 AIDS related deaths (Appendix A). In 1999 Montana's AIDS case rate was 1.9 cases per 100,000 people, compared to 3.1 in 1998, and 5.2 in 1997 (Damrow &



Murphy, 2000). Montana's case rate is much lower than the national case rate of 16.5 cases per 100,000 people. Due to the availability of effective drug treatments, the number of AIDS cases has not only decreased on a national level but in Montana as well. In 1999 there was a 30% decrease in the number of AIDS cases reported in Montana. The decline in AIDS cases, however, does not reflect a similar decline in HIV-transmission (Damrow & Murphy, 2000).

Since the beginning of the AIDS epidemic, the general characteristics of Montana's AIDS cases have not showed many changes. AIDS continues to be reported ten times more frequently among males than females, and individuals aged 30-39 continue to account for almost half of the reported cases. One-fifth of the AIDS cases in Montana are among people in their twenties. AIDS cases among racial and ethnic groups in Montana generally reflect each group's distribution among the state's population. Because of low minority population, Montana's statistics do not show the increase in incidence among racial and ethnic minority groups that the statistics show on a national level (Damrow & Murphy, 2000).

Montana has not seen the increase in AIDS cases among IDUs and heterosexual contact that the rest of the nation is experiencing. MSM and IDUs continue to constitute the majority of Montana's AIDS cases, while on a national level the incidence of these groups is declining, MSM and IDUs account for almost 80% of the AIDS cases occurring. This

percentage has changed very little over the last ten years. The remaining cases of AIDS in Montana consist of heterosexual contact. While the AIDS cases among women are low, 41 cases (Appendix A), 63% contracted AIDS through heterosexual contact (Damrow & Murphy, 2000).

### Needs of People with HIV/AIDS

#### Introduction.

A need is the difference between the present situation and a more desirable situation (Gilmore & Campbell, 1996, p.5), while an unmet need involves not receiving a treatment or service that would improve the health of or benefit the individual. In other words, an unmet need exists if a person's functional performance is not up to standard and if support available is not able to meet the person's need (Smith & Rapkin, 1995). The needs of people with HIV are varied and include both health care and basic necessity needs. These needs can include, but are not limited to, medical, dental, mental health, alternative therapies, drug treatments, transportation, social support, childcare and living expenses (Cunningham et al., 1999, Marx et al., 1997, Bunuck et al., 1996).

According to Smith & Rapkin (1995), needs of the HIV positive population have become more varied in part because of an emphasis on decreased hospitalization, better outpatient services and the growing trend for home and community based services. This trend toward independent living may place people with HIV/AIDS at greater risk for having unmet

needs, which in turn poses serious threat to individual quality of life (Smith & Rapkin, 1995).

Following is a discussion of the most salient needs identified in the literature.

### Health Care Needs.

A study conducted by Marx et al. (1997) surveyed over 1000 HIV-infected clients at San Francisco Ryan White Comprehensive AIDS Resources Emergency Act (CARE) funded agencies. The majority of the sample surveyed were male, non-white and uninsured or underinsured. Almost half of the respondents had a CD4 count of <200 cells. The most common HIV risk groups were gay/bisexual male non-injection drug users and gay/bisexual male IDUs. The authors found the most common health care needs of this population were medical, dental and mental health. Over half of those surveyed showed basic necessity needs for food and living expenses. The most common unmet service needs included dental care, mental health care, home health care, and alternative therapies such as massage, herbs and vitamins. According to this study poor people, those with dependents, and gay/bisexual male IDUs had greater unmet need. The authors indicated women and minorities did not necessarily have greater unmet need than the rest of the sample.

Bonuck et al. (1996) studied self-perceived needs concerning health care among people with HIV. Participants in this study completed a comprehensive survey of HIV-related service use and costs.

Respondents were also asked to identify unmet health service needs. Dental service was the most common unmet need, followed by mental health services and medications. HIV status, insurance status and living alone were significantly associated with unmet need. According to this study there were no statistically significant differences in the report of unmet need by race, ethnicity, gender or manner of infection with the virus.

Dental care, mental health care and medication services are more likely to be unmet needs for people with HIV than emergency room and hospital care services (Bonuck et al. 1996). Several studies identified dental services as a common unmet need among HIV positive people. Those persons with HIV not receiving dental care are at increased risk for gingival inflammation, abscesses, and sepsis (Boncuk et al. 1996, Capilauto et al. 1991). Capilauto et al. (1991) surveyed almost 900 hundred clients of the Robert Wood Johnson Foundation's Health Services program in nine cities in the United States. Over half of the respondents reported a need for dental care more than any other service need.

#### Subsistence Needs.

In a number of studies, basic necessities or subsistence needs, which include clothing, food, housing, childcare, household help, and transportation were found to be unmet for people with HIV (Cunningham et al 1999, Marx et al. 1997). These subsistence needs may become

barriers to meeting medical needs. The person may have to make a choice between buying food and going to the doctor. Going to the doctor could be hard for people who work, who have limited mobility due to AIDS or have limited transportation. According to Cunningham et al (1999), competing subsistence needs and other barriers are prevalent among persons receiving care for HIV in the United States, and often act as restraints to receiving medical care. Approximately 17,000 people receiving care for HIV/AIDS went without food, clothing or housing because they needed the money for medical care (Cunningham et al. 1999).

Smith and Rapkin (1995) interviewed 224 people living with AIDS. The majority of the participants were male; almost half were African American and Latino. Sex with men was the most common HIV risk factor, followed by sharing needles and sex with women. They investigated the prevalence of unmet need for assistance using six different categories, including personal care, activities of daily living, social functioning, and role performance, taking care of one's health and negotiating systems. The authors also examined the characteristics associated with having unmet need. Almost half of the respondents reported having unmet and partially met needs in the category of activities of daily living. For example, the highest unmet need in this area was doing strenuous jobs and activities, while the highest partially unmet need was accessing transportation.

### Social Support Needs.

The more social support HIV positive people have, the less likely they are to become depressed (Hays, Turner & Coates, 1992).

Unfortunately, as persons with AIDS spend more of their time at home, their need for support from family and friends increases, and this seems to be the time that family members withdraw their support. Reasons for this may include the multiple demands placed on caregivers, the caregivers' concerns about stigma surrounding the disease, fear of homosexuality and/or infection (Smith & Rapkin, 1995).

### Mental Health Needs.

Murphy et al. (1992) surveyed 50 HIV-infected men being treated at a county medical facility to determine which of seventeen needs were being met and the importance attributed to each need. More than 30% of the sample indicated that five of the seventeen needs were completely unmet. Three of the five completely unmet needs were psychological in nature, such as being able to talk about fears of the future and having someone to help with their feelings of depression, helplessness, anxiety or anger.

One study of HIV positive gay men found that learning HIV status leads to a number of losses. These losses experienced can encompass a variety of issues including sexual freedom, the sense of self as physically healthy, and looking forward to a normal healthy life span. Feared losses can also be experienced, such as normal cognitive functioning, financial

security, social support, and independence (Weiss, 1997). People with mental health service needs may remain isolated and depressed, which may add to the symptoms of their disease. In order to design successful mental health services for HIV positive people, it is important to identify factors that place this population at risk for psychological problems, such as depression, and ways to prevent or reduce those psychological problems (Hays, Turner & Coates, 1992).

#### Need by Risk and Demographic Categories.

Need and unmet need differed somewhat among the risk and demographic categories of HIV/AIDS. Piette et al (1993) interviewed a nonrandom cross-sectional sample of 907 HIV positive people in nine cities across the United States. The findings of this study indicate that women, people of color and injecting drug users (IDUs) were more likely to report unmet service needs in a number of different areas than the male non injecting drug users. IDUs reported more needs on average than non-IDUs. They were more likely to report unmet need for entitlements, housing and drug treatment. Women were more likely to report needs in all service areas. They also experienced higher unmet needs in mental health, drug treatment, childcare and transportation. According to Bunting et al. (1999) women living with HIV were more likely than their male counterparts to be living in poverty, more likely to be members of ethnic minority groups, more likely to have responsibilities for dependent children. Women were diagnosed later in the course of their disease and

were under treated for their HIV-related infections and symptoms. HIV positive women were more apt to live alone than HIV positive men.

Bonuck et al. (1996) indicated those living alone show more unmet need than those living with someone. However, in contrast to the above-cited research, Bonuck also reported no statistical difference in the report of unmet need by race, ethnicity, and gender or how they became infected. In a similar study, Marx et al. (1997) found women and minorities did not necessarily have greater need than the rest of their sample.

Demographic characteristics such as SES, insurance status and employment can influence the needs of people with HIV. One survey reported 60% of the respondents listed financial assistance as a need and because of lack of financial assistance, 33% were unable to obtain medicines, health insurance, legal assistance or mental health services (Bonuck et al. 1996). Unemployed and publicly insured people with HIV/AIDS were more likely to report need for all service areas (Piette et al. 1993). According to two different studies, one by Bonuck et al. (1996) and the other by Cunningham et al. (1993), the unemployed had more needs than the employed, the uninsured had more problems accessing care than the insured and were more apt to have unmet need.

### Housing Survey Results

The Analysis by Action Research Group conducted a housing survey for people living with AIV/AIDS in Montana, North Dakota, and



South Dakota. The respondents of this survey reported very low incomes. Some would have to move if their financial situation changed by \$50 a month. Forty-five Montana HIV positive residents responded to this survey. Of that number 13% receive help paying for housing and 11% are on a waiting list for help. The top five support service needs reported by respondents (n=45) included the following:

- Legal services (27%)
- Benefits counseling (24%)
- Dental Care (22%)
- Vocational rehab and employment services (22%)
- Food bank, food vouchers, and/or groceries (20%)

### **Ryan White CARE Act**

In 1990, Congress enacted the Ryan White Comprehensive AIDS Resources Emergency (CARE) Act into public law. In 1996, this act was amended to the Ryan White CARE Act of Amendments of 1996. This act illustrates the largest dollar investment made by the federal government for the provision of services for people living with HIV (Ryan White CARE Act Title II Manual, 1999).

The purposes of the Ryan White CARE Act are to help communities increase the availability of primary health care and support services, increase access to care for underserved populations, and to improve the quality of life of those people living with HIV/AIDS (Ryan

White CARE Act Title II Manual, 1999). Assistance from Ryan White CARE Act is directed through Title I, Title II, and Title III. Title I is eligible for metropolitan areas with the greatest number of reported AIDS cases. They receive grants to meet the emergency service needs of people with HIV. Title II is available for all states to receive grants to improve the quality, availability, and organization of health care and support services to people living with HIV and their families. Title III supports outpatient HIV early intervention services for low income and medically underserved people in existing primary care systems.

Title II grants are usually awarded to the Health Department on a formula basis to provide health care and support services to people living with HIV. These funds can be used to support a number of services, including, but not limited to, home- and community-based health care, support services, health insurance coverage programs, and drug therapy treatments (Ryan White CARE Act, Title II Manual, 1999).

States can either provide the services directly to those living with HIV, or they can subcontract with local Title II HIV care consortia. "A consortium is a group of public and nonprofit health care and support service providers and community-based organizations that plans, develops and delivers services for people living with HIV" (Ryan White CARE Act Title II Manual, 1999).

According to the literature the needs and unmet needs of HIV positive people cover a broad area. These needs include, but are not

limited to, medical, dental, social, mental, and basic necessity. The expressed needs of people living with HIV in Montana are not known, and therefore will be assessed.

## **Chapter III**

### **Methodology**

The purpose of this study was to assess the needs of people living with HIV in Montana; to identify the current resources available to meet those needs; and to determine the gaps between needs and services. In addition, the barriers to receiving HIV related services were examined. The results gathered from this study will be used as a guide to develop appropriate health services, programs, and assistance for this population.

### **Description of Target Population**

The population assessed in this study was HIV positive people over the age of 18 in Montana. For the purpose of this study, HIV positive includes those individuals diagnosed with HIV and/or AIDS. There were approximately 195 people living with AIDS in Montana and an estimated 500 to 600 people living with HIV (Damrow & Murphy, 2000).

### **Protection of Human Subjects**

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

## **PROCEDURES**

### **Selection of Sample**

#### **Survey**

The selection criteria for volunteer participation in this study was that individuals must be 18 years of age or older and diagnosed with HIV. Two strategies were used to recruit volunteers. First, Ryan White Title II case managers asked for volunteers among clients visiting the office. Participants received five dollars as an incentive to complete the survey. Case managers also were asked to mail the surveys to clients who did not make an office visit during the data collection period. There are seven Ryan White Title II, and three Title III case managers throughout the state of Montana. The Title II case managers and one Title III case manager were interviewed.

Second the reputational approach was used to recruit HIV positive individuals who did not access Ryan White Title II care. The reputational approach identifies individuals who have influence in the targeted population (Nix, 1977). These individuals were identified as indigenous leaders. Indigenous leaders were recognized from their participation and involvement with the target population. Once identified, the indigenous leaders provided access to the target population through the snowball technique. This technique was appropriate for a rural state such as Montana where access to high-risk groups can be difficult. The snowball

technique involved indigenous leaders who contacted individuals from the target population and requested their participation in the voluntary survey. Survey participants were then asked to provide the name and contact information of the indigenous leader to others in the target population. Persons who contacted the indigenous leader were asked to take part in the study. With this technique it was hoped that a good representation of the target population would be reached.

### Focus Groups

Five focus groups were conducted, two HIV positive mixed gender groups, two male HIV positive groups, and one HIV positive female group. Individuals were invited to participate on a volunteer basis from existing Ryan White HIV positive support groups. Food and beverages were served as incentive to participate in the group. At the time there were six active support groups in Montana. An effort was made to obtain participation from groups meeting in different geographical regions of the state. The facilitators of the support groups were contacted and asked to solicit volunteers to participate in these focus groups. The focus groups took place in Great Falls, Billings and Missoula.

### Key Informant Interviews

Case managers from each Ryan White Consortium in Montana were asked to participate in a face-to-face interview with the researcher

concerning their clients' needs. These people worked closely with their HIV positive clients and thus were a valuable resource for information regarding the needs of their clients.

## **Instrumentation**

### **Survey**

A survey instrument was developed to identify the needs of the HIV positive people in Montana (Appendix C). Survey questions were adapted from a number of existing survey instruments and from the issues addressed in the review of literature. The survey was divided into five sections: living arrangements, demographics, HIV status, behaviors, and service needs. Included in these sections was an assessment of housing needs, demographics of the population, HIV/AIDS status, high-risk behaviors of the population, medical and health care needs, mental health needs, social support needs, basic needs, such as transportation, and other needs expressed by the target population.

The survey was reviewed by an expert panel including: university professors, Ryan White case managers, members of the target population, and state public health HIV prevention staff. The survey was pilot tested on members of the target population and was revised accordingly.

### **Focus Groups**

Five focus groups were conducted throughout the state of Montana. Individuals from existing Ryan White Title II HIV support groups were invited to participate. The focus group questions were developed based on the categories of needs covered in the survey instrument. The focus group questions (Appendix D) supplemented the information gathered from the survey.

### Key Informant Interviews

Key informant, or formal, structured face-to-face interviews were conducted with each of the Ryan White, Title II case managers throughout the state of Montana. This interview process was selected to supplement the information gathered from the survey. Questions for the key informant interviews (Appendix E) were similar to the questions for the focus groups and also reflected the main issues in the survey instrument.

## **Data Collection**

### Survey

The researcher met with each case manager to describe the purpose of the project and to explain the procedures involved in the distribution of the survey. The case managers were asked to distribute the survey to clients who came into the office. Each client was asked to read a modified consent form (Appendix F), which included information



typically found in an informed consent. Those individuals taking part in the study were able to complete the survey in the office or take it with them and return it in a self-addressed stamped envelope. Case managers were asked to mail the survey, cover letter (Appendix G), and modified consent form to clients not visiting the office.

In hopes of a snowball effect, the survey was also given to indigenous leaders from the target population, who were asked to distribute the survey, cover letter and modified consent forms to other members of the target population. Participants were asked to return the survey in a self-addressed stamped envelope, which was included with the survey packet.

Surveys were color coded according to the six health regions in the state. This was done in an effort to assure that completed surveys were representative of all the regions in Montana.

### Focus Groups

Five focus groups were conducted with existing Ryan White HIV support groups throughout the state of Montana. Participation in the group was by invitation and was voluntary. Individuals were invited to participate from existing Ryan White, Title II HIV support groups. At the time of the invitation, participants received general information about the session, but were not given the specifics. This precaution helped insure that the responses were on target yet spontaneous (McKenzie & Smeltzer,

1997 p. 43). In conjunction with the support group facilitators, a time and meeting place for the focus groups was arranged. Upon meeting with the support group members, the focus group facilitators explained the purpose of the meeting and distributed the modified informed consent papers (Appendix H) and a brief demographic questionnaire (Appendix I). The questionnaire was adapted from the Ryan White Title II Manual (1999). A research assistant was present to take notes and the focus group sessions were audio recorded to assure accurate records of responses.

### Key Informant Interviews

Eight key informant interviews were conducted with the Ryan White, Title II and Title III case managers in the state of Montana. Each case manager was contacted and asked to volunteer. Once the case manager agreed to participate, a time and place to conduct the interviews was arranged. Upon meeting the case manager, they were asked to sign a consent form (Appendix J). The researcher conducted the interviews and took notes. Each session was audio recorded to assure accurate records of responses. Before the interview, each case manager was asked to sign an informed consent, given a list of questions to be asked and the proceedings were verbally explained.

## **Data Analysis**

Collected data for this study came from a survey, five focus groups, and eight key informant interviews. Quantitative and qualitative analysis was completed for the survey. Qualitative analysis was completed on the focus group and interview data.

### **Survey Analysis**

Survey responses were statistically analyzed using a SPSS computer program. Survey analysis included descriptive statistics to report the perceived needs among HIV positive people of Montana. Frequencies were reported by actual count and sample sizes. Frequencies were reported in charts and graphs when appropriate. Wherever deemed necessary a Chi-Squared Goodness-of-Fit test, with an alpha of 0.05, was conducted on categorical data, to determine unusual response patterns.

### **Focus Groups and Interviews**

Focus group and interview data was qualitatively analyzed. Immediately following the sessions, the researcher reviewed the notes and the tapes to make sure they made sense, identified any areas of ambiguity or uncertainty, and reviewed the overall quality of the information received from participants. Observational data, such as where the interview/focus group concurred, how many were present, participant's

reactions to interview/focus group, and any additional information needed to make sense of the focus group/interview, was recorded. The notes from the focus groups and interviews were compared with the audio recordings to check for accuracy. Analysis involved identifying themes, patterns, perceptions, the general impression and concerns identified by participants. Significant data, unusual and informative findings were reported.

## **CHAPTER IV**

### **Results**

The purpose of this study was to assess the needs of people living with HIV/AIDS in Montana, including both those receiving and those not receiving HIV related services. In addition barriers to receiving HIV/AIDS related care were examined.

### **Survey Results**

#### **Demographics**

HIV positive people throughout the state of Montana were surveyed using the Consumer Questionnaire for People Living with HIV/AIDS in Montana (see appendix I). Of the 145 surveys that were distributed throughout the state via Ryan White Title II and Title III case managers and indigenous leaders, 88 were completed for a return rate of 61%.

#### **Age and gender.**

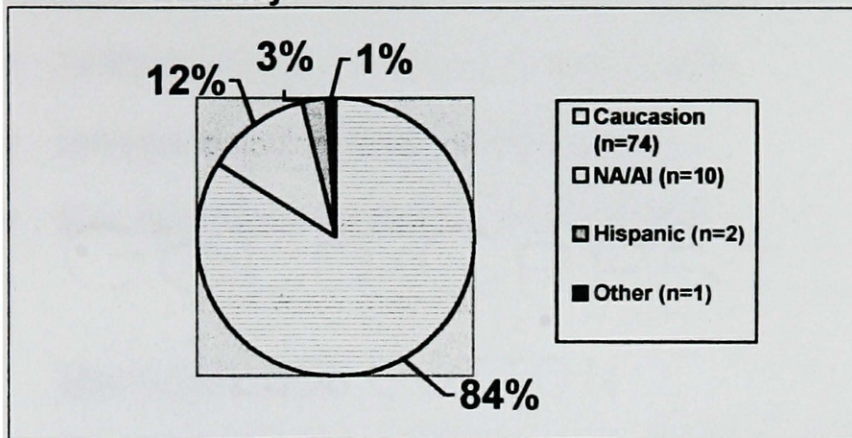
The respondents (n=88) age and gender was as follows:

- Average age was 40
- The majority (91.1%) were between the ages of 30 and 48
- 48.1% were between the ages of 30 and 39
- 17% (n=14) of the respondents were female
- 84.1% (n=74) were male.

### Ethnicity.

See Chart 1 for reported ethnicity of respondents (n=87).

**Chart 1. Ethnicity.**

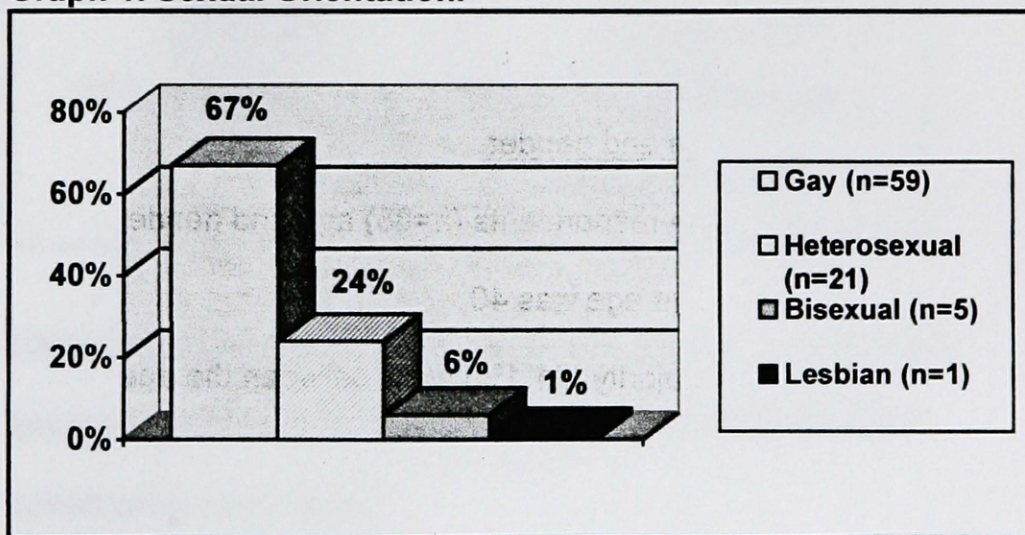


Canadian Indian was listed under the "other" category.

### Sexual orientation.

Respondents (n=86) were asked to identify with a sexual orientation. See Graph 1 for reported results.

**Graph 1. Sexual Orientation.**



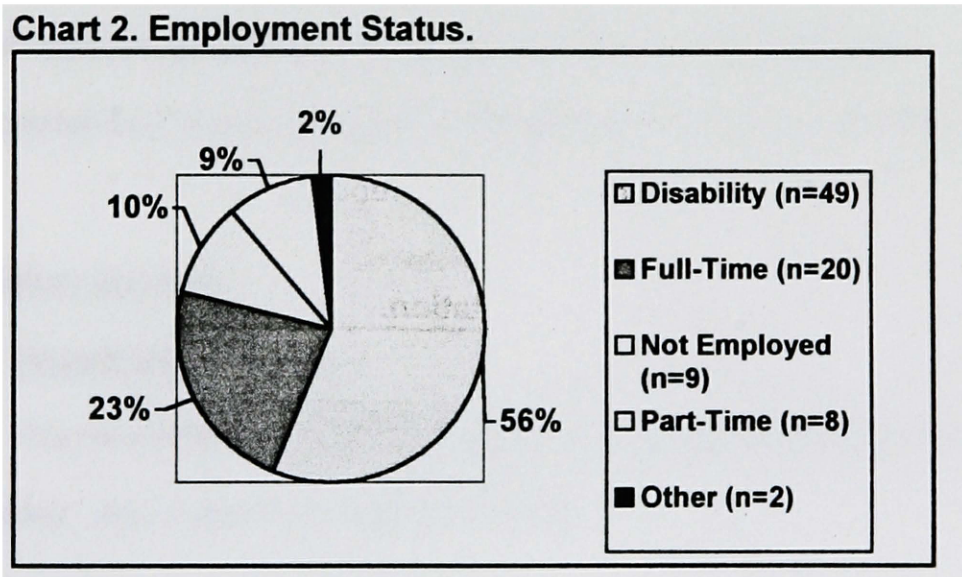
### Income.

Respondents (n=88) reported the following:

- 84% (n=74) of respondents reported a steady income
- 14.8% (n=13) did not report a steady income.
- Average monthly income of \$888 dollars
- 50% reported living on \$700 less per month.

### Employment status.

See Chart 2 for reported employment status of respondents (n=88).



“Other” comments included the following quotes: “Unemployed because of non-HIV illness” and “Trying to get disability, been turned down many times”.

### Level of education.

Respondents (n=88) were asked to report their highest level of education completed. See Table 1 for reported results.

**Table 1. Level of Education.**

<b>Education Level</b>	<b>%</b>	<b>(n)</b>
Some College	36.4	(32)
High School Graduate or GED	23.9	(21)
College Graduate	18.2	(16)
Vocational Certification	8.0	(7)
Some High School	5.7	(5)
Other	6.8	(6)

“Other” comments included the following: “FVCC”, “Graduate of a professional dog grooming school”, “Management training”, and “PhD”.

### Descriptive Analysis

#### Household members.

The respondents (n=88) were asked how many adults lived in their household. See Table 2 for reported results.



**Table 2. Adults in Household.**

<b># of Adults in Household</b>	<b>%</b>	<b>(n)</b>
One Other Adult	48.9	(43)
Two Other Adults	10.2	(9)
Three Other Adults	2.3	(2)
Four Other Adults	1.1	(1)

**Number of Children.**

Of the respondents (n=88), 28.4% (n=25) reported having children.

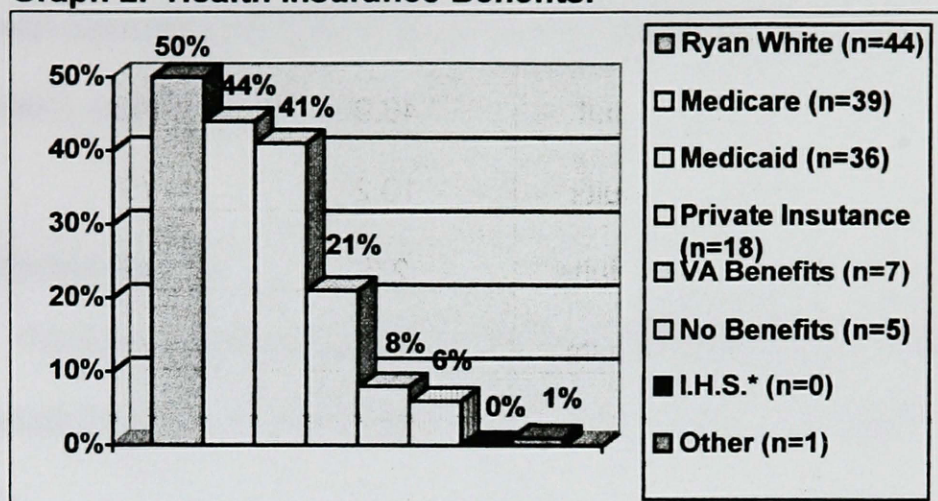
See Table 3 for reported number of children. Eleven percent (n=10) reported having children live with them and 4.5% (n=4) reported sometimes having children live with them.

**Table 3. Number of Children**

<b># Of Children</b>	<b>%</b>	<b>(n)</b>
0	71.6	(63)
1	14.8	(13)
2	8.0	(7)
3	3.4	(3)
6	1.1	(1)
7	1.1	(1)

**Health insurance.**

The respondents (n=88) reported using or receiving health insurance benefits. See Graph 2 for reported results.

**Graph 2. Health Insurance Benefits.**

\*I.H.S. stands for Indian Health Services.

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

Medicare supplement was listed under "other".

### Housing arrangements.

The respondents (n=88) were asked to report their living arrangements. See Table 4 for reported results.

**Table 4. Living Arrangements.**

Living Arrangements	%	(n)
Alone	33.0	(29)
Domestic Partner	33.0	(29)
Own Home	20.5	(28)
With Parents	13.6	(12)
With Roommates	10.2	(9)
In Public Housing	3.4	(3)
In Halfway House or Drug Program	2.3	(2)
In Health Care Facility	--	--
On Streets	--	--
In Shelter	--	--
Other	20.5	(18)

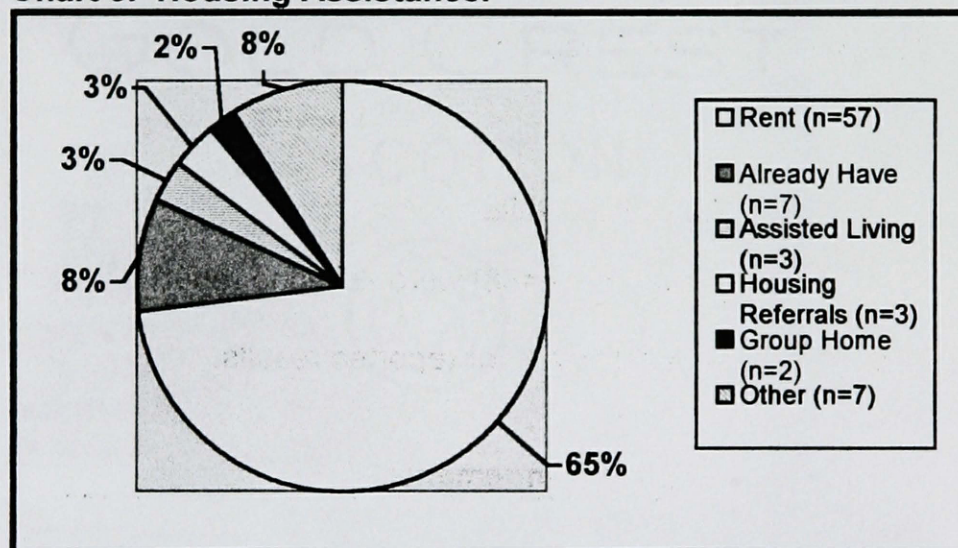
\*Percentages do not add up to 100. Respondents checked all that applied.

“Other” comments included renting, living with sister, living with children, living with husband and child, living in duplex that the mother owns, prerelease, and housing assistance.

### Housing Assistance.

The respondents (n=88) were asked to report which type of housing assistance would be most important to them. See Chart 3 for reported results.

**Chart 3. Housing Assistance.**



“Other” requirements included waiting on section 8, utility assistance and mortgage assistance, help with buying own home and down payment, own private residence, and taxes and insurance.

The respondents (n=88) reported the following:

- Living at present address an average of 3.3 years
- 75% (n=66) reported moving since becoming HIV positive

- 21% reported not moving since becoming HIV positive, 4.5% did not report moving since becoming HIV positive.

See Table 5 for reasons for moving.

**Table 5. Reasons for Moving.**

<b>Reasons</b>	<b>%</b>	<b>(n)</b>
Moving had nothing to do with HIV	28.4	(25)
Not enough money to pay rent	17.0	(15)
To live with or near family	25.0	(22)
To be closer to doctor	11.4	(10)
To get better HIV related care	10.2	(9)
New job	10.2	(9)
End, layoff or termination of job	10.2	(9)
To be with friends	4.5	(4)
Forced or asked to move because of HIV	3.4	(3)
To be with care giver	3.4	(3)
Asked to move because of alcohol/drug problem	1.1	(1)
Other	12.5	(11)

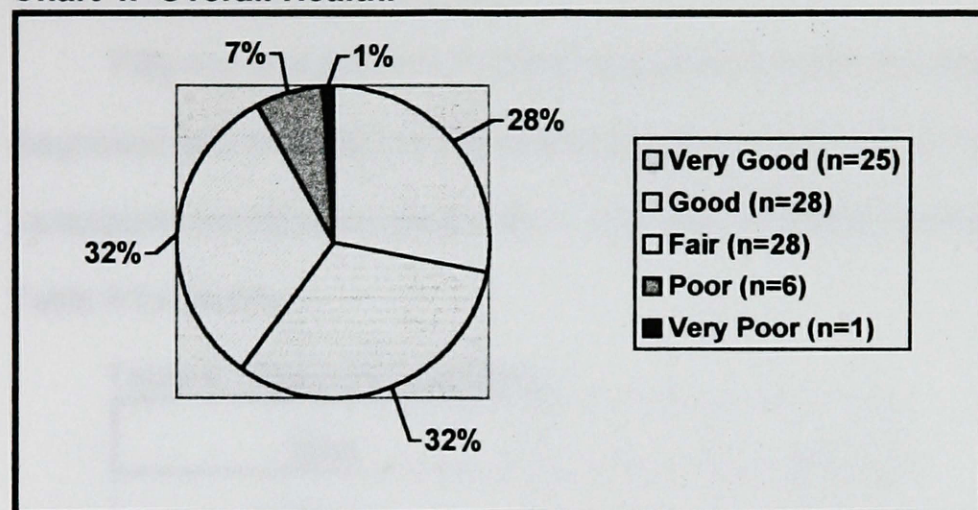
\*Percentages do not add up to 100. Respondents checked all that applied.

“Other” reasons why people moved included the following quotes: “could no longer do upkeep on house or meet payments”, “bankruptcy”, “to be closer to domestic partner”, “change from destructive environment”, “better quality of life”, “was asked to move and was homeless for one month then got subsidized housing and moved to Miles City, MT”, “to escape domestic violence”, “moved from different state”, and “to go back to college”.

### HIV/AIDS status.

The respondents (n=84) were asked to rate their overall health. A five point Likert Scale of “very good”, “good”, “fair”, “poor”, and “very poor” was used for response categories. See Chart 4 for responses.

**Chart 4. Overall Health.**



### Current Diagnosis.

The respondents (n=86) reported the following:

- 56.8% (n=50) currently diagnosed with AIDS
- 37.5% (n=33) not currently diagnosed with AIDS
- 3.6% (n=3) did not know current diagnosis
- 80.7% (n=71) know CD4 count
- 79.5% (n=70) reported knowing their viral load.
- Average of 2.5 months since last blood test

### Initial Diagnosis.

Of the respondents (n=86), 22.7% (n=20) reported initially being diagnosed with HIV and AIDS simultaneously. The remaining 72.7% (n=64) reported initially being diagnosed with HIV but not AIDS, 2.4% (n=2) reported not remembering.

Fifty-one percent (n=43) of the respondents reported being diagnosed with HIV/AIDS in the state of Montana. The remaining participants (n=39) were diagnosed in a number of different states. See Table 6 for results.

**Table 6. State Diagnosed In.**

State	%	(n)
Montana	51.0	(43)
Washington	10.2	(9)
California	9.1	(8)
Texas	5.7	(5)
Oregon	4.5	(4)
Arizona	3.4	(3)
Colorado	3.4	(3)
Utah	3.4	(3)
Nevada	2.3	(2)
Alaska	1.1	(1)
Minnesota	1.1	(1)
New York	1.1	(1)
District of Colombia	1.1	(1)
Indonesia	1.1	(1)

### Years living with HIV.

The survey respondents (n=87) reported living with HIV/AIDS an average of nine years, with a minimum of less than one year and a maximum of 19 years.

- 50% (n=44) lived with HIV/AIDS between 10 and 20 years
- 93% (n=82) received HIV related care
- 95.5% (n=84) have a regular place for HIV related care
- Visited doctor an average of 4 times in six months

### HIV medications.

Of the respondents (n=88), 73.9% (n=65) reported taking Antiretroviral drug combinations, 14.8% (n=13) reported not being on drug therapy, and 10.2% (n=9) reported being on drug therapy in the past but are not currently on drug therapy, 1.1% (n=1) did not answer this question. Of the respondents, 80 of them reported paying for drug therapies in the following manner:

- |                               |              |
|-------------------------------|--------------|
| ▪ Medicaid                    | 38.6% (n=34) |
| ▪ ADAP                        | 29.5% (n=26) |
| ▪ Private Insurance           | 13.6% (n=12) |
| ▪ Veteran's Benefits          | 3.4% (n=3)   |
| ▪ Family and friends help pay | 1.1% (n=1)   |
| ▪ Other                       | 4.5% (n=4)   |

"Other" methods of payment included the following: "Medicaid, plus I pay for those not covered by Medicaid", "V.A.B., what they don't cover I pay for

myself”, “Health Department, Ryan White Title III”, “Private insurance and Ryan White pays my co-payment”.

### Alternative therapies.

The respondents (n=88) were asked if they used alternative therapies, 35.5% (n=33) reported using them, 59.1% (n=52) reported not using them, and 3.4% (n=3) did not answer this question. See Table 7 for therapies used.

**Table 7. Alternative Therapies.**

<b>ALTERNATIVE THERAPY</b>	<b>%</b>	<b>(n)</b>	<b>TOTAL (n)</b>
Vitamins and Minerals	34.1	(30)	(88)
Prayer/Spiritual	23.9	(21)	(88)
Herbal Therapies	18.2	(16)	(88)
Massage	14.8	(13)	(88)
Acupuncture	8.0	(7)	(88)
Other	10.2	(9)	(88)

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

“Other” alternative therapies included chiropractor, yoga, 12 step programs and programs that focus on well being, physical therapy, and proto-vaccine.

Respondents (n=88) were asked to report reasons for not using alternative therapies. See Table 8.



**Table 8. Reasons for not Using Alternative Therapies.**

<b>REASONS</b>	<b>%</b>	<b>(n)</b>	<b>TOTAL (n)</b>
Not Affordable	28.4	(25)	(88)
Not Interested	11.4	(10)	(88)
Not Available	10.2	(9)	(88)
Don't Think They Work	6.8	(6)	(88)
Other	18.2	(16)	(88)

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

“Other” reasons included the following quotes: “Not covered by Medicaid”, “Got enough meds to take”, “I have always been strong minded about my disease and the doctors said whatever I am doing to keep it up”, “Don’t know much about them”, “I watched several people get very sick and die within a short amount of time after getting on treatments”, “Haven’t really studied about them. Also my provider hasn’t really said that I need any”, “Ignorant of them”, and “my situation is stable and I concentrate on being healthy day to day”.

The respondents (n=33) who reported using alternative therapies paid for the therapies in the following manner:

- Pay for alternative therapies myself      88.0% (n=29)
- Friends and family help pay              12.0% (n=4)
- Private insurance                              6.0% (n=2)
- Other    33.0% (n=11)

“Other” methods of paying for alternative therapies included Ryan White, Medicare, County Health Department, Title III, AIDS Council, barter, and “some are free like 12-step and church”.

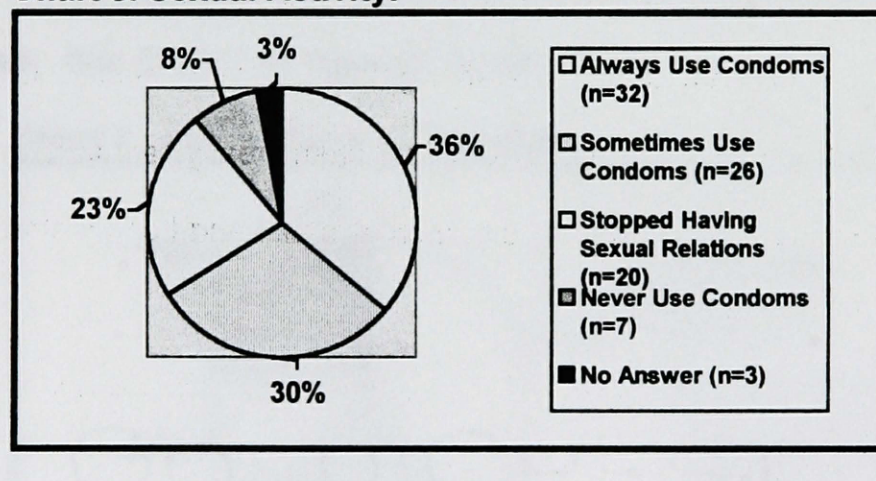
### Case manager.

Of the respondents (n=88), 59.1% (n=52) reported having a Ryan White Title II or III case manager, 38.6% (n=34) reported not having a case manager and 2.3% (n=2) did not answer this question.

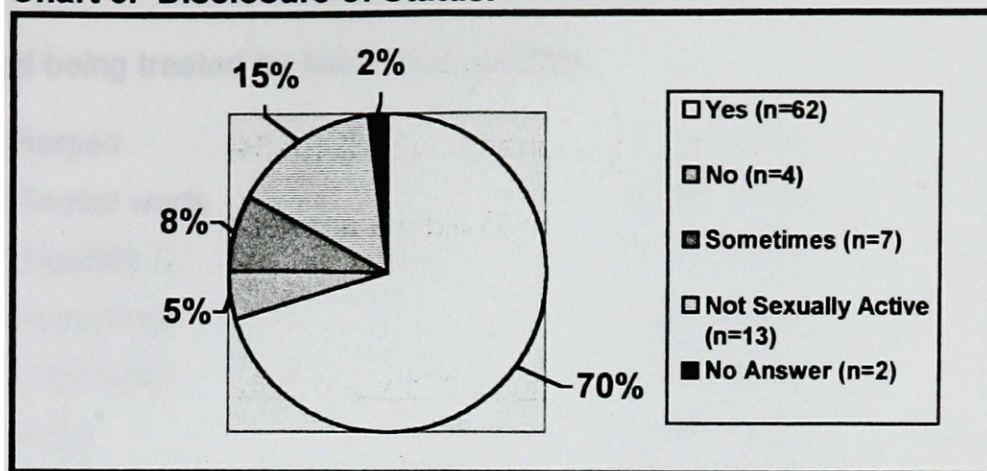
### Behaviors since becoming HIV positive.

The respondents (n=88) were asked to report their sexual activity since becoming HIV positive. See Chart 5 for reported results.

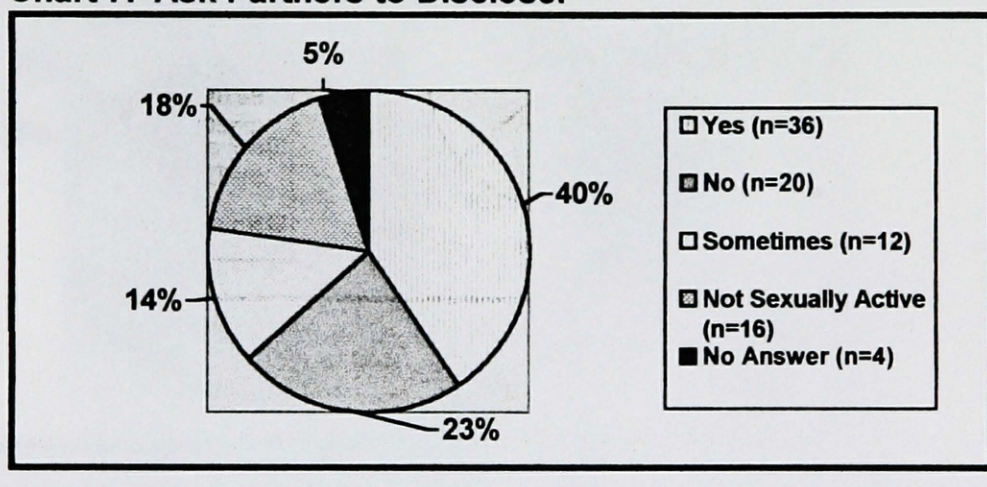
**Chart 5. Sexual Activity.**



The survey respondents (n=88) were asked if they disclose their HIV status to sexual partners. See Chart 6 for reported results.

**Chart 6. Disclosure of Status.**

Respondents (n=88) were asked if they ask the status of sexual partners. See Chart 7 for reported results.

**Chart 7. Ask Partners to Disclose.**

### **Sexually Transmitted Infections.**

Respondents (n=88) were asked if they had been treated for a sexually transmitted infection (STI) in the last two years. Sixteen percent (n=14) of the survey respondents reported being treated for a STI in the last two years, 82.1% (n=69) reported not being treated for an STI in the

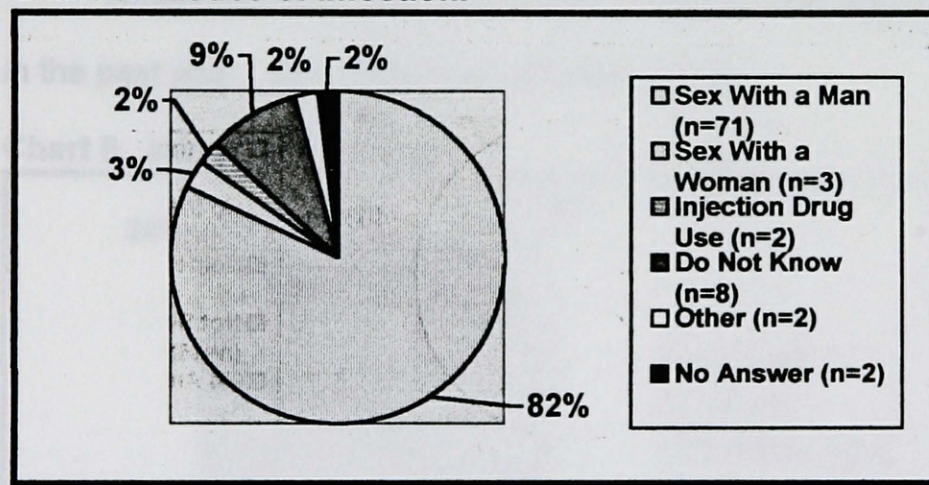
last two years, 1.1% (n=1) did not answer this question. The respondents reported being treated for the following STIs:

▪ Herpes	7.1% (n=6)
▪ Genital warts	6.0% (n=5)
▪ Hepatitis C	3.6% (n=3)
▪ Gonorrhea	1.2% (n=1)
▪ Chlamydia	1.2% (n=1)
▪ Other	6.0% (n=5)

“Other” STIs included Moluscum, HIV, yeast infection, and AIDS.

The respondents (n=88) were asked to report how they became infected with HIV. See Chart 8 modes of transmission.

**Chart 8. Modes of Infection.**



“Other” reported responses include the following quotes: “Direct blood contact through open sore as a nurse”, the other respondent did not disclose how he/she became infected with the virus.

#### Drug use behaviors.

The respondents (n=88) were asked if they had used any substances in the past year. Sixty-one percent (n=54) reported using, 35.2% (n=31) reported not using, and 3.4% (n=3) did not answer this



question. Respondents (n=88) were asked which substances they have used in the past year. See Table 9 for reported results.

**Table 9. Substances Used.**

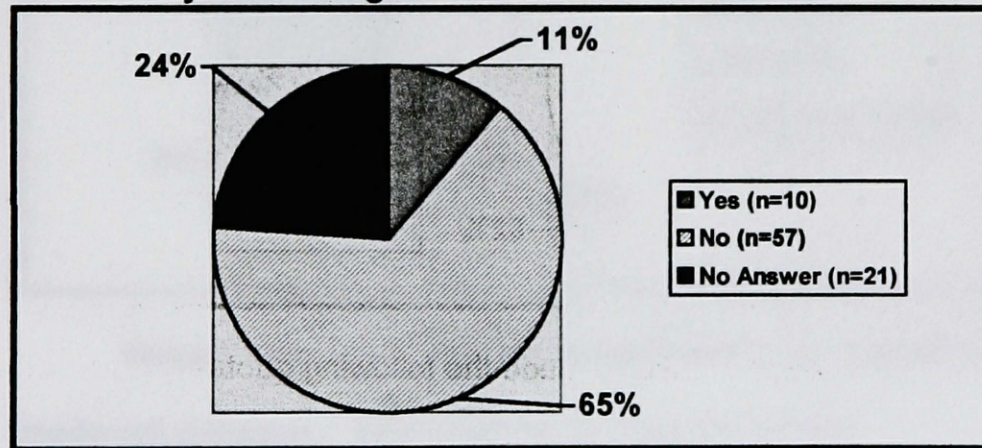
SUBSTANCE	%	(n)
Alcohol	43.2%	(38)
Marijuana	39.8	(35)
Methamphetamine	17.0	(15)
Downers	2.3	(2)
Cocaine	1.1	(1)
Crack	--	--
Heroin	--	--
Other	4.5	(4)

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

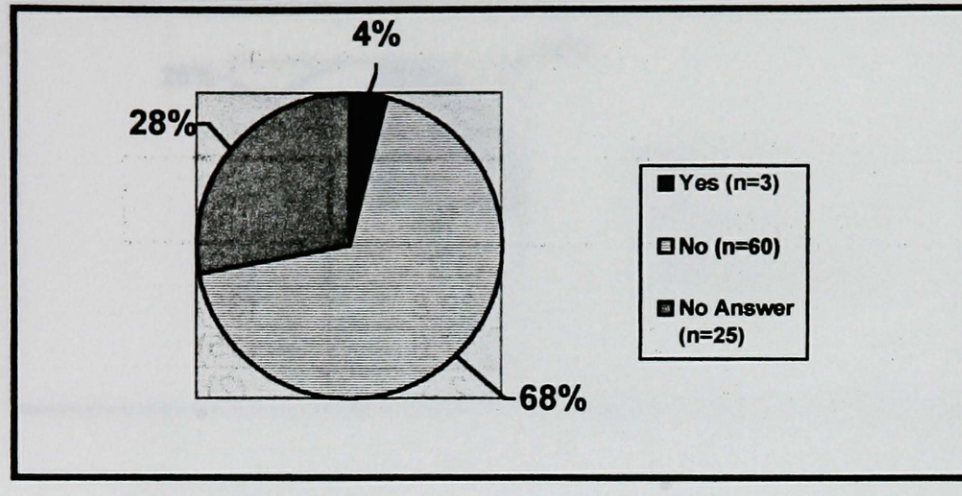
“Other” responses included ACID, poppers, and tobacco.

Respondents (n=88) were asked to report if they had injected drugs in the past year. See Chart 9 for reported results.

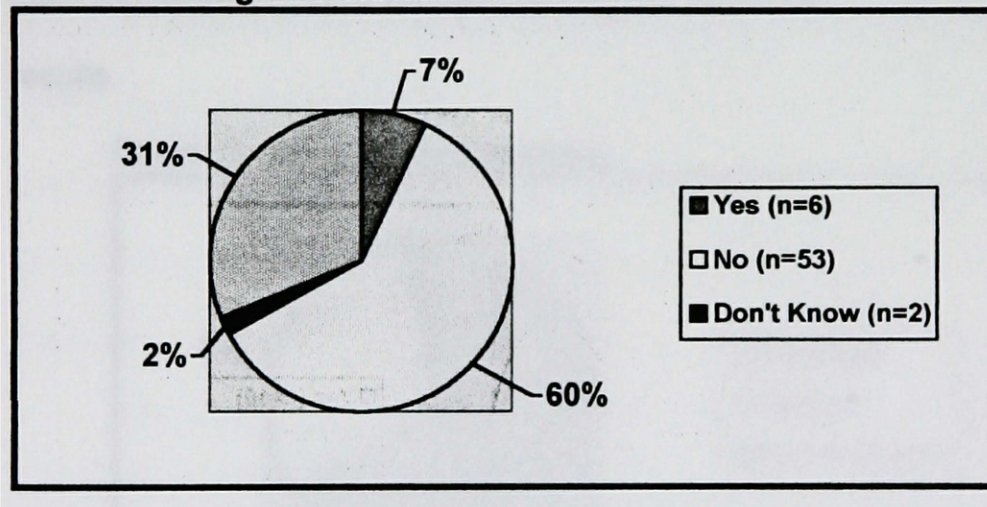
**Chart 9. Injection Drug Use.**



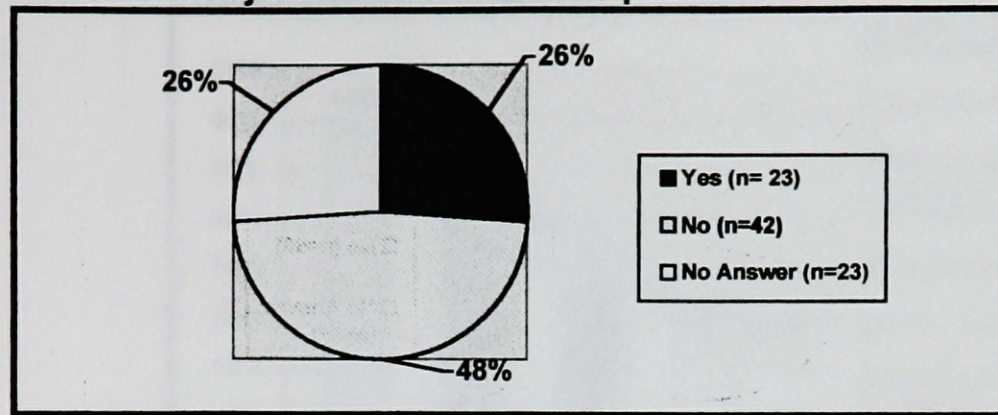
Respondents (n=88) were asked to report if they had shared needles in the past year. See Chart 10 for reported results.

**Chart 10. Shared Needles.**

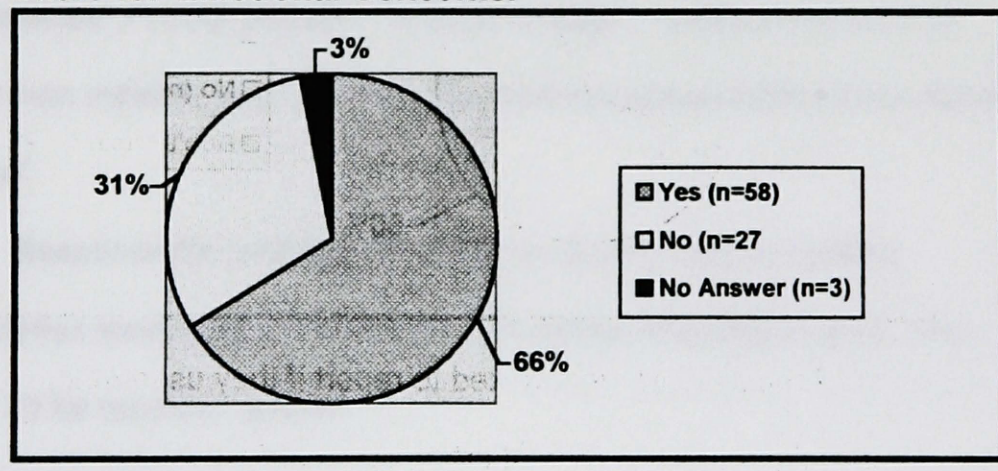
The respondents (n=88) were asked if they thought their drug use was a problem. See Chart 11 for reported results.

**Chart 11. Drug Use Viewed as Problem.**

Respondents were asked to report if they used marijuana for medicinal purposes. See Chart 12 for reported results.

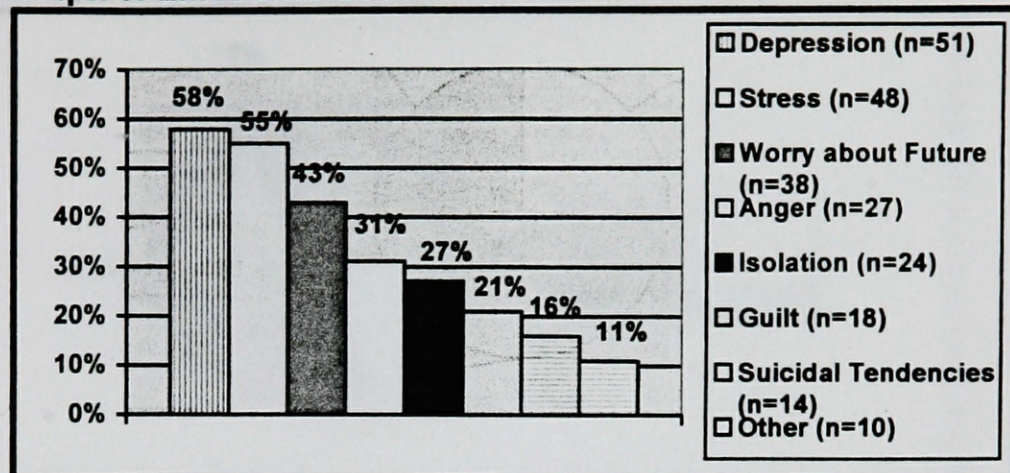
**Chart 12. Marijuana for Medicinal Purposes.****Emotional Concerns.**

The respondents (n=88) were asked if they had emotional concerns that caused problems in the last six months. See Chart 13 for reported results.

**Chart 13. Emotional Concerns.**

The respondents (n=88) were asked to report the emotional concerns that have caused them problems in the last six months. See Graph 3 for reported results.

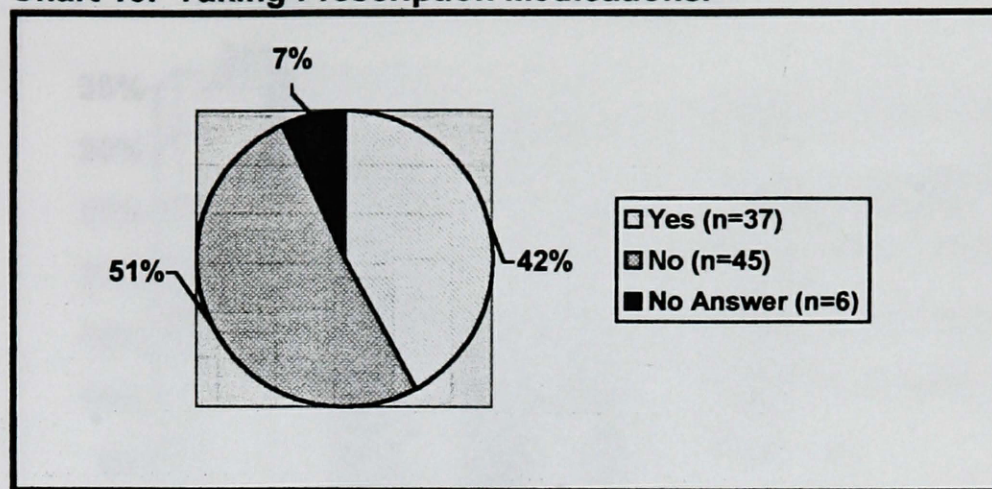


**Graph 3. Emotional Issues.**

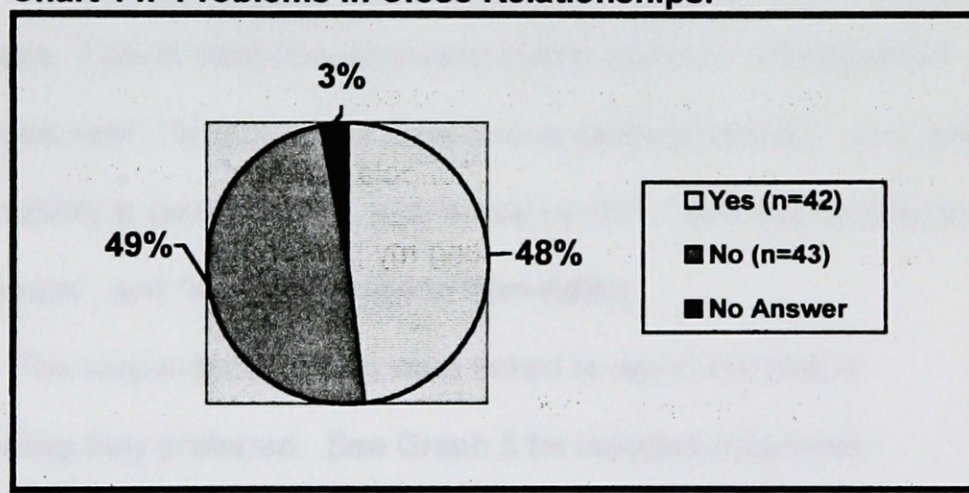
“Other” responses included the following quotes: “Death”, “Worried about children”, “My mother died seven months ago and I am dealing with a lot of emotions”, “eating disorders and emotional problems”, “working through relationships”, “social anxiety”, “bi-polar swings”, “death of my parents rather than myself”, and “affecting my personal sexual relationship with my spouse”.

Respondents (n=88) were asked to report if they are taking prescription medications for emotional or stress related problems. See Chart 13 for reported results.

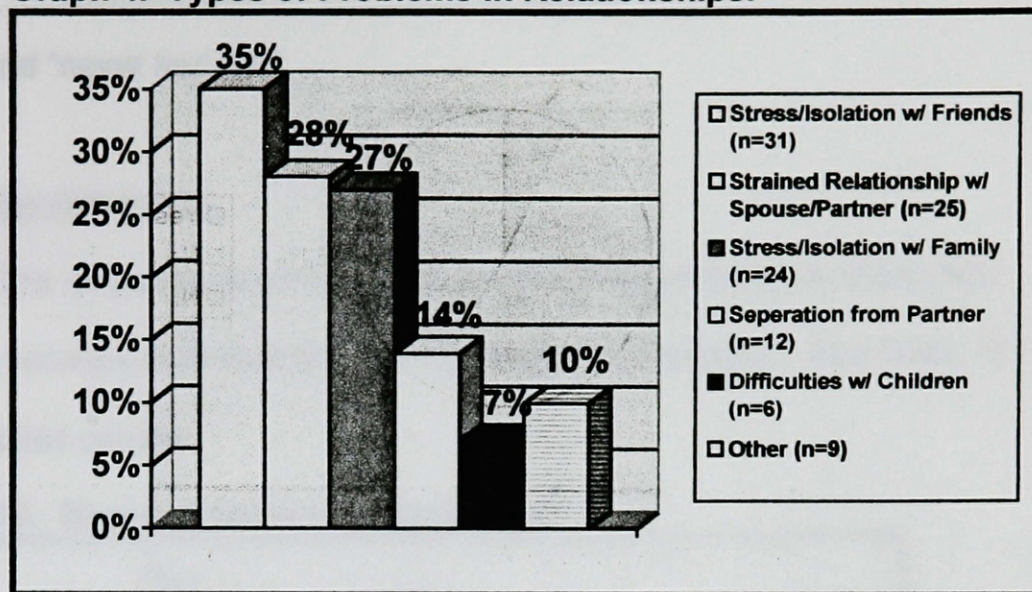


**Chart 13. Taking Prescription Medications.**

Respondents (n=88) were asked if being HIV positive has caused problems in close relationships. See Chart 14 for reported results.

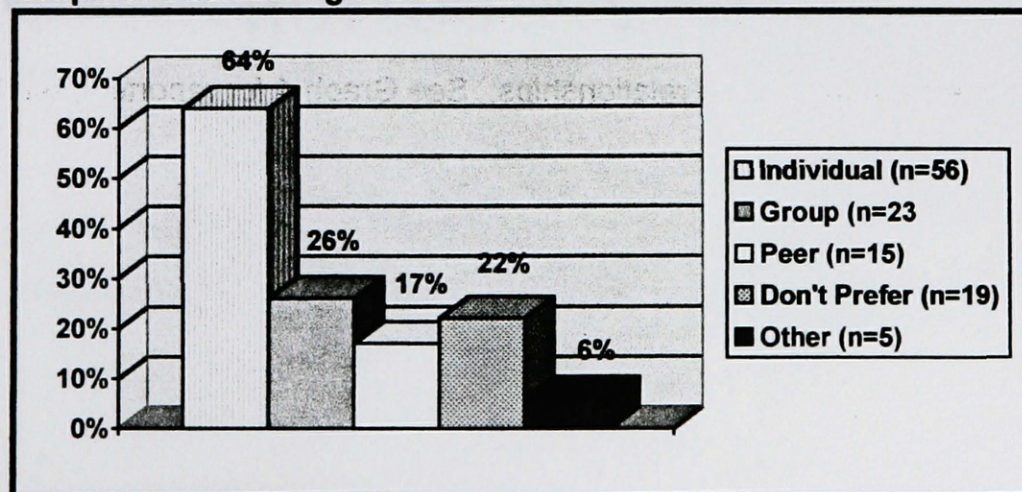
**Chart 14. Problems in Close Relationships.**

Respondents (n=88) were asked to report the issues that caused problems in their close relationships. See Graph 4 for reported results.

**Graph 4. Types of Problems in Relationships.**

“Other” responses included the following quotes: “first partner split after ten years. I am in second relationship, seven years in”, “divorced but remarried now”, “loss of sexual drive due to antidepressants”, “just stress over inability to work, income, total denial by SSI”, “fear and ignorance of Montanans”, and “stress or isolation from dating”.

The respondents (n=88) were asked to report the type of counseling they preferred. See Graph 5 for reported responses.

**Graph 5. Counseling Preferred.**

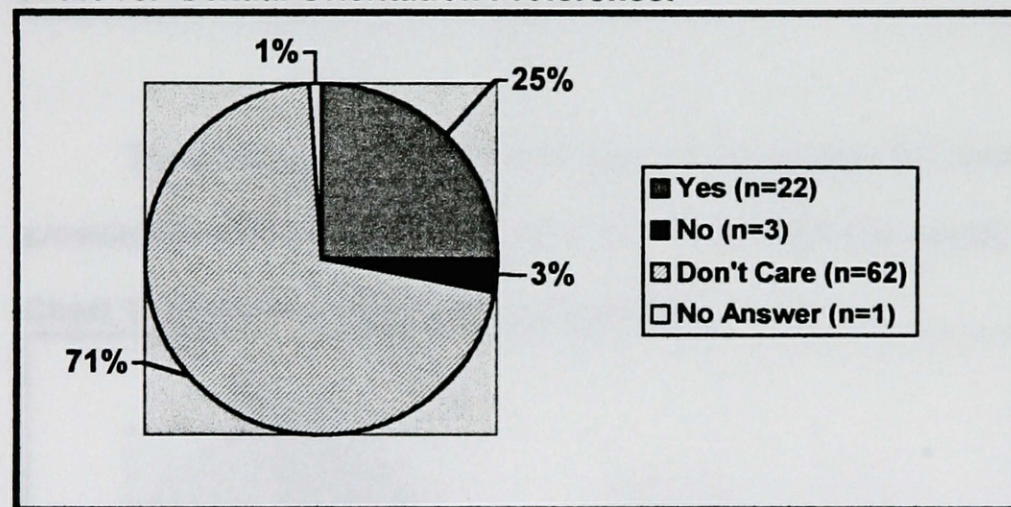


“Other” comments included the following quotes: “county caseworker and wife”, and “never had any”.

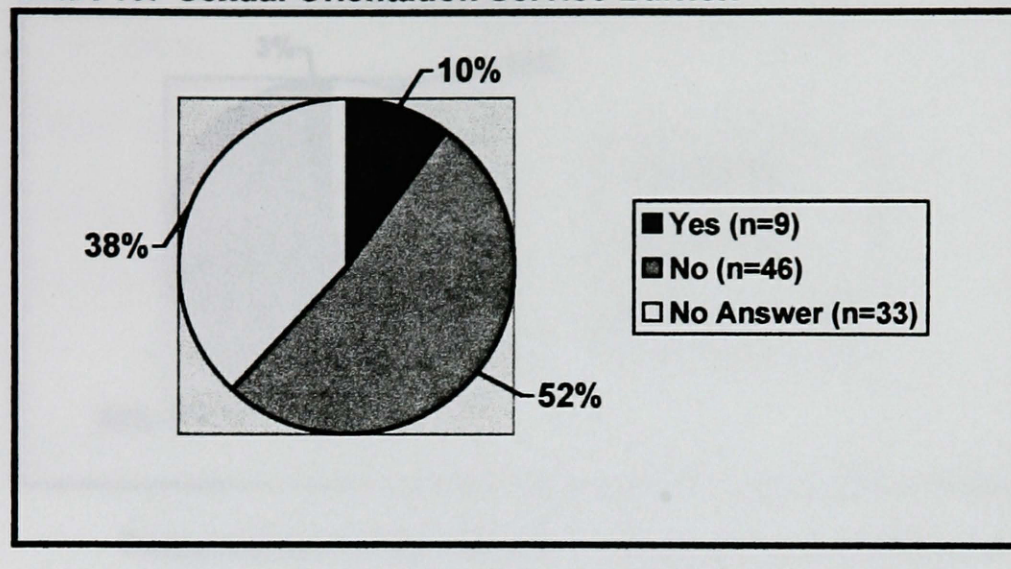
Service needs.

The respondents (n=88) were asked if they preferred to obtain HIV related services from staff with the same sexual orientation. See Chart 15 for reported results.

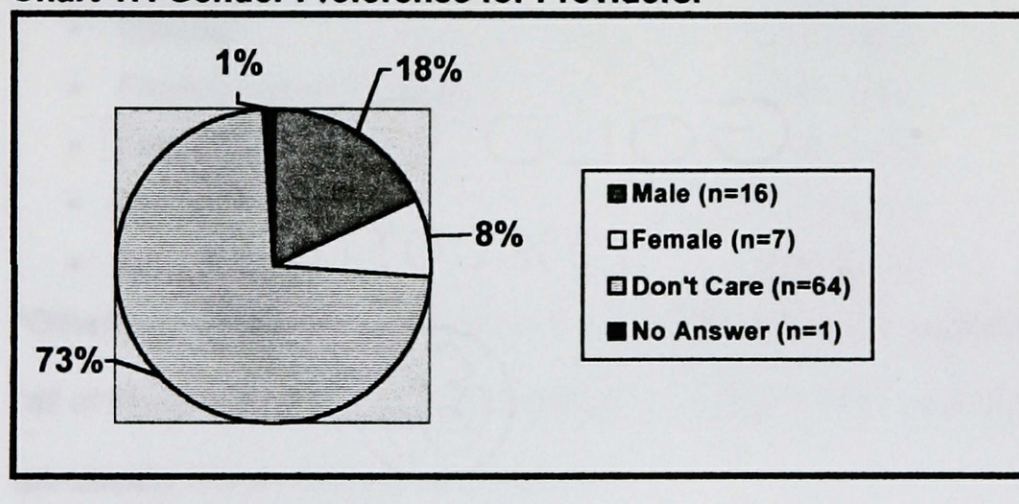
**Chart 15. Sexual Orientation Preference.**



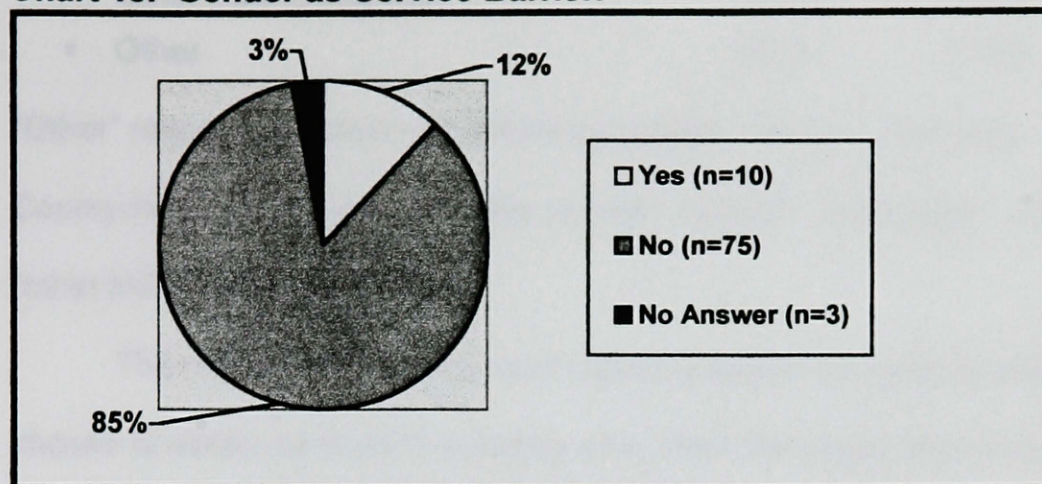
The respondents (n=88) were asked if sexual orientation interfered with accessing care. See Chart 16 for reported responses.

**Chart 16. Sexual Orientation Service Barrier.**

The respondents (n=88) were asked if they prefer HIV service providers to be male or female. See Chart 17 for reported results.

**Chart 17. Gender Preference for Providers.**

The respondents (n=88) were asked if gender interferes with accessing care. See Chart 18 for reported responses.

**Chart 18. Gender as Service Barrier.**

Respondents (n=88) reported contacting the following sources first when wanting to find out about an HIV/AIDS related service:

- |                           |              |
|---------------------------|--------------|
| ▪ Medical Care Provider   | 38.6% (n=34) |
| ▪ Ryan White Case Manager | 34.1% (n=30) |
| ▪ Friends                 | 10.2% (n=9)  |
| ▪ Internet                | 3.4% (n=3)   |
| ▪ Family/Partner/Spouse   | 2.3% (n=2)   |
| ▪ Written Literature      | 2.3% (n=2)   |
| ▪ Other                   | 7.1% (n=6)   |
| ▪ No answer               | 2.2% (n=2)   |

“Other” responses included the following quotes: “to vague a question”, “all of the above”, “county case manager”, “my case worker and doctor”, “I am usually told by friends”, and “MAC”.

When needing help with an HIV related concern the respondents (n=88) reported turning to the following sources for advice:

- |                           |       |        |
|---------------------------|-------|--------|
| ▪ Medical Provider        | 72.7% | (n=64) |
| ▪ Ryan White Case Manager | 34.1% | (n=30) |
| ▪ Partner/Spouse          | 26.1% | (n=23) |
| ▪ Close Friend            | 26.1% | (n=23) |



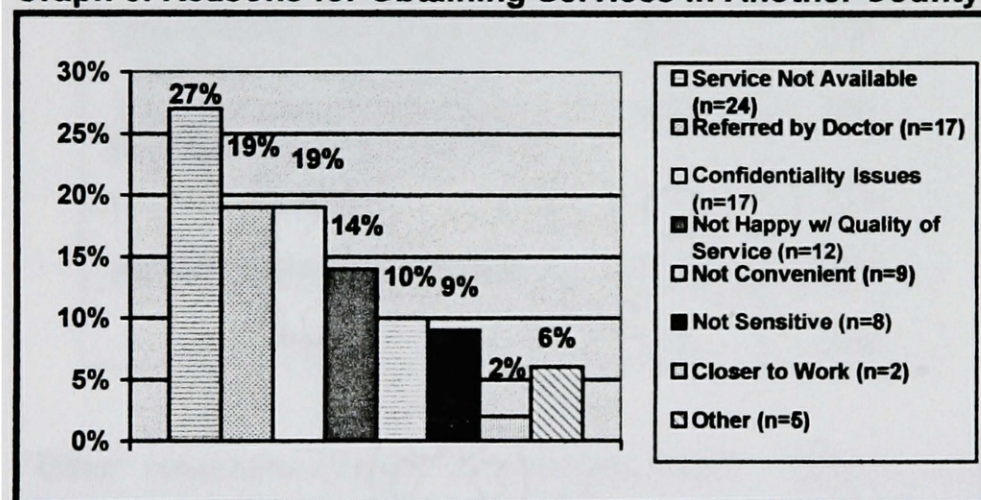
- Other Family Member 11.4% (n=10)
- Other 10.2% (n=9)

“Other” responses include the following quotes: “clergy”, “Sonoma County Health Services”, “my case worker”, “myself”, “counselor”, and “other HIV positive person”.

The respondents (n=88) were asked to report the reasons why they choose to obtain services in a county other than the county they lived in.

See Graph 6 for reported responses.

**Graph 6. Reasons for Obtaining Services in Another County.**



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

“Other” responses included the following quotes: “can’t afford to get to town as often as I would like”, “more progressive”, “don’t need to”, “no VA office in this city”, “great service in my county”, and “to be involved with clinical trials and doctors that are researchers at university hospitals”.

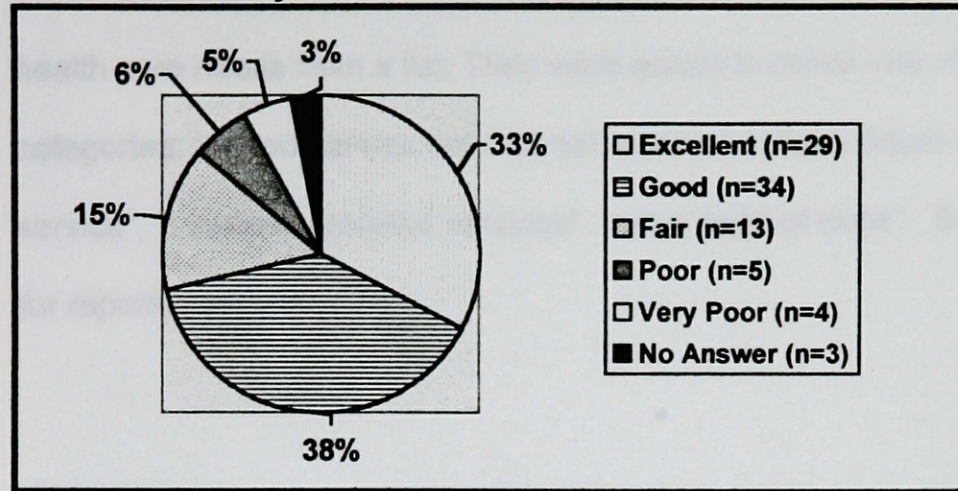
The survey respondents (n=88) were asked to report barriers to accessing services. See Table 10 for reported barriers.

**Table 10. Barriers to Accessing Services.**

<b>BARRIER</b>	<b>%</b>	<b>(n)</b>
Not Aware Service Exists	44.3	(39)
No Money/Insurance to Pay for Service	35.3	(31)
Services Were too Far to Travel	14.8	(13)
Don't Want to Disclose Status	11.4	(10)
No Transportation	8.0	(7)
Time Offered not Convenient	5.7	(5)
Services not Sensitive to Gender/Sexual Orientation	4.5	(4)
Services are not Sensitive to Drug Use	1.1	(1)
Already Obtaining Services	37.5	(33)
Other	11.9	(10)

“Other” responses included the following quotes: “travel is too costly”, “I would like to go see an HIV specialist”, “services don’t exist”, “costs too much to travel”, “knowledgeable individuals are hard to find, no experts”, “I am really not looking right now”, “I get great services”, “confidentiality”, “no VA doctors in town”, and “getting my HIV managed is my first priority and I will make other sacrifices for that”.

The survey respondents (n=88) were asked to rate the quality of HIV/AIDS service that they have received in Montana. A five point Likert Scale of “excellent”, “good”, “fair”, “poor”, and “very poor” was used for response categories. See Chart 19 for report responses.

**Chart 19. Quality of Service.**

The respondents were asked to make additional comments: “my doctor learned how to treat HIV people when I insisted he remain as my doctor. He also referred me to a disease specialist for a consultation, this specialist said my doctor was doing a great job”, “Good, if you are willing to manage your own care”, “quality good, overall knowledge of up to date treatments and services is lacking by doctors”, “better here in Montana then what I had in Houston, Texas, a larger community with lots of resources”, “need to get clinical trials here”, “very friendly, they don’t make me feel bad about my HIV”, “don’t know, not much here”, “my doctor is very knowledgeable about HIV positive therapy and my med costs are covered by ADAP”, and “some poor, some excellent”.



**Medical and health care needs.**

The respondents (n=88) were asked to determine their medical and health care needs from a list. They were asked to check one of four categories: "I need service but I do not receive", "I have future need for service", "I currently receive services", "not a need of mine". See Table 11 for reported results.

**Table 11. Medical and Health Care Needs.**

TYPE OF CARE/SUPPORT SERVICE	NEED SERVICE BUT DON'T RECEIVE		FUTURE NEED FOR SERVICE		NOT A NEED		RECEIVE SERVICES		TOTAL
Medical and Health	%	(n)	%	(n)	%	(n)	%	(n)	(n)
Alternative Therapies	29.5	(26)	13.6	(12)	33.0	(29)	17.0	(15)	(82)
Dental Care	27.4	(23)	17.9	(15)	–	–	50	(42)	(80)
Professional Therapy / Counseling	25.0	(22)	12.5	(11)	34.1	(30)	21.6	(19)	(82)
Eye Care	23.9	(21)	15.9	(14)	8.0	(7)	45.2	(38)	(78)
Mental Health	20.5	(18)	12.5	(11)	37.5	(11)	21.6	(19)	(82)
Nutritional Counseling Services	15.9	(14)	10.2	(9)	61.4	(54)	4.5	(4)	(81)
Residential Care (help with room & Board)	9.1	(8)	12.5	(11)	65.9	(58)	4.5	(4)	(81)
Emergency Medical Care	9.1	(8)	13.6	(12)	25.0	(22)	44.3	(39)	(81)
Physical/Occupational Therapy	6.8	(6)	14.8	(13)	60.2	(53)	8.0	(7)	(79)
In-Home Health Care	3.4	(3)	15.9	(14)	72.7	(64)	1.1	(1)	(82)
Medical Equipment	3.4	(3)	13.6	(12)	73.9	(65)	2.3	(2)	(82)
Hospice Care	2.3	(2)	25.0	(22)	63.6	(56)	1.1	(1)	(81)
Medical Care	1.1	(1)	1.1	(1)	1.1	(1)	93.2	(82)	(85)
Nursing Home Care	1.1	(1)	13.6	(12)	72.7	(64)	3.4	(3)	(80)
Medicines (Antiretroviral, antibiotics, other)	1.1	(1)	11.4	(10)	8.0	(7)	72.7	(64)	(82)
Substance Abuse Treatment/Counseling	1.1	(1)	3.4	(3)	77.3	(68)	8.0	(7)	(79)
Adult Day Health/on-site, on going supervision & support	–	–	10.2	(9)	79.5	(70)	2.3	(2)	(81)
Respite Care	–	–	12.5	(11)	79.5	(70)	–	–	(81)
Other medical and Health Care Needs	–	–	1.1	(1)	4.5	(4)	1.1	(1)	(6)

“Other” medical and health care need responses included the following quotes: “I am not sure how much the Navy will cover in the future for boxes where I marked ‘future need’, they may cover all”, and “volunteers to visit and help with housekeeping”.

### Basic Necessity Needs.

The respondents (n=84) were asked to determine their basic necessity needs from a list. They were asked to check one of four categories: "I need service but I do not receive", "I have future need for this service", "not a need of mine", "I currently receive services". See Table 12 for reported results.

**Table 12. Basic Necessity Needs.**

TYPE OF CARE/SUPPORT SERVICE	NEED SERVICE BUT DON'T RECEIVE		FUTURE NEED FOR SERVICE		NOT A NEED		RECEIVE SERVICES		TOTAL
Basic Necessity Need	%	(n)	%	(n)	%	(n)	%	(n)	(n)
Housing or Rent Assistance	33.0	(29)	12.5	(11)	34.1	(30)	14.8	(13)	(83)
Assistance with paying household bills	31.8	(28)	13.6	(12)	39.8	(35)	6.8	(6)	(81)
Emergency Financial Assistance	18.2	(16)	31.8	(28)	33.0	(29)	8.0	(7)	(81)
Insurance/HMO/Medicaid	14.8	(13)	14.8	(13)	20.5	(18)	43.2	(38)	(82)
Food Bank	13.6	(12)	13.6	(12)	47.7	(42)	17.0	(15)	(81)
Transportation	13.6	(12)	10.2	(9)	61.4	(54)	6.8	(6)	(81)
Financial Assistance with Medications	13.6	(12)	11.4	(10)	21.6	(19)	48.9	(43)	(84)
Home delivered Meals/Groceries	9.1	(8)	10.2	(9)	69.3	(61)	2.3	(2)	(81)
Clothing	9.1	(8)	6.8	(6)	73.9	(65)	2.3	(2)	(81)
Practical Support (help with shopping, cooking, chores, etc.)	9.1	(8)	14.8	(13)	64.8	(57)	2.3	(2)	(81)
Other Basic Needs	1.1	(1)	—	—	5.7	(5)	3.4	(3)	(9)

"Other" basic need responses included the following quotes: "oral and denture", "I am okay on all these (basic needs) but may need help in the future", "school money", and "assistance to keep my private insurance".

### Social support service needs.

The respondents (n=88) were asked to determine their social support service needs from a list. They were asked to check one of four categories: "I need service but I do not receive", "I have future need for this service", "not a need of mine", "I currently receive services". See Table 13 for reported results.

**Table 13. Social Support Needs.**

TYPE OF CARE/SUPPORT SERVICE	NEED SERVICE BUT DON'T RECEIVE		FUTURE NEED FOR SERVICE		NOT A NEED		RECEIVE SERVICES		TOTAL
<b>Social Support Needs</b>	%	(n)	%	(n)	%	(n)	%	(n)	(n)
Social/Recreation Activities	26.1	(23)	5.7	(5)	48.9	(43)	13.6	(12)	(83)
Legal Services	26.1	(23)	15.9	(14)	46.6	(41)	3.4	(3)	(81)
Information and Referral for Services	25.0	(22)	9.1	(8)	22.7	(20)	35.2	(31)	(81)
Client Advocacy	21.6	(19)	5.7	(5)	42.0	(37)	18.2	(16)	(77)
Case Management Services	19.3	(17)	5.7	(5)	25.0	(22)	45.8	(40)	(84)
Support Group/Peer Counseling	19.3	(17)	9.1	(8)	48.9	(43)	17.0	(15)	(83)
Buddy/Companion Volunteer Support	17.0	(15)	12.5	(11)	55.7	(49)	8.0	(7)	(82)
Spiritual Support	9.1	(8)	2.3	(2)	55.2	(46)	29.5	(26)	(82)
Child Care	3.4	(3)	2.3	(2)	83.0	(73)	2.3	(2)	(81)
Adoption/Foster Care for Children	—	—	2.3	(2)	87.5	(77)	2.3	(2)	(81)
Other Social Support	1.1	(1)	—	—	5.7	(5)	—	—	(6)

"Other" social support responses included the following quotes: "help with alternative therapies", and "financial advice and counseling".

The survey participants (n=88) were asked to respond to three open ended questions. The number of participants who responded and their responses to each question are as follows.

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

The respondents who replied to this question (n=14) reported wanting access to the following:

- HIV/AIDS specialists (n=3)
- Help with filling out Medicaid and benefit forms (n=2)
- Help in finding a job
- Access to acupuncture and massage
- Assistance in fitness and exercise programs
- Debt management/financial advice
- Sex positive education for HIV positive people
- Need a sense of community
- HIV positive retreats for heterosexuals
- Need dental services
- Support for food for pets

***Question #2: Of the HIV/AIDS services you have used, which helped the most? Why?***

Of the 88 total respondents, 59 reported the following services that have helped the most:

- Ryan White Consortium (n=27)
- Doctors and medical care (n=14)
- County Health Department (n=7)
- Counseling and therapy (n=5)
- Missoula AIDS Council (n=4)
- Department of Veterans Affairs (n=2)

The respondents were asked to comment on why these services have helped the most. Ryan White Title II and Title III Consortium pays for or help pays for medication was among the most popular responses. The following quote is about why Ryan White is the service that helps the most: "Ryan White has been BY FAR the greatest assets in my battle with HIV/AIDS. Their financial assistance, referrals, information and peer support have always gone above and beyond expectations".

***Question #3: Of the HIV/AIDS services you have used, which helped the least? Why?***

The respondents who replied to this question (n=14) reported the following services that have helped them the least:

- Support groups (n=3)
- Dental services (n=2)
- Case Management

- Residential care
- Financial services
- Legal services
- Housing and welfare
- Deering Clinic
- Educational seminars
- Safe sex workshops
- The system

The respondents were asked to comment on why these services have helped the least. The failure of support groups was the most popular response. The following quote is one of the “why” responses on support groups: “Support group, lack of organization for group facilitator, not gay friendly or having experience with HIV positive people”. Another popular response revolved around dental care. More resources for dental care are needed. Dental professionals who are educated about HIV/AIDS are also needed. “Dental, only allowed \$500 per year and I need \$1500 of immediate work done”, and “dental care, the little dental care I have found was very poor. It seems dentists are poorly educated on HIV/AIDS” were among the quotes concerning dental services.

## **Key Informant Interview Results**

Eight key informant interviews were conducted with the Ryan White Title II and Title III case managers with each consortium in Montana. Immediately after each interview the researcher noted observational data and audiotapes were transcribed and data was organized into common themes. Themes for each interview question are reported below.

**Question 1: *What do you believe are the three greatest problems that your clients face?***

### **Theme 1: Access to Medicaid**

Access to Medicaid was reported by the majority of the case managers, as one of the greatest problems their clients face. Filling out the paper work can be a challenge as well as getting on and keeping Medicaid benefits. One case manager stated: *"It is a process. Some people get on it (Medicaid) right away and some people have to wait until they are very, very terminal. So I think that is their greatest problem".*

### **Theme 2: Stigma of HIV**

The majority of the key informants believed that the stigma of having HIV was one of the greatest problems clients face. They believed that clients fear being stigmatized by the rural communities they live in and worry about being accepted in their communities. They also deal with the fear of discrimination and hate crimes in the communities in which they live. One case manager stated: *"The stigma attached to being HIV*



*positive is still seen, at least in our community, as the homosexual disease". Another stated: "I think some of the biggest problem clients face is just the stigma of getting this medical condition which has evolved from being known as a fatal disease to becoming a chronic but manageable disease, to becoming a disability, but the stigma has not changed with it".*

### **Theme 3: Lack of Sense of Community**

Lack of sense of community and the lack of community awareness were reported by the majority of the key informants as a problem clients face. There is a lack of networking and participation in support groups among the HIV positive community. The numbers of HIV positive people in Montana communities are small and it is difficult to organize successful support groups. One case manager stated: *"It is difficult to get a support group going, not everybody needs a support group. They need it sometimes and don't need it others. It kind of goes in phases and the people who do come feel frustrated because no one is showing up. So I think there is not a lot of support or sense of community".* Another responded: *"People that are HIV positive tried to start a support group and it hasn't been well attended, mainly because the people that are positive have such different experiences and are at different levels, some have lots of support from their family and others have no one".* Another stated: *"I don't know if it is because we don't have as many HIV positive people, but we don't have a whole lot of community awareness at work here".*

#### **Theme 4: Basic Needs:**

It is believed by most of the key informants that having basic needs met, being able to work and being productive will help prevent clients from engaging in the behaviors that led them to become HIV positive in the first place. One case manager stated: *"The reason why I look at basic necessity stuff is because I feel that if those basic levels of need are not being met then how does that effect a person's coping skills to look at their health behavior and their health choices. If that person is worried about housing they are more apt to go back to the behaviors that led to their HIV transmission".* Another responded: *"If they could be employed it would make them feel more productive, it's a big, big thing. They have too much time where they don't have anything to do".* Another stated: *"When it comes to developing solidarity in promoting prevention and health it gets really fragmented. They go through a lot of losses and people go back to their comfort levels and their previous lifestyles".*

Other problems that were mentioned by some of the key informants included isolation, access to mental health services, fear of disclosing status, and having specialized HIV care.

**Question #2: *What do you believe are your clients major concerns regarding employment?***

**Theme 5: Social Security System**

Fear of losing social security benefits if employed was reported by most of the key informants as the major concern regarding employment. One case manager responded: *"It is difficult at best to get disability and the social security system is really hard here"*. Another responded: *"I think individuals who can't get on social security is the biggest issue with employment. It is the ones that can't get social security and can't work and Ryan White is trying to support. We can support them medically but not financially"*. It was also stated: *"the ones who are on social security and don't have a lot of opportunistic infections and they can only make \$600 per month while on Social security, they don't want to sit at home but they can't afford lose their social security because they will never get it back again"*. Another stated: *"if I were accessing a program I would lose my benefits if I found a job"*.

**Theme 6: Disclosure of Status**

Disclosure of status was reported as a major concern regarding employment. There is a fear among their clients of disclosing their status to management and coworkers. They live in small communities and if people at work discover they are HIV positive confidentiality will not be honored. One case manager stated: *"Their employers will find out that*

*they have HIV and they will lose their job and their insurance and their coworkers will know”.*

#### **Theme 7: Not Feeling Well**

Most of the key informants reported not feeling well and the side effects of the medications as a major concern regarding employment.

One case manager stated: *“Fatigue is an issue that a lot of these folks deal with, they have to go back to work to live and pay bills and they don’t always feel that well”.* Another responded: *“I also think the major issue is they have too many side effects from the disease and are too far-gone to where they are deteriorating and they can’t work”.*

Other major concerns included: stigma of disease, employers not offering flexible schedules, and discrimination were also reported as major concerns regarding employment.

**Question #2a: What do you see as their barriers to obtaining and keeping employment?**

#### **Theme 8: Barriers to obtaining employment**

Most of the key informants believed that not feeling well and the fear of disclosing HIV status as the biggest barriers to obtaining employment. Discrimination, lack of decent employment, transportation, losing Medicaid benefits and lack of flexible schedules are also seen as barriers by some of the key informants. One key informant stated: *“I think*

*the side effects to the medications are barriers to employment, but the first thing I thought of was discrimination in the work place”.*

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

**Theme 9: Drug and alcohol abuse**

Drug and alcohol use was reported by each of the key informants as the behavior that is the most detrimental to their client's health. One key informant stated: *“Especially drugs, they are less apt to take care of themselves when they are drinking and drugging”*. The majority believed unprotected sex, not disclosing status to partners, and having unsafe sex with other positive partners as another behavior that is detrimental to their client's health. One key informant stated: *“Because they have such a small pool of people there is not disclosure prior to engaging in sexual activities”*. Smoking, missing pills, and side effects of medications were also mentioned by some of the key informants as behaviors that are detrimental to client's health.

**Question #4: *What risky behaviors do you believe your clients engage in that put other people's health at risk?***

**Theme 10: Unsafe sex and lack of disclosure**

Unsafe sex and not disclosing to sexual partners was believed by most of the key informants as the behavior that is most detrimental to

other people's health. A case manager stated: *"It is very, very difficult to disclose in a little tiny community about your status because people don't keep secrets"*. Intravenous drug use was also believed as a behavior that is detrimental to other people's health. One case manager believed the use of drugs and alcohol leads to unsafe sexual behavior. Another felt her clients did not engage in any behaviors that put other people's health at risk. She stated: *"I haven't seen them engage in any risky behaviors. Very few are drug users, the vast majority are not"*.

**Question #5: *What services do you believe your clients need the most?***

#### **Theme 11: Housing**

Most of the case managers believed that affordable housing is a service that their clients need the most. A case manager stated: *"Just looking through our drawers here, housing, we have spent a tremendous amount of resources on housing"*. One key informant did not believe housing is a needed service for clients. She stated: *"I continue to anticipate that at some point in time housing may be an issue, but so far is really hasn't been an issue"*.

#### **Theme 12: Access to Mental Health**

Access to Mental Health services and lack of counselors trained to assist HIV positive people, was believed by the case managers to be a service needed by their clients. Limited funding is available through the

Ryan White Consortium but if someone needs extensive therapy it is not available. One key informant stated: *“The funding just isn’t there to support the level of mental health services that are needed in this community and probably any other community in the state”*. Another stated: *“Mental health is definitely a needed service, and if it is available, sometimes they are hesitant to use it”*. If mental health services are available, finding a counselor that is educated and trained to deal with people with HIV/AIDS and the issues concerning the disease. One key informant stated: *“There are only a couple psychologists and one psychiatrist in town that I would even consider sending my clients to. It does limit them”*.

#### **Theme 13: Lack of Knowledge of Available Resources**

A resource library and a list of available resources for clients are believed by some of the key informants as a needed service. Clients do not know where to go to access available services and available resources. Some of them do their own research but it’s not available to all clients. One key informant stated: *“A lot of them don’t have access to the resource. So something is needed that they can use as a resource library or maybe have a community base organization set something up regarding available resources”*.

#### **Theme 14: Specialized Care**

Some of the key informants believe specialized HIV/AIDS care is needed. Clients need people who are trained and specialize in HIV.

Since the HIV/AIDS population is small in Montana, most doctors cannot afford to specialize in HIV. Having somebody come in two or three times a year to meet with HIV positive people in different communities could be an option. One key informant stated: *"Maybe there could be an HIV specialist or a clinic in the state that deals with HIV and people could get that second opinion".*

Other needed services mentioned by the key informants included: support groups, transportation, dental services, credit counseling and vocational rehabilitation.

**Question #6: *What barriers do you see your clients facing in regards to obtaining these services?***

**Theme 15: Barriers to obtaining services**

The barriers believed clients face in regards to obtaining services included a variety of responses. None of the barriers were believed to be most important. Two of the key informants mentioned limited affordable housing and lack of money and resources for services as two barriers. The following barriers were also mentioned: pride, non-supportive families, denial of disease, lack of HIV specialists in mental health, long waiting lists for services, not aware of the system and how it works, services not available, lack of available resources for counseling, and lack of access to services.



**Question #7: Do you have any more thoughts regarding your client's needs?**

Four of the key informants did not have any more thoughts regarding their client's needs. One case manager reported meeting basic necessity needs as a priority. *"These needs take up a lot of time to live. Some clients have to make choices between medication and food"*. They cannot afford regular lives. Another case manager reported clients having enough money for food as an overall concern.

One case manager believes HIV positive clients need to have a sense of community and a feeling of safety in their communities. She stated: *"People have to feel like they belong and it is really hard for a lot of gay people to do that living in this state when you have your government body who is trying to disenfranchise you and ignoring hate crimes and pretending they do not happen"*.

One case manager believes clients are in need of legal services. She stated: *"It seems like all of them (clients) are in need of or referred to legal services. And it is not directly related to HIV, it is related to the drugs and alcohol and other issues in their lives"*.

One case manager believed employment is a major issue regarding HIV positive people. She stated: *"I just think probably the employment thing is the biggest. There will always be people who do not want to work and want to be taken care of, but I think they are the minority and the majority of the people we serve would be glad to go back to work"*.

## **Focus Group Results**

Five focus groups were conducted with HIV positive people in three of the six regions of Montana. Each participant completed a demographic questionnaire (Appendix I). Immediately after each focus group the researcher noted observational data and audiotapes were transcribed and data was organized into common themes.

### **Demographic questionnaire results.**

A total of 21 HIV positive people participated in the five focus groups. The reported of the demographic questionnaire are as follows:

- 67% (n=14) were male, 27% (n=6) were female
- 48% reported being between the ages of 28-37
- 76% (n=16) were Caucasian, 19% (n=4) were Native American, and 5% (n=1) were African American
- 81% (n=17) rent or own their own house/apartment
- 80% (n=17) live alone, 5% (n=1) live with family, 5% (n=1) live on streets, 10% (n=2) marked other
- 62% (n=13) identified as gay, 24% (n=5) identified as heterosexual, 14% (n=3) identified as bisexual
- 33% graduated from high school/GED, 10% (n=2) have vocational certificates, 38% (n=8) attended some college, and 14% (n=3) graduated college
- 48% (n=10) are on disability, 33% (n=7) work full time, 10% (n=2) work part time, 10% (n=2) are unemployed
- 72% (n=15) reported their overall health as good or very good, 24% (n=5) reported health as fair, and 5% (n=1) reported health as poor
- Participants have been living with HIV/AIDS an average of 11 years

The following themes are reported below by focus group question.

**Question #1: *What do you believe are the three greatest problems facing people with HIV in Montana?***

**Theme 1: Affordable Housing**

Lack of affordable housing was believed by the majority of the participants as one of the three greatest problems people with HIV in Montana face. Waiting lists for housing vouchers are long, housing assistance has requirements that are sometimes hard to meet and the lack of decent, affordable housing in Montana cause problems when in need of housing. One participant stated: *"I was considered homeless until a few weeks ago. I was filling out all the paperwork from the shelter and I was number 76 on the voucher list and they were closed out in March of this year".* Another stated: *"I wanted to get a house and have roommates where I could keep my horses and afford the rent. I was on Section 8 and I found the perfect house. I wanted this person to be my roommate and they wouldn't approve him, he didn't count. So they told me if I wanted to keep my housing assistance I couldn't move into that house. You know they say if you are on a voucher you can rent anything you want, that is a lie".*

**Theme 2: Lack of Resources**

Lack of resources and not knowing what resources are available was believed by the majority of the participants to be a problem. It is believed that people with HIV are not told about available services. They

have to find out on their own what they qualify for and what they do not qualify for. Problems have risen with discrimination from workers in Medicaid, and the Social Security System. If they know what to ask for then they can get it, but if they do not know what to ask for they will not be told about it. The following quotes deal with not knowing what resources are available: *"Not knowing what is available is a big problem. We don't know where to go and get certain things and if you don't know what to ask for specifically, nobody will tell you what you are entitled to",* and *"Social Security policy is if you don't have a direct question, they will not answer or provide the information to you",* and *"If I know something is available and I need it, I will go get it. But I am not going to comb the city, knocking on doors sounding like I am begging".*

### Theme 3: Stigma of HIV

The stigma of being HIV positive and the loss of identity are viewed by most of the participants as a problem HIV positive people face. Once you are diagnosed with HIV and start disclosing status other people no longer see you as a individual. You lose your identity and become known as someone with HIV. The following quotes deal with the stigma of HIV and losing your identity: *"When you announce you are HIV positive, that is what they see, you lose you identity as a woman, as an artist, as a mother, as all that and they only see you as a person with HIV",* and *"Its like being shoved into a category and being treated as if you were something different just because you are HIV positive. I mean given all the*

*things that I have done, it really pisses me off to all of a sudden be treated by people who should know better as if I am a victim and I exist in a slightly different category from being human”.*

#### **Theme 4: Lack of Sense of Community**

Lack of community support from the HIV positive community and the community at-large is viewed by most of the participants as a problem. Networking among a wide variety of positive individuals does not seem to happen. Very few people show up for functions, yet there are many people affected by the disease. More people need to be involved but it is not known how that can be accomplished. Support groups do not seem to work. Only a few people attend support groups and it is the same people that participate on a regular basis. People with HIV are a diverse group. They deal with different issues and it is hard to find a common ground. Some heterosexuals do not feel comfortable participating in support groups that are mostly gay, and most women want all female groups. Participants mentioned barriers to becoming involved. The barriers included: fear of disclosure, burnout of talking about it, tired of dealing with HIV, the stigma of being involved, discouragement, and it is viewed as not being needed. Some quotes dealing with the lack of community includes: *“Support groups don’t seem to work here. There is no support group for us, no support group for our families”, “Very few people show up, but so many are involved and the repercussions are they can’t obtain the needed information because they do not put in the input that is needed”, and “I am*

*burnt out. I am tired. I am tired of dealing with it. Excuse me but I am really bored with it. I can hardly assimilate any more knowledge about it. I am at an overloaded point”.*

#### **Theme 5: Unsupportive Communities**

Most of the participants believe that the outside community is unsupportive. There is a lack of public awareness about HIV/AIDS. One participant stated: *“Its ignorance, simple ignorance, they choose not to know even though the information is there”*. They are not educated about HIV/AIDS and the majority of the community does not support those with HIV. They view people with HIV in a different way. There must be something wrong with them because they are positive. More people from the outside community need to become involved, the fight against HIV has to a group effort. Some quotes dealing with the outside community includes: *“More people have to be involved in it. It is like all of the case managers and people and volunteers for the foundations, they participate but without the outside help of the community, that are interested, the bottom line is they are not interested”, and “I would say the services that HIV positive people in Montana need the most is community awareness, lobby activism and political advocacy”*.

#### **Theme 6: Problems with Medicaid**

The majority of the participants believe there are problems with Medicaid and the system. These groups of people have concerns about not being able to return to work. Even if they are asymptomatic they could

not return to work because of fear of losing their benefits. Most would not be able to afford the monthly costs of the medications. They live below poverty level just to get the cost of the medications covered. They must survive on \$530 a month to qualify for medication and medical benefits. There is a fear of getting cut off of Medicaid for any reason. The fear of losing personal resources in order to be covered by Medicaid is also a concern. The paperwork required can sometimes be overwhelming. Some have encountered prejudice and discrimination within the system. The following are participant's quotes concerning Medicaid: *"You are not allowed to go out and get a job. You are not allowed to make any money, you are not allowed to try and better yourself, or you lose your Medicaid and you lose your medicines, and you get sick and you die". "Those of us on Medicaid are actually prevented from making a living, because everything we earn goes toward our meds", and "Social Security doesn't allow the people who are sick and that are trying to maintain life on life's terms to be able to exist".*

#### Theme 7: HIV positive women's issues

Having an on going support group for HIV positive women was an issue during the female HIV positive focus group. These women felt the support of other HIV positive women would be helpful for their state of mental health. The focus group evolved into more of a support group and for that reason not all the questions were covered. One participant stated: *"I am realizing the damage of being separate, not having someone to talk*

*to allows me not to face my HIV". Another stated: "Not that I wish anybody else to be sick, but there are not enough women, in this area that are ill. That doesn't lend to much of a group". The women in the Billings group voiced a similar concern. There was a fear that the female retreat was going to be cut due to low numbers of participation. They feel the retreat is one of the only times available to them to network with other HIV positive women. A participant stated: "Because of the low numbers of HIV positive women in the state we invite women from other states to join ours. It is the only time we get to network with other positive women".*

The following concerns were also voiced by some of the participants in the focus groups: isolation, disclosure of status, transportation, lack of HIV specialists, in need of legal services, dental services and lack of social activities.

**Question #2: *What do you believe are the major concerns regarding employment with HIV positive people in Montana?***

#### **Theme 8: Lack of Employment Options**

Most of the respondents reported lack of employment options as a major concern regarding employment. There are not many jobs that offer salaries and insurance that can cover the costs of the medications. It is believed you cannot go back to work because of the risk of losing social security benefits. One participant stated: *"Unless somebody is wealthy, they cannot obtain and keep employment. Once you are retired from*



*work, as a person with AIDS, once you have left work as a person with AIDS, you cannot afford to be rehired in Montana”.*

### **Theme 9: Disclosure of Status in the Workplace**

Participants also view having to disclose status in the work place as a major concern regarding employment. They do not want coworkers to know about their status. Confidentiality and gossip in the workplace is an issue, communities are small and people from work talk to people in the community. They do not feel safe working in an environment where the consequences of disclosure can be negative. One participant stated:

*“From my own experience it was a fear factor. I was working at a resort and my coworkers found out about my status. They became very negative and the associations I was building were cut off. They didn’t want to deal with, they didn’t want to accept it and they had no compassion for the disease”.*

### **Question #2a: *What do you believe the barriers are for people with HIV in obtaining and keeping employment?***

The majority of the participants did not voice one or two overall barriers in regards to keeping and obtaining employment. The participants mentioned the following barriers: disclosure of status, discrimination in the work place, physical condition, non-flexible employment, lack of insurance benefits and fear of losing social security benefits.

**Question #3: *What risky behaviors do you believe HIV positive people in Montana engage in that are detrimental to their health?***

This question was presented to the first three focus groups.

Participants did not respond well to this question. One respondent wanted to rephrase the question as “what behaviors do others engage in that put our health at risk?” Due to this fact and time constraints it was not presented at the last two focus groups. Participants mentioned the following as risky behaviors: use of drugs and alcohol, smoking, isolating self and the drug treatments.

**Question #4: *What services do you believe people with HIV need the most?***

There was not a general consensus among participants concerning any one service. A number of different services were mentioned. It was believed by some of the participants that mental health services and psychosocial services are needed among the HIV population. One participant stated: “Psychosocial services are the most important thing. All the medical provision is secondary because people have such a hard time maintaining and using the medical resources if they do not have the psychosocial support to do so”. Some of the participants believed access to specialized care and HIV specialists were needed services. Alternative therapies were also believed to be a needed service for people with HIV. Medicaid and most insurance companies did not cover these types of

therapies. One participant has been trying to get alternative care covered for twenty years. Dental services and legal services were mentioned as needed services.

**Question #5b: What barriers do you believe people with HIV in Montana face in regards to obtaining these services?**

Most of the participants believed not knowing the service exist to be a barrier in accessing care. One participant stated: *"We need to be informed of what we have. Being told I could get therapy changed my life, and I didn't know that was available until I casually mentioned it"*. Most of the respondents believe that there needs to be more information available about existing services, this lack of information can be a barrier to accessing the service. Not having access to services was also mentioned as a barrier.

**Question #6: What risky behaviors do you believe people with HIV engage in that put other people's health at risk?**

This question was only presented at one focus group and the response was not good. One respondent stated: *"There is a loaded question, nobody puts anybody's health at risk. I find this an insulting question. Being alive, that is the risky behavior I engage in"*. Because of the poor response and fear of insulting participants this question was not asked again.

**Question #7: What would be the single most important change you would suggest to improve the lives of people living with HIV in Montana?**

The general themes and ideas from this question revolved around becoming empowered as a citizen, creating a greater sense of community and normalizing the disease, making it like any other disease without the stigmatism. One participant stated: *"I felt that when I was dying that I was empowered, but since in recovery I haven't felt empowered to recover"*.

Educating the general public and the professional community about HIV/AIDS. By increasing knowledge, some of the participants believed there would be less discrimination and the stigma surrounding the disease would dissipate. One participant responded: *"With more information, the legal services, the doctors and everything else would probably start to remedy itself, at least to some degree, they would be more educated and more aware"*. Another participant stated: *"The most important change I would suggest would be to change the rest of the people's attitudes in this state by educating and informing them. It would make our lives a whole lot easier"*.

## **CHAPTER V**

The purpose of this study was to assess the needs of people living with HIV/AIDS in Montana, including both those receiving, and those not receiving HIV related services. In addition barriers to receiving HIV/AIDS related care were also examined.

### **Summary of Findings**

#### **Demographics**

The demographics of the HIV positive individuals who participated in the survey closely mirror the HIV/AIDS epidemic in Montana. Eighty-four percent of the respondents were male, 12% were female and almost half of the respondents reported being between the ages of 30 and 39. Of the focus group participants 67% were male and 27% were female, 48% reported being between the ages of 28 and 37.

#### **Behaviors of Respondents**

Analysis of survey data revealed several behaviors worth highlighting. First, it is somewhat alarming to note that 38% of respondents reported using condoms sometimes or never. Since 82% of HIV positive individuals reported contracting HIV through sex with a man, understanding why individuals engage in unsafe sex is an important first step in designing prevention strategies.

Second, while 11% of survey respondents reported injecting drugs in the past year, only 4% reported sharing needles during that time period. While this percentage is low, the potential for infection among this population is high and should not be overlooked.

### **Medical and Health Care Needs**

The top three medical and health care needs reported by the survey respondents and supported by the literature (Marx et al, 1997 Bonuck et al, 1996) included alternative therapies, dental care, and professional therapy and counseling.

It is important to note that while Ryan White Title II provides limited funding for dental care and counseling, no funds have been available for alternative therapies. Yet, nearly 43% of the respondents reported a current or future need for alternative therapies. It is also interesting to note that case managers did not mention alternative therapies as a need of their clients perhaps because of the lack of information available about the efficacy of these therapies on the progression HIV.

Not surprisingly, 22% of survey respondents reported dental care as a need while 18% indicated a future need. This number parallels the Housing Survey (2001) where 27% of Montana's respondents reported a need for dental care.

The concerns of focus group participants and key informants revolved around the cost of dental services. Ryan White funding allocates

\$500 a year for dental services. This amount covers the basic treatments. Since people with HIV are a higher risk for developing tooth and gum disease \$500 does not cover all the services needed. One focus group participant needed \$1500 worth of immediate work done on his teeth.

Sixty percent of survey respondents reported a current need, future need or are already receiving professional therapy or counseling services. It is significant that of those individuals who had a preference for the type of counseling they receive, 81% preferred individual counseling. The key informants and focus group participants supported these findings. However, they voiced concern with their choices of therapists and counselors. Both believed that people living with HIV need mental health professionals who are educated about the disease and know how to treat people who are HIV positive.

### **Social Support Needs**

The top three social support needs were social and recreation activities, legal services and information and referral for services. It was surprising to find social and recreation activities as the number one social support need according to survey participants. Thirty-two percent of the participants identified this as a current or future need. This finding was confirmed by some of the focus group participants and key informants but it was not supported by the literature.

It is important to recognize what HIV positive individuals mean when they indicate a need for social and recreational activities. More group social activities for people who are living with HIV/AIDS are not what is needed. According to the results of this study, people with HIV do not want to engage in activities with other people just because they are HIV positive. They want to be able to afford individual activities and be able to choose the people with whom they do these activities. Simple activities like going to the movies or out for dinner at a nice restaurant are not affordable by most people with HIV in Montana since most live on \$700 a month or less, which is below poverty level in Montana.

The need for legal services runs parallel to the need for legal services in the 2001 Housing Survey. Twenty-six percent reported needing legal services in this study (16% reported a future need), while 27% reported needing legal services in the Housing Survey. The key informants and focus group participants support this notion of a need for legal services. People with HIV need to know what legal services are available. Having professionals in the legal field who are educated about HIV/AIDS was a concern.

Information and referral for services was the third most needed social support need. The focus group participants and key informants supported this need. It is important to note that those persons with case managers were receiving services more often than those without case managers.



### **Basic Necessity Needs**

The top two basic necessities needs revolved around housing needs. Thirty-three percent need help with housing or rent assistance and 32% need assistance with paying household bills. Lack of affordable housing in Montana is a problem. Since the majority of respondents reported living on \$700 a month or less it is hard to find decent affordable housing. The key informant and focus group participants also supported the notion of housing as a need among people with HIV. The 2001 Housing Survey reported 33% of respondents would have to move if their financial situation changed as little as \$50 per month. Twenty-five percent reported spending more than 50% of their income on rent/mortgage and utilities.

Emergency financial assistance was reported by 50% of the survey respondents as a current or future basic necessity need. This notion was supported by some of the key informants and the focus group participants. Because the majority of HIV positive people in Montana survive on \$700 a month or less any type of financial emergency would break them financially.

### **Current Resources**

The HIV positive people in Montana reported using the following resources: Medicaid, Medicare, Ryan White Consortium and ADAP, private insurance, Veterans benefits and Social Security benefits. Both focus group participants and key informants voiced a concern regarding lack of knowledge about additional resources and methods of accessing them.

### **Barriers to Accessing Services**

The most frequently reported barrier (44%) was not being aware of what services were available. No money or insurance to pay for services was reported by 35% of the respondents as a barrier. The focus group participants and the key informants supported these findings. Surprisingly, gender and sexual orientation of service providers was not a barrier for accessing services. Transportation issues (8%) and fear of disclosure of status (11%) also were not issues for the majority of respondents.

### **Emerging Needs**

Focus group participants and key informants were not asked to talk about emerging or future needs. However, future needs that were identified by 15% or more of survey respondents include: emergency financial assistance (32%), hospice care (25%), dental care (18%), in home health care (16%), eye care (16%), legal services (16%),

insurance/HMO/Medicaid (15%), practical support with shopping, cooking and household chores (15%), physical and occupational therapy (15%).

### **Recommendations for closing Gaps between Needs and Services**

Based on a review of all sources of existing data, recommendations are as follows:

#### **Safer Sex Practices**

Since 38% of HIV positive individuals who participated in this study reported engaging in sexual activities at least sometimes without the use of a condom, it would seem important to understand and address predisposing, reinforcing and enabling factors which contribute to this behavior.

#### **Alternative Therapies**

Forty three percent of survey respondents reported a current or future need for alternative therapies. Researching the effects of various therapies on the progression of HIV and exploring sources of funding for these therapies is critical.

#### **Individual Counseling**

Eighty-one percent of individuals who expressed a preference for the type of counseling they receive preferred individual counseling. Concern was expressed, however, regarding the sensitivity of counselors to the needs of HIV positive individuals. Education and training for counselors regarding issues faced by HIV positive persons is important.

### **Social and Recreational Activities**

While 32% of the survey respondents reported social and recreational activities as a current or future need, focus group participants and key informants made it clear that people with HIV do not want to be involved in activities with other people simply because the other people are HIV positive. Rather, HIV positive individuals want to be able to afford activities such as movies or dinners out, and be able to choose the people with whom they do these activities. It is important for prevention specialists to explore sources of funding that will allow HIV positive individuals to engage in social and recreational activities that help them feel like “normal, healthy” people.

### **Resources and Services**

Lack of knowledge regarding availability of resources and services was found to be a major social support services issue, and was also listed as a major barrier to accessing services. Professionals working in HIV prevention arena should undertake creating a user-friendly resource guide and developing a mechanism for distributing the guide to individuals in need.

### **Financial Assistance**

Since nearly 50% of HIV positive individuals who participated in this study were living below poverty level, the importance of the emergency financial assistance fund should not be minimized. About half of all survey respondents reported a current or future need for such a fund.

## **Conclusion**

The findings from this study will assist those working in the HIV prevention field meet the needs of HIV positive individuals. In addition, protocol and instruments for this study should be useful in conducting future needs assessments for people living with HIV/AIDS in Montana. The differences found from the key informants and the focus groups should be taken into account when developing programming for this population.

The results of this study show that professionals working in HIV prevention should take the individual needs of HIV positive people into consideration when developing and implementing programs. HIV prevention should begin with those who are HIV positive.

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**Appendix A**  
**Montana HIV/AIDS Incidence Report**

# Montana AIDS Cases as of December 31, 2000

Includes all cases reported to the Montana Department of Public Health & Human Services since 1985.

Reported Cases meeting CDC AIDS Case Definition	Adult/Adolescent		Pediatric (<13)		Total	
	Cases (%)	Deaths (%)	Cases (%)	Deaths (%)	Cases (%)	Deaths (%)
Total:	433 (100)	234 (54)	4 (100)	4 (100)	437 (100)	238 (55)

Exposure Category- Adults and Adolescents	Males (%)	Females (%)	Total (%)
Men who have sex with men	239 (61)	0 (0)	239 (55)
Injecting Drug Use (IDU)	48 (12)	5 (12)	53 (12)
Men who have sex w/ men & IDU	44 (11)	0 (0)	44 (10)
Hemophilia/Coagulation Disorder	9 (2)	0 (0)	9 (2)
Heterosexual Contact	15 (4)	26 (63)	41 (9)
Transfusion with Blood or Blood Products	6 (2)	4 (10)	10 (2)
None of the Above/Under Investigation	31 (8)	6 (15)	37 (9)
Total:	392 (100)	41 (100)	433 (100)

Exposure Category- Pediatric Cases (<13)	Males (%)	Females (%)	Total (%)
Mother with/at risk for HIV infection	3 (100)	1 (100)	4 (100)
Total:	3 (100)	1 (100)	4 (100)

Age at Time of Diagnosis	Cases (%)
Under 5	4 (1)
5-12	0 (0)
13-19	2 (0)
20-29	91 (21)
30-39	212 (49)
40-49	81 (19)
Over 49	47 (11)
Unknown	0 (0)
Total:	437 (100)

Race/Ethnicity	Adult/Adolescent	Pediatric <13)	Total
	Cases (%)	Cases (%)	Cases (%)
White	380 (88)	2 (50)	382 (87)
Black	12 (3)	0 (0)	12 (3)
Hispanic	12 (3)	0 (0)	12 (3)
Asian/Pac.Isr	0 (0)	0 (0)	0 (0)
AmerInd/Alskn	27 (6)	2 (50)	29 (7)
Unknown	2 (0)	0 (0)	2 (0)
Total:	433 (100)	4 (100)	437 (100)

## Other HIV/AIDS Related Information:

US AIDS Cases as of November 30, 2000: 769,853

Montana AIDS Cases reported in 2000: 20

HIV testing at the Public Health Lab since 1985 (testing contains duplicates): 139,617 (643+) In 2000: 9,240 (23+)

Cases include 323 Montana cases & 114 individuals diagnosed in other states who moved to, or returned to Montana.

For more information contact Jim Murphy at (406) 444-0274 or the *STD/HIV Info Line* at 1-800-233-6668.  
Detailed statistics are also available on the web at [www.dphhs.state.mt.us/hpsd/pubheal/disease/commdis/stats.htm](http://www.dphhs.state.mt.us/hpsd/pubheal/disease/commdis/stats.htm)

**Appendix B**  
**Institutional Review Board Approval**

For Internal  
Use Only**RECEIVED**The University of Montana <sup>#22-01</sup>  
INSTITUTIONAL REVIEW BOARD (IRB)  
CHECKLIST

FEB 01 2001

UNIVERSITY OF MONTANA  
VICE PRESIDENT FOR RESEARCH

Submit one completed copy of this Checklist, including any required attachments, for each course involving human subjects. The IRB meets monthly to evaluate proposals, and approval is granted for one academic year. See IRB Guidelines and Procedures for details.

Project Director: Annie Sondag Dept.: HHP Phone: 243-5215

Signature: [Signature] Date: 2-1-01

Co-Director(s): Laura Oyler ✓ Dept.: HHP Phone: 243-6988

Project Title: Needs Assessment for HIV Positive People of Montana

Project Description: To assess the service needs of the HIV positive people in Montana using surveys, focus groups and key informant interviews

All investigators on this project must complete the NIH self-study course on protection of human research subjects. Certification: I/We have completed the course - (Use additional page if necessary)

Signature	Date	Signature	Date
<u>[Signature]</u>	<u>2-1-01</u>		
<u>[Signature]</u>	<u>2-1-01</u>		

**Students Only:**

Faculty Supervisor: \_\_\_\_\_ Dept.: \_\_\_\_\_ Phone: \_\_\_\_\_

Signature: \_\_\_\_\_

(My signature confirms that I have read the IRB Checklist and attachments and agree that it accurately represents the planned research and that I will supervise this research project.)

For IRB Use Only

**IRB Determination:**

\_\_\_ Approved Exemption from Review

\_\_\_ Approved by Administrative Review

X Full IRB Determination:

- X Approved
- \_\_\_ Conditional Approval (see attached memo)
- \_\_\_ Resubmit Proposal (see attached memo)
- \_\_\_ Disapproved (see attached memo)

washer of signed informed  
consent granted. However,  
must obtain verbal informed  
consent

Signature IRB Chair: [Signature] Date: 2/15/01  
(over)

**Appendix C**  
**Survey Instrument**

## CONSUMER QUESTIONNAIRE FOR PEOPLE LIVING WITH HIV/AIDS IN MONTANA

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

- Your participation in this study is **VOLUNTARY**
- Do **NOT** put your name on this survey
- Only complete this survey if you have tested HIV positive and/or diagnosed with AIDS
- The answers you give are **ANONYMOUS**
- Please return the survey to your case manager or mail in the self-addressed stamped envelope
- Only complete the survey **ONCE**

**THANK-YOU VERY MUCH**

### TELL US ABOUT YOUR LIVING ARRANGEMENTS

1) Where are you living now? Check all that apply.

- ☐ Living alone
- ☐ Living with domestic partner
- ☐ Living with parents
- ☐ Living with roommate(s)
- ☐ Living in health care facility
- ☐ Living in halfway house or drug program
- ☐ Living in public housing
- ☐ Living on the streets, no home
- ☐ Living in a shelter
- ☐ Own home
- ☐ Other (please specify) \_\_\_\_\_

2) If you were to require housing assistance, which type would be most important to you? (check one only)

- ☐ Rent assistance to allow you to live in your own place
- ☐ Housing referrals
- ☐ Public housing
- ☐ Group home
- ☐ Assisted living
- ☐ Already have housing assistance
- ☐ Other (please specify) \_\_\_\_\_

3) How long have you lived at your present address? \_\_\_\_\_

4) Have you moved *since* you learned you were HIV positive?

- ☐ Yes
- ☐ No (skip to #6)

5) If you answered yes to question #4, why did you move? Check all that apply.

- ☐ New job
- ☐ End, layoff or termination of job (got fired)
- ☐ To live with/near family
- ☐ To be with caregiver
- ☐ To be with friends
- ☐ To be closer to doctor
- ☐ To get better HIV/AIDS related services
- ☐ Asked to move because of drug/alcohol problem
- ☐ Forced or asked to move because of HIV status
- ☐ Not enough money to pay rent
- ☐ Moving had nothing to do with HIV
- ☐ Other (please specify) \_\_\_\_\_

### TELL US ABOUT YOURSELF

**6) Gender**

- ☐ Female  
☐ Male  
☐ Transgender

**7) How old are you? \_\_\_\_\_**

**8) Ethnicity/Race**

- ☐ Native American/AK Indian  
☐ Asian/Pacific Islander  
☐ African American  
☐ Caucasian  
☐ Hispanic  
☐ Other (please specify) \_\_\_\_\_

**9) Do you have a steady income?**

- ☐ Yes  
☐ No

**10) What is your monthly income? \_\_\_\_\_**

**11) Current employment status**

- ☐ Employed full-time  
☐ Employed part-time  
☐ Not employed  
☐ On disability  
☐ Other (please specify) \_\_\_\_\_

**12) What is your *highest* level of education completed?**

- ☐ 8<sup>th</sup> grade or less  
☐ some high school, didn't graduate  
☐ High school or GED  
☐ Vocational certification  
☐ Some college  
☐ College graduate  
☐ Other (please specify) \_\_\_\_\_

**13) What is the total number of adults (including yourself) living in your household? \_\_\_\_\_**

**14) Do you have children?**

- ☐ Yes  
☐ No (skip to #17)

**15) If yes, how many? \_\_\_\_\_**

**16) If yes, do they live with you?**

- ☐ Yes  
☐ No  
☐ Sometimes

**17) Health Insurance Check all that apply.**

- ☐ Medicaid  
☐ Medicare  
☐ Private insurance  
☐ Ryan White Title II and/or Title III Assistance  
☐ Veterans benefits  
☐ Indian health service  
☐ None  
☐ Other (please specify) \_\_\_\_\_

### TELL US ABOUT YOUR HIV/AIDS STATUS

**18) In general, how would you rate your overall health?**

- ☐ Very good  
☐ Good  
☐ Fair  
☐ Poor  
☐ Very poor

**19) Are you currently diagnosed with AIDS?**

- ☐ Yes  
☐ No  
☐ I don't know

**20) Do you know your CD4 count?**

- ☐ Yes  
☐ No

**21) Do you know your viral load?**

- ☐ Yes  
☐ No

**22) How many months ago was your last blood test? \_\_\_\_\_**

**23) What state were you living in when you found out you were HIV positive? \_\_\_\_\_**

**24) How many years ago did you learn you were HIV positive? \_\_\_\_\_ year(s)**

**25) When you found out you were HIV+, were you also diagnosed with AIDS?**

- ☐ Yes  
☐ No  
☐ Don't remember

**26) Do you receive HIV/AIDS related medical care?**

- ☐ Yes  
☐ No

27) If yes, how many months after finding out you had HIV/AIDS did you receive HIV related medical care? \_\_\_\_\_

28) Do you have a regular place to go for HIV/AIDS health care?

- ☐ Yes  
☐ No

29) In the last 6 months, how many times have you visited a doctor or other health care provider for help with HIV? \_\_\_\_\_

30) Are you taking a combination of antiretroviral, HIV drugs? (cocktail)

- ☐ Yes  
☐ No  
☐ Not now, but took them in the past

31) If you are taking medications, how do you pay for them? Check one only.

- ☐ Pay for them myself  
☐ Family/friends help pay for them  
☐ Private insurance  
☐ Medicaid  
☐ Veteran benefits  
☐ Clinical trials  
☐ Indian health services  
☐ AIDS Drug Assistance Program (ADAP) with Title II  
☐ Other (please specify) \_\_\_\_\_

32) Do you use alternative therapies?

- ☐ Yes  
☐ No (skip to #34)

33) If yes, which of the following do you use? Check all that apply.

- ☐ Herbal therapies  
☐ Vitamins and minerals  
☐ Massage  
☐ Acupuncture  
☐ Prayer/Spiritual  
☐ Other (please specify) \_\_\_\_\_

34) If no, why don't you use alternative therapies? Check all that apply.

- ☐ Can't afford them  
☐ Not available  
☐ Not interested  
☐ Don't think they work  
☐ Other (please specify) \_\_\_\_\_

35) If you use alternative therapies how do you pay for them? Check all that apply.

- ☐ Pay for them myself  
☐ Family/friends help pay for them  
☐ Private Insurance  
☐ Other (please specify) \_\_\_\_\_

36) Do you have a Ryan White Title II or III case manager?

- ☐ Yes  
☐ No

**TELL US ABOUT YOUR  
BEHAVIORS SINCE BECOMING  
HIV POSITIVE**

**This is anonymous and you don't  
have to answer any questions that  
make you feel uncomfortable**

37) Which best describes your sexual activity since becoming HIV positive?

- ☐ Stopped having sexual relations  
☐ Never use condoms  
☐ Sometimes use condoms  
☐ Always use condoms

38) What is your sexual orientation?

- ☐ Heterosexual (straight)  
☐ Lesbian  
☐ Gay  
☐ Bisexual

39) Does your sex partner(s) know your HIV status?

- ☐ Yes  
☐ No  
☐ Sometimes  
☐ Not sexually active

40) Do you ask the HIV status of your sex partners?

- ☐ Yes  
☐ No  
☐ Sometimes  
☐ Not sexually active

41) Have you been treated for sexually transmitted diseases in the last two years?

- ☐ Yes  
☐ No



**42) If yes, check all that apply.**

- ☐ Syphilis
- ☐ Genital warts
- ☐ Gonorrhea
- ☐ Herpes
- ☐ Chlamydia
- ☐ Hepatitis B
- ☐ Hepatitis C
- ☐ Other (please specify)\_\_\_\_\_

**43) How do you believe you became HIV positive? Check one only.**

- ☐ Sex with a man
- ☐ Sex with a woman
- ☐ Injection drug use
- ☐ Blood transfusion
- ☐ Do not know
- ☐ Other (please specify)\_\_\_\_\_

**44) Have you used any substances in the past year?**

- ☐ Yes
- ☐ No (skip to #50)

**45) If you answered yes to question #44, which ones? Check all that apply.**

- ☐ Alcohol
- ☐ Marijuana
- ☐ Crack
- ☐ Cocaine
- ☐ Heroin
- ☐ Methamphetamine
- ☐ Downers
- ☐ Other (please specify)\_\_\_\_\_

**46) Have you injected any drugs in the past year?**

- ☐ Yes
- ☐ No

**47) Have you shared needles while injecting drugs in the past year?**

- ☐ Yes
- ☐ No

**48) Do you believe your drug use to be a problem?**

- ☐ Yes
- ☐ No
- ☐ I don't know

**49) Do you use marijuana for medicinal purposes?**

- ☐ Yes
- ☐ No

**50) Do you have emotional concerns, which have caused a problem for you in the last 6 months?**

- ☐ Yes
- ☐ No (skip to #51)

**51) If yes, check all that apply.**

- ☐ Stress
- ☐ Depression
- ☐ Guilt
- ☐ Suicidal tendencies
- ☐ Anger/resentment
- ☐ Worry/fear (concern about future)
- ☐ Loneliness (isolating yourself)
- ☐ Other (please specify)\_\_\_\_\_

**52) Are you taking any prescription medications for emotional (depression) or stress related problems?**

- ☐ Yes
- ☐ No

**53) Has becoming HIV+ caused problems in your close relationships?**

- ☐ Yes
- ☐ No (skip to #55)

**54) If you answered yes on #50, check all that apply.**

- ☐ Relationship with partner/spouse more strained
- ☐ HIV/AIDS related problems caused separation from partner
- ☐ Stress or isolation in relationships with friends
- ☐ Stress or isolation in relationship with family
- ☐ More difficulties in relationships with children
- ☐ Other (please specify)\_\_\_\_\_

**55) What type of counseling do you prefer? Check all that apply.**

- ☐ Individual (me and the counselor)
- ☐ Group (with other HIV+ people)
- ☐ Peer counseling (by other HIV+ people)
- ☐ I don't prefer counseling
- ☐ Other (please specify)\_\_\_\_\_

<p align="center"><b>TELL US ABOUT YOUR SERVICE NEEDS</b></p>
---

**56) Do you prefer to obtain HIV related services from staff with your same sexual orientation?**

- ☐ Yes
- ☐ No
- ☐ Don't care

57) If yes, does this interfere with you accessing care?

- ☐ Yes
- ☐ No

58) Do you prefer your HIV service providers to be male or female?

- ☐ Male
- ☐ Female
- ☐ Don't care

59) Does the service provider's gender interfere with you accessing care?

- ☐ Yes
- ☐ No

60) When you want to find out about an HIV/AIDS related service, who would you contact first? (Check one only)

- ☐ Medical care provider
- ☐ Friends
- ☐ Family/partner/spouse
- ☐ Ryan White Case manager
- ☐ Written literature
- ☐ Internet
- ☐ Other (please specify) \_\_\_\_\_

61) When you need help with an HIV related concern, who is the person you turn to for advice? Check all that apply.

- ☐ Partner/spouse
- ☐ Other family member
- ☐ Close friend
- ☐ Ryan White Case Manager
- ☐ Medical provider
- ☐ Other (please specify) \_\_\_\_\_

62) If you choose to get services in a county other than the county that you live in, check all the reasons why.

- ☐ Confidentiality issues
- ☐ Service isn't available
- ☐ Not happy with quality of service
- ☐ Closer to where I work
- ☐ Services in my community were not sensitive to my race, gender, sexual orientation, drug use or disability
- ☐ Referred by doctor or health care provider
- ☐ Services not convenient-too far to travel, or time service offered
- ☐ Other (please specify) \_\_\_\_\_

63) What are your biggest barriers to accessing services? Check all that apply.

- ☐ Not aware services exist
- ☐ Services were too far to travel
- ☐ No money or insurance to pay for services
- ☐ Had no way to get to service (no car, taxi/bus)
- ☐ Time of day services offered is not good for me
- ☐ Available services are not sensitive to my gender or sexual orientation
- ☐ Available services are not sensitive to my drug use
- ☐ I don't want to disclose my HIV status to the local service agency
- ☐ I am getting the services I need
- ☐ Other (please specify) \_\_\_\_\_

64) How do you feel about the quality of HIV/AIDS related care you have received in Montana?

- ☐ Excellent
- ☐ Good
- ☐ Fair
- ☐ Poor
- ☐ Very poor
- ☐ Comments \_\_\_\_\_

**PLEASE HANG IN THERE!!! YOU ARE ALMOST FINISHED!!! AGAIN, THANK YOU VERY MUCH!! :)**

Below is a partial list of care and support services for people with HIV/AIDS. Please check the boxes that apply to you for each service.  
PLEASE CHECK ONLY ONE BOX FOR EACH ROW!!

TYPE OF CARE/SUPPORT SERVICE I NEED	NOT A NEED OF MINE	I CURRENTLY RECEIVE SERVICES	I NEED SERVICE BUT I DO NOT RECEIVE	I HAVE FUTURE NEED FOR THIS SERVICE
<b>MEDICAL AND HEALTH CARE</b>				
Medical Care (doctor, nurse, clinic)				
Dental Care				
Eye Care				
Emergency medical care				
Physical or Occupational Therapy				
In-Home Health Care (nurse, aide)				
Hospice Care (end of life care)				
Residential Care (help with room&board)				
Nursing Home Care				
Medicines (antivirals antibiotics, other)				
Alternative Therapies (massage, meditation, acupuncture, herbs, etc.)				
Medical Equipment (wheelchair, etc)				
Adult Day Health (on-site, ongoing supervision and support)				
Respite Care (relief for person caring for you)				
Nutritional Counseling Services				
Mental Health				
Professional Therapy/Counseling				
Substance Abuse Treatment/Counseling				
Other (please specify)				
<b>BASIC NEEDS</b>				
Assistance with paying household bills				
Housing or Rent Assistance				
Food Bank				
Home Delivered Meals./groceries				
Clothing				
Transportation				
Practical support (help with shopping, cooking, cleaning, laundry, chores, moving, pets, etc.)				
Financial Assistance with Medications				
Insurance/HMO/Medicaid				
Emergency financial assistance				
Other (please specify)				

TYPE OF CARE/SUPPORT SERVICE I NEED	NOT A NEED OF MINE	I CURRENTLY RECEIVE SERVICES	I NEED SERVICE BUT I DO NOT RECEIVE	I HAVE FUTURE NEED FOR THIS SERVICE
<b>SOCIAL SUPPORT SERVICES</b>				
Case Management Services				
Client Advocacy				
Information and Referral for Services				
Child Care				
Legal Services				
Adoption/Foster Care for Children				
Social/Recreation Activities				
Buddy/Companion Volunteer Support				
Support Groups/Peer Counseling				
Spiritual Support				
Other (please specify)				

**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 in the space below and the back of this page if you need more room)**

**Of the HIV/AIDS services you have used, which helped the most? Why?**

**Of the HIV/AIDS services you have used, which helped the least? Why?**

**THANK YOU  
THANK YOU  
THANK YOU**

**Appendix D**  
**Focus Group Questions**

## Focus Group Questions

### **\*Ice Breaker—Determining your color, personality test**

- 1. What do you believe are the three greatest problems facing people with HIV in Montana?**
- 2. What do you believe are the major concerns regarding employment with HIV positive people in Montana?**
  - a. What do you believe the barriers are for people with HIV in obtaining and keeping employment?**
- 3. What risky behaviors do you believe HIV positive people in Montana engage in that are detrimental to their health?**
- 4. What services do you believe people with HIV in Montana need the most?**
- 5. Do you believe people with HIV in Montana are able to access these services?**
  - b. If so, do you think people with HIV are satisfied with these services? Why or why not?**
  - c. What barriers do you believe people with HIV in Montana face in regards to obtaining these services?**
  - d. Are there any services you need but can't get?**
- 6. What risky behaviors do you believe people with HIV engage in that put other people's health at risk?**
- 7. What would be the single most important change you would suggest to improve the lives of people living with HIV in Montana?**
- 8. What other thoughts do you have regarding the needs of people with HIV in Montana?**

**Appendix E**  
**Key Informant Interview Questions**

### **Interview Questions-Case managers**

**\*Ice breaker—How did you become a Ryan White Title II and/or Title III case manager?**

- 1. What do you believe are the three greatest problems that your clients face?**
- 2. What do you believe are your clients major concerns regarding employment?**
  - a. What do you see as their barriers to obtaining and keeping employment?**
- 3. What risky behaviors do you believe your clients engage in that are detrimental to their health?**
- 4. What risky behaviors do you believe your clients engage in that put other people's health at risk?**
- 5. What services do you believe your clients need most?**
- 6. What barriers do you see your clients facing in regards to obtaining these services?**
- 7. Do you have any more thoughts regarding your client's needs?**



## **Appendix F**

### **Modified Informed Consent Form for Survey**

## **IMPORTANT INFORMATION for Survey Participants**

**TITLE:** Determining the Needs of HIV Positive People in Montana

**PROJECT DIRECTORS:** Annie Sondag: 243-5215; UM, McGill Hall, Missoula, MT 58912  
Laura Dybdal: 243-6988, UM, McGill Hall, Missoula, MT 59804

Please read this information carefully before you make a decision about whether to complete the survey. This information sheet may contain words that are 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 project is to assess the needs of people who are HIV positive, or living with AIDS in Montana. Information gathered from this study will be made available to Montana's Department of Health and Human Services (DPHHS) and Ryan White's Title II and III CARE Act. This information will be used to provide better services and care to those living with HIV/AIDS in Montana. By filling out this survey you will help provide valuable information, which in turn will help you meet your needs and the needs of other HIV positive people in Montana.

### **PROCEDURES**

Participation in this project is **VOLUNTARY**. If you agree to participate you will be asked to fill out a survey covering various topics. The questionnaire will take approximately 30 minutes to complete. You will receive five dollars for your time and effort in completing this survey. Once completed, either hand the survey back to the person who gave it to you, or mail it in the self-addressed stamped envelope.

### **RISKS/DISCOMFORTS**

You may find some of the questions very personal. If a question makes you uncomfortable, you do not have to answer it. If, after taking this survey you have questions about HIV/AIDS or you would like to talk to someone about HIV/AIDS you may call the Montana HIV/AIDS Hotline or the Ryan White case manager in your region. A list of these resources is attached to this sheet.

### **BENEFITS**

Your help with this project will provide valuable information to DPHHS and Ryan White staff. By participating in this project, your answers will help staff offer services and develop programs to meet the needs of HIV positive people in Montana. By meeting these needs, the quality of your life and the lives of others with HIV may improve.

**CONFIDENTIALITY**

Because the survey may bring up some issues that may be sensitive to some subjects, the following steps will be taken to minimize potential risks:

1. Participants' identities will remain anonymous and will not be associated with research findings in any way.
2. At the conclusion of the study, any information pertaining to participants' identities will be destroyed.
3. All data will be reported as group data.

**COMPENSATION FOR INJURY**

Although we believe that the risk of taking part in this study is minimal, 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 or compensation pursuant the Comprehensive State Insurance Plan established 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 may withdraw from this study for any reason.

**QUESTIONS**

If you have any questions about the research now or later, you may contact Annie Sondag: 243-5215, Laura Dybdal: 243-6988, Rick Holman: 723-5242, Nancy Mulla: 243-4291, or Jennifer Hackenbruch: 243-4291.

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 also 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 that this consent form is mine to keep.

**THANK YOU VERY MUCH FOR YOUR PARTICIPATION**

**Appendix G****Cover Letter**

Hello.

Please allow me to introduce myself. My name is Rick Holman and I live in Butte. I have been involved with the Statewide Planning Group in the fight against HIV/AIDS and I volunteer with the Butte AIDS Support Services. Recently Dr. Annie Sondag with the University of Montana asked me to help with a Needs Assessment document for the year 2001. This survey is very important to YOU and everyone fighting the battle against HIV/AIDS. The Ryan White office will use this document when funding is requested. It will be used by the Department of Health and Human Services to find out what services are needed and in what part of the state. The State of Montana will use the information that is compiled to try to access more funds from the Center for Disease Control. So this is a win win situation for people living with HIV/AIDS.

Enclosed you will find a copy of the new Needs Assessment Survey. I cannot over emphasize the importance of this survey to any person living with HIV/AIDS. This is not a repeat of the housing survey that you may have filled out recently.

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

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

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

Sincerely,

Rick Holman

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 2001. This survey is very important to YOU and everyone fighting the battle against HIV/AIDS. The Ryan White office will use this document when funding is requested. It will be used by the Department of Health and Human Services to find out what services are needed and in what part of the state. The State of Montana will use the information that is compiled to try to access more funds from the Center for Disease Control. So this is a win win situation for people living with HIV/AIDS.

Enclosed you will find a copy of the new Needs Assessment Survey. I cannot over emphasize the importance of this survey to any person living with HIV/AIDS. This is not a repeat of the housing survey that you may have filled out recently.

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

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

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

Sincerely,

Rick Holman

## **Appendix H**

### **Modified Informed Consent Form for Focus Group**

## **IMPORTANT INFORMATION for Focus Group Participants**

**TITLE:** Determining the Needs of HIV Positive People in Montana

**PROJECT DIRECTORS:** Annie Sondag: 243-5215; UM, McGill Hall, Missoula, MT 58912  
Laura Dybdal: 243-6988, UM, McGill Hall, Missoula, MT 59804

Please read this information carefully before you make a decision about whether to participate in the focus group. This information sheet may contain words that are 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 project is to assess the needs of people who are HIV positive, or living with AIDS in Montana. Information gathered from this project will be made available to Montana's Department of Health and Human Services (DPHHS) and Ryan White's Title II and III CARE Act. This information will be used to provide better services and care to those living with HIV/AIDS in Montana. By participating in this focus group you will help provide valuable information, which in turn will help you and other people living with HIV/AIDS meet their needs.

### **PROCEDURES**

Participation in this study is **VOLUNTARY**. If you agree to participate you will be asked to take part in a focus group covering various topics. The focus group will take approximately 1 to 2 hours. The session will be audio recorded and transcribed for accuracy of responses. Pizza and snacks will be served.

### **RISKS/DISCOMFORTS**

You may find some of the questions very personal. If a question makes you uncomfortable, you do not have to answer it. If, after taking part in this focus group, you have questions about HIV/AIDS or you would like to talk to someone about HIV/AIDS you may call the Montana HIV/AIDS Hotline or one of the HIV Prevention Sites in your area. A list of these resources is attached to this sheet.

### **BENEFITS**

Your help with this project will provide valuable information to DPHHS and Ryan White staff. By participating in this project, your answers will help staff offer services and develop programs to meet the needs of HIV positive people in Montana. By meeting these needs, your quality of your life may improve.



### **CONFIDENTIALITY**

All of the information we collect here today is confidential. We will not identify any of the participants. For example, we will not use your name, or any other identifying information in reports or other materials related to this study.

1. Participants' identities will remain anonymous and will not be associated with research findings in any way.
2. At the conclusion of the study, any information pertaining to participants' identities will be destroyed.
3. All data will be reported as group data.

### **COMPENSATION FOR INJURY**

Although we believe that the risk of taking part in this project is minimal, 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 or compensation pursuant the Comprehensive State Insurance Plan established 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 project is entirely voluntary. You may withdraw from this project for any reason.

### **QUESTIONS**

If you have any questions about this project now or later, you may contact Annie Sondag: 243-5215, Laura Dybdal: 243-6988, Rick Holman: 723-5242, Nancy Mulla: 243-4291, or Jennifer Hackenbruch: 243-4291.

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 project. I am at least 18 years old. I understand that I will receive a copy of this consent form.

**THANK YOU VERY MUCH FOR YOUR PARTICIPATION**

**Appendix I**  
**Demographic Questionnaire**

## RESPONDENT QUESTIONNAIRE

**Note:** All the information collected here will be kept strictly anonymous. If you feel uncomfortable answering any question, you can leave it blank.

**1. Gender**

- ☐ Female
- ☐ Male
- ☐ Transgender

**2. Age**

- ☐ 18-27 years
- ☐ 28-37 years
- ☐ 38-47 years
- ☐ 48-57 years
- ☐ Over 58 years

**3. Race/ethnicity**

- ☐ Native American or Alaska Native
- ☐ Asian
- ☐ Black or African American
- ☐ Hispanic or Latino
- ☐ Native Hawaiian/Pacific Islander
- ☐ White

**4. Where are you living now?**

- ☐ Rent/own house/apartment
- ☐ Live with family
- ☐ Staying with friends
- ☐ Halfway house or drug treatment program
- ☐ Shelter
- ☐ On the street-no home
- ☐ Other (please specify)\_\_\_\_\_

**5. What is your sexual orientation?**

- ☐ Heterosexual/straight
- ☐ Gay
- ☐ Lesbian
- ☐ Bisexual
- ☐ Other (please specify)\_\_\_\_\_

**6. Highest level of education completed?**

- ☐ 8<sup>th</sup> grade or less
- ☐ Some high school
- ☐ High school graduate/GED
- ☐ Vocational certification
- ☐ Associate degree
- ☐ Some college
- ☐ Graduated college
- ☐ Other (please specify)\_\_\_\_\_

**7. Current employment status**

- ☐ Employed full-time
- ☐ Employed part-time
- ☐ Unemployed
- ☐ Disability
- ☐ Volunteer work
- ☐ Other (please specify)\_\_\_\_\_

**8. How long ago did you learn you were HIV positive?\_\_\_\_\_**

**9. In general, how would you rate your overall health at the present time?**

- ☐ Very good
- ☐ Good
- ☐ Fair
- ☐ Poor

**THANK YOU VERY MUCH!!!!!!**

**Appendix J**  
**Key Informant Consent Form**

**KEY INFORMANT  
PARTICIPANT INFORMATION AND CONSENT FORM**

**TITLE:** Determining the Needs of HIV Positive People in Montana

**PROJECT DIRECTORS:** Annie Sondag: 243-5215; UM, McGill Hall, Missoula, MT 58912  
Laura Dybdal: 243-6988, UM, McGill Hall, Missoula, MT 59804

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

**PURPOSE**

The purpose of this project is to assess the needs of people who are HIV positive, or living with AIDS in Montana. Information gathered from this project will be made available to Montana's Department of Health and Human Services (DPHHS) and Ryan White's Title II and III CARE Act. This information will be used to provide better services and care to those living with HIV/AIDS in Montana. By participating in this interview you will help provide valuable information to meet the needs of HIV positive people in Montana.

**PROCEDURES**

Participation in this study is **VOLUNTARY**. If you agree to participate you will be asked to answer a number of questions covering various topics concerning your HIV positive clients. You will be asked to read and sign the consent form. The interview will take approximately one hour. The session will be audio recorded and transcribed for accuracy of responses. A WalMart gift card will be given to you for your time spent.

**RISKS/DISCOMFORTS**

You may find some of the questions personal or may feel that you do not know the answer. If a question makes you uncomfortable, you do not have to answer it.

**BENEFITS**

Your help with this study will provide valuable information to DPHHS and Ryan White staff. By participating in this study, your answers will help staff offer services and develop programs to meet the needs of HIV positive people in Montana.

**CONFIDENTIALITY**

All of the information we collect here today is confidential. We will not identify any of the participants. For example, we will not use your name, or any other identifying information in reports or other materials related to this study.

1. Subjects' identities will remain anonymous and will not be associated with research findings in any way.
2. At the conclusion of the study, any information pertaining to subjects' identities will be destroyed.
3. All data will be reported as group data.