A Health Needs Assessment of People Living with HIV in Montana

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A Health Needs Assessment of People Living with HIV in Montana

BY
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2017
*

PROFESSIONAL PAPER
presented in partial fulfillment of the requirements
for the degree of
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Introduction

History of HIV/AIDS

Human immunodeficiency virus (HIV) attacks an individual’s immune system by targeting the CD4 cells (T cells) which aid the immune system in fighting off infections (CDC, 2018c). Without proper treatment, HIV can destroy the body’s T cells, essentially rendering the body unable to defend itself against infections, making an individual more likely to contract an opportunistic infection, and signaling the arrival of AIDS, the last stage of an HIV infection (CDC, 2018c). HIV is transmitted from a person who is infected through certain bodily fluids including blood, semen, vaginal fluids and breast milk (CDC, 2018c).

HIV is believed to originate from the chimpanzee form of the immunodeficiency virus, and it was passed onto humans after the chimpanzee version mutated into HIV (CDC, 2018c). Researchers have been aware of HIV’s existence in the United States since the mid-1970s. The Centers for Disease Control and Prevention (CDC) released information on the first cases of opportunistic infection in young gay men, later shown to be AIDS related, in 1981 (AIDS Foundation of Chicago, n.d.). By 1992, AIDS became the number one cause of death in American men between the ages of 25 to 44 (AIDS Foundation of Chicago, n.d.). By 2000, HIV/AIDS was declared a threat to United States national security (Gellman, 2000). By 2001, national efforts were undertaken to reduce the rate of HIV transmission in the United States, ranging from drug manufactures lowering the price of HIV/AIDS drugs to the CDC creating a new HIV Prevention Strategic Plan to reduce the number of annual HIV infections in the United States by 50% in five years (HIV.gov, n.d.). The CDC’s high impact approach has been successful, evident with an estimated 18% decline in annual HIV infections in the United States from 2008-2014 (CDC, 2017).

As a result of the high number of AIDS related deaths, prevention and treatment of HIV infection has been well-researched. HIV is a retrovirus, and the specific drugs used to treat a retrovirus are called antiretrovirals or ARV (HIV.gov, n.d). The first antiretroviral drug approved by the FDA in 1987 was named azidothymidine (AZT), a type of medicine that helps prevent the production of DNA and limit the replication of the retrovirus in the blood (Corbett, 2010). However, because of its toxicity, the drug became controversial, and eventually proved
ineffective at treating HIV due to HIV’s ability to develop resistance to single-drug treatments (Corbett, 2010; Food and Drug Administration, 1999).

By 1995, the “AIDS cocktail,” otherwise known as highly active antiretroviral therapy (HAART), was introduced, and the HIV death rate declined by 47% in 1997 (Food and Drug Administration, 1999). AIDS cocktails are successful due to their ability to prevent the resistance to a single drug, but with the rise of HIV strains that are drug-resistant, it is important to understand the spectrum of treatment and prevention options (World Health Organization, 2017).

Treatments have been effective, and HIV is now characterized as a manageable, chronic condition. Despite this fact, individuals living with HIV have a lower life expectancy, and are more susceptible to comorbidities and functional decline than the general United States population (Chu & Selwyn, 2011; Langebeek et al., 2017; Nasi et al., 2017).

HIV treatment progressed further with the introduction of pre-exposure prophylaxis (PrEP) and post-exposure prophylaxis (PEP). PrEP is a medicine taken daily by people at very high risk for HIV to lower their chances of becoming infected. Individuals can reduce their risk of contracting HIV from sex with an injection drug using partner by over 70% through consistent PrEP usage (CDC, 2018d). PEP is an antiretroviral medication administered to an individual after a possible exposure to HIV to prevent that individual from contracting HIV. PEP must be started within 72 hours of a possible exposure to be effective (CDC, 2018b).

Epidemiology of HIV in the United States
The Centers for Disease Control and Prevention reports that, in the United States, more than one million people age 13 and older live with HIV (CDC, 2016). Between 2010 and 2014, the annual number of new HIV diagnoses decreased by 9%, with 39,513 new cases reported in 2015 (CDC, 2016). Some behaviors can lead to a greater chance of HIV transmission (CDC, 2015). It is important to note that engaging in small risks repeatedly can still lead to a higher overall risk of contracting HIV (CDC, 2015).
Table 1 illustrates the demographics of people living with HIV in Montana

<table>
<thead>
<tr>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Total</td>
<td>21</td>
<td>21</td>
<td>22</td>
<td>14</td>
<td>18</td>
<td>706</td>
</tr>
<tr>
<td><strong>Sex</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>17</td>
<td>17</td>
<td>20</td>
<td>11</td>
<td>17</td>
<td>607 (86%)</td>
</tr>
<tr>
<td>Female</td>
<td>4</td>
<td>4</td>
<td>2</td>
<td>3</td>
<td>1</td>
<td>99 (14%)</td>
</tr>
<tr>
<td><strong>Age at HIV diagnosis</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>&lt;13</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>4 (1%)</td>
</tr>
<tr>
<td>13–24</td>
<td>2</td>
<td>3</td>
<td>3</td>
<td>2</td>
<td>5</td>
<td>98 (14%)</td>
</tr>
<tr>
<td>25–34</td>
<td>3</td>
<td>6</td>
<td>7</td>
<td>6</td>
<td>5</td>
<td>252 (36%)</td>
</tr>
<tr>
<td>35–44</td>
<td>7</td>
<td>5</td>
<td>5</td>
<td>4</td>
<td>4</td>
<td>208 (29%)</td>
</tr>
<tr>
<td>45–54</td>
<td>5</td>
<td>7</td>
<td>4</td>
<td>2</td>
<td>1</td>
<td>94 (13%)</td>
</tr>
<tr>
<td>≥55</td>
<td>4</td>
<td>3</td>
<td>3</td>
<td>1</td>
<td>3</td>
<td>50 (7%)</td>
</tr>
<tr>
<td><strong>Race</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>White</td>
<td>19</td>
<td>14</td>
<td>13</td>
<td>11</td>
<td>15</td>
<td>592 (84%)</td>
</tr>
<tr>
<td>American Indian/Alaska Native</td>
<td>1</td>
<td>3</td>
<td>2</td>
<td>1</td>
<td>--</td>
<td>51 (7%)</td>
</tr>
<tr>
<td>Black/African American</td>
<td>--</td>
<td>1</td>
<td>1</td>
<td>--</td>
<td>1</td>
<td>21 (3%)</td>
</tr>
<tr>
<td>Other</td>
<td>--</td>
<td>2</td>
<td>5</td>
<td>1</td>
<td>--</td>
<td>17 (3%)</td>
</tr>
<tr>
<td><strong>Hispanic, any race</strong></td>
<td>1</td>
<td>1</td>
<td>1</td>
<td>1</td>
<td>2</td>
<td>25 (4%)</td>
</tr>
<tr>
<td><strong>Transmission category Male only</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male/Male sex (MSM)</td>
<td>11</td>
<td>10</td>
<td>17</td>
<td>5</td>
<td>8</td>
<td>369 (61%)</td>
</tr>
<tr>
<td>Injection drug use (IDU)</td>
<td>2</td>
<td>1</td>
<td>--</td>
<td>1</td>
<td>1</td>
<td>61 (10%)</td>
</tr>
<tr>
<td>MSM/IDU</td>
<td>1</td>
<td>1</td>
<td>1</td>
<td>2</td>
<td>4</td>
<td>65 (10%)</td>
</tr>
<tr>
<td>Heterosexual contact</td>
<td>1</td>
<td>2</td>
<td>--</td>
<td>1</td>
<td>1</td>
<td>29 (5%)</td>
</tr>
<tr>
<td>Other §</td>
<td>--</td>
<td>--</td>
<td>--</td>
<td>--</td>
<td>--</td>
<td>16 (3%)</td>
</tr>
<tr>
<td>No identified risk</td>
<td>2</td>
<td>3</td>
<td>2</td>
<td>2</td>
<td>3</td>
<td>67 (11%)</td>
</tr>
<tr>
<td><strong>Transmission category Female only:</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Heterosexual contact</td>
<td>2</td>
<td>--</td>
<td>2</td>
<td>3</td>
<td>--</td>
<td>55 (56%)</td>
</tr>
<tr>
<td>Injection drug use (IDU)</td>
<td>1</td>
<td>1</td>
<td>--</td>
<td>--</td>
<td>--</td>
<td>20 (20%)</td>
</tr>
<tr>
<td>Other §</td>
<td>--</td>
<td>--</td>
<td>--</td>
<td>--</td>
<td>--</td>
<td>6 (6%)</td>
</tr>
<tr>
<td>No identified risk</td>
<td>1</td>
<td>3</td>
<td>--</td>
<td>--</td>
<td>1</td>
<td>18 (18%)</td>
</tr>
</tbody>
</table>

**Note:** Reprinted from 2017-2021 Montana Integrated HIV Prevention and Care Plan and the Statewide Coordinated Statement of Need (2016)
Epidemiology of HIV in Montana

One important demographic that influences access to care for people infected with HIV is geographic location. Montana is a rural state in the northwestern United States with a population of over one million residents (United States Census Bureau, 2017). In 2015, the Montana Department of Health and Human Services (MTDPHHS) reported 595 individuals living with HIV in Montana, which included people living out of state at the time of diagnosis who later became residents. Most cases are from the six most populous state counties - Missoula, Flathead, Gallatin, Cascade, Yellowstone, and Lewis and Clark. In line with Montana demographics, most new infections are among non-Hispanic, White males (MTDPHHS, 2017). Since 2000, 14-32 new cases are reported annually in the state. In 2015, men accounted for 17 new HIV cases, while there was only one new infection among Montana women. This Montana trend parallels the national pattern with HIV being transmitted primarily among men who have sex with men, while female infection is largely due to high-risk heterosexual contact (MTDPHSS, 2017).
Table 2 illustrates the groups most at risk for contracting HIV in the state of Montana

<table>
<thead>
<tr>
<th>Characteristics</th>
<th>Number</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Sex</strong></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>19</td>
</tr>
<tr>
<td>Female</td>
<td>3</td>
</tr>
<tr>
<td><strong>Age at diagnosis (years)</strong></td>
<td></td>
</tr>
<tr>
<td>≤14</td>
<td>1</td>
</tr>
<tr>
<td>15-24</td>
<td>1</td>
</tr>
<tr>
<td>25-34</td>
<td>10</td>
</tr>
<tr>
<td>35-44</td>
<td>4</td>
</tr>
<tr>
<td>45-54</td>
<td>5</td>
</tr>
<tr>
<td>≥55</td>
<td>1</td>
</tr>
<tr>
<td><strong>Ethnicity, race</strong></td>
<td></td>
</tr>
<tr>
<td>Non-Hispanic, white</td>
<td>19</td>
</tr>
<tr>
<td>Hispanic, any race</td>
<td>1</td>
</tr>
<tr>
<td>Non-Hispanic, other</td>
<td>2</td>
</tr>
<tr>
<td><strong>Transmission category by sex</strong></td>
<td></td>
</tr>
<tr>
<td>Male only</td>
<td></td>
</tr>
<tr>
<td>Male sexual contact w/ another male (MSM)</td>
<td>9</td>
</tr>
<tr>
<td>Injection drug use (IDU)</td>
<td>1</td>
</tr>
<tr>
<td>MSM &amp; IDU</td>
<td>3</td>
</tr>
<tr>
<td>Heterosexual contact‡</td>
<td>2</td>
</tr>
<tr>
<td>No identified risk</td>
<td>4</td>
</tr>
<tr>
<td>Female only</td>
<td></td>
</tr>
<tr>
<td>Injection drug use (IDU)</td>
<td>2</td>
</tr>
<tr>
<td>No identified risk</td>
<td>1</td>
</tr>
</tbody>
</table>

*Non-Hispanic, other is all other races including multiple races
†Transmission category describes the combinations of risk factors by which a person may have acquired HIV
‡Heterosexual contact with a person known to have, or to be at high risk for, HIV infection


Treatment as Prevention

Providing treatment and care for people living with HIV in a rural or frontier environment can provide unique challenges, such as: economic disincentives for private providers; reliance on generalists; provider shortages; greater use of paraprofessional staff; geographic isolation; and informal family and community support systems (Nayar et al., 2013; Winbush & Crichlow, 2005). The percentage of people without health insurance is also higher in rural areas. On a national level, 20% of the 41 million uninsured Americans live in rural areas. In Montana, 70%
of the uninsured population lives in a rural area. Oftentimes, decisions must be made about whether the expense of health insurance is worth the peace of mind that coverage can provide (Winbush & Crichlow, 2005).

In spite of obstacles to effective care, HIV positive individuals need to manage their HIV in order to have the best chance at staying healthy while living with the disease (CDC, 2018). Additionally, keeping an individual’s viral load under control helps prevent transmission to others, otherwise known as “treatment as prevention” (CDC, 2018g). Treatment as prevention is an important component of the HIV care continuum, a system that aides and tracks patients over time through a comprehensive array of health services (CDC, 2018a). The continuum of care attempts to reach individuals from a variety of backgrounds who need care, despite the apparent obstacles to accessing care. The continuum of care is tracked in four areas by the CDC as illustrated by figure one.

Figure 1. HIV continuum of care as outlined by the CDC


Understanding the HIV care continuum

Ryan White Care Act
On August 18, 1990, the groundbreaking Ryan White Comprehensive AIDS Resources Emergency (CARE) Act was passed by a wide margin in both houses of Congress (Health Resources and Services Administration, n.d.) An important component of the HIV continuum of care, the Ryan White HIV/AIDS program is a wide-ranging system of care that comprises medical care and vital support services for individuals living with HIV who are underinsured or
uninsured (Health Resources & Services Administration, 2016). The Ryan White Program is the third largest source of federal funding to support HIV care in the United States, playing a critical role in helping to provide care for moderate to low-income individuals (Kaiser Family Foundation, 2017) The Ryan White HIV/AIDS Program is divided into five parts and is described below (U.S. Department of Health and Human Services, 2016):

<table>
<thead>
<tr>
<th>The Ryan White HIV/AIDS Program consisted of 5 sections:</th>
</tr>
</thead>
<tbody>
<tr>
<td>➢ Part A: provides grant funding for medical and support services to population centers more affected by HIV/AIDS</td>
</tr>
<tr>
<td>➢ Part B: provides grants to states and territories to improve the availability, quality, and organization of HIV/AIDS health care and support services</td>
</tr>
<tr>
<td>➢ Part C: provides grant funding to support outpatient HIV early intervention services and ambulatory care</td>
</tr>
<tr>
<td>➢ Part D: provides grant funding to support comprehensive, family-centered care to women, infants, children and youth living with HIV</td>
</tr>
<tr>
<td>➢ Part F: provides grant funding for research, access-to-care, and technical assistance</td>
</tr>
</tbody>
</table>

Barriers to Accessing Treatment and Prevention Services

To more fully comprehend the experience of living with HIV in Montana and the barriers associated with this disease, it is imperative to learn from and work with individuals living with HIV. Barriers to treatment and care persist in affecting the quality of life for individuals living with HIV (Eastwood et al., 2015). Barriers can differ across a variety of demographic factors such as race, sex, place, ethnicity, and place of residence. Even though HIV is conceptualized as a chronic, manageable disease, obstacles to care, testing, and treatment remain a vital concern for individuals of low income, of color, or social or geographic isolation. For health outcomes to improve for individuals living with HIV, barriers need to be closely analyzed and addressed in a planned and unified way that is specifically targeted for each HIV subgroup (Pellowski, 2013).
Several research studies have demonstrated that individuals living with HIV in rural and urban areas experience disparate health concerns (Costelloe et al., 2015; Kalichman, Katner, Banas, & Kalichman, 2017; Pellowski, 2013). For instance, stigmatization aids social distancing, avoidance, prejudice, discrimination, and self-devaluation (Kalichman et al., 2017). Furthermore, research shows that individuals living with HIV that experience greater stigma have poorer mental and physical health outcomes along with decreased medication adherence (Kalichman et al., 2017). Even though stigma only represents one component of living with HIV, it highlights the multifaceted relationships that need to be addressed in an integrated manner to effectively prevent HIV infection.

Other barriers in Montana arise from the rural nature of the state and the economic status of the residents. Individuals living with HIV in Montana typically are poor, and this status directly correlates to how these individuals pay for HIV services, (Montana Department of Public Health and Human Services, 2012). Stigma presents itself in individuals’ fear of lack of secrecy in small rural communities that decrease the chance for privacy and augment the risk for discrimination (Montana HIV Prevention Plan, 2012). Another barrier is lack of experienced HIV/AIDS healthcare providers in Montana (Montana Department of Public Health and Human Services, 2012).

Finally, inconvenient times of operation and locations of services makes it difficult for individuals to access care. Operation hours often conflicted with HIV-positive work schedules, making it difficult for individuals to receive care during the work week (Montana Department of Public Health and Human Services, 2012). Regarding location, individuals found facilities inaccessible to them because of the great distances between their place of residence and the facilities along with their lack of transportation options (Montana Department of Public Health and Human Services, 2012).
Definition of Terms

- **ARV**: Antiretroviral viral drugs used to treat, not cure, HIV.
- **HIV**: Human Immunodeficiency Virus, typically now a manageable disease.
- **IDU**: An HIV transmission category relating to injection drug use.
- **MSM**: An HIV transmission category relating to men who have sex with men.
- **PEP**: Post-exposure prophylaxis can be used after potentially being exposed to HIV; it must be taken within 72 hours after the potential exposure for maximum efficacy.
- **PLWH**: People living with HIV.
- **PrEP**: Pre-exposure prophylaxis can be used when people are at very high risk for HIV to lower their chances of getting infected. It is typically taken daily if someone is perpetually at a high risk for developing HIV.

Purpose

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

By understanding the experiences of individuals living with HIV in Montana as they relate to testing, treatment, and navigating the rural healthcare continuum, interventions can be better enacted to improve health outcomes and quality of life for this demographic.

Research Questions

Below are the guiding research questions for this project:

1. What do individuals living with HIV perceive to be their greatest needs?
   - Medical needs, basic living needs, counseling, treatment and support needs
2. In what behaviors do individuals engage that may contribute to transmission of the virus?
3. What are the barriers to accessing HIV testing, prevention and/or treatment services?
   - Individual, interpersonal, community, and policy level barriers

4. What are the changes between 2012 and 2018?
   - Barriers to testing
   - Barriers to treatment

**Methods**

**Research Design**

This study employed a cross-sectional design. Cross-sectional studies have numerous strengths. First, this design allowed for the study to be conducted quickly and easily because there were no long periods of follow-up. Second, the methods were regulated by the researchers, and clear definitions were utilized, avoiding misconceptions during implementation (Thelle & Laake, 2015). Third, multiple outcomes and exposures were studied at one time (Mann, 2003).

For this study, data was gathered via an electronic and paper survey on a sample of HIV-positive individuals living in Montana at a single point in time for the purpose of identifying the health-related needs of the study population between June to July of 2018. Consequently, this paper is an examination of secondary data analysis based off of the data collected during summer. By directly asking HIV-positive Montanans about their health needs, public health officials, health care providers, and prevention specialists involved in the planning and allocation of health resources can be better informed when developing interventions designed to prevent the spread of HIV and improve the health and well-being of Montanans infected with HIV.

**Instrumentation**

The questionnaire for this study, available in a paper format and online\(^1\), was developed in 2011\(^2\) and based on a review of literature including previously developed HIV positive needs

---

1. The online version of this survey can be found at the link below:
   https://umt.co1.qualtrics.com/jfe/form/SV_RJXSYm1lqT6uh

2. The 2011 questionnaire can be found in the following thesis: Epperson, Emily Olive, "A Needs Assessment of People Living with HIV in Montana" (2012). Graduate Student Theses, Dissertations, & Professional Papers. 276. Below is the link to the thesis:
assessment questionnaires used throughout the country. The 2011 questionnaire was designed to gather information about the demographics of the target population, HIV/AIDS status, behaviors since becoming HIV positive, assistance and/or prevention and/or treatment service use, and barriers to assistance and/or prevention and/or treatment services.

Several revisions were made to the existing survey to reflect changes in HIV treatment and prevention in the past seven years. Specifically, questions were added regarding PrEP and PEP. The 2018 questionnaire was reviewed by university faculty and by state public health department staff and edited and revised. Ryan White Case Managers were then asked to review and comment on the questionnaire, after which further revisions were made. Finally, a small group of people living with HIV (PLWH) were asked to pilot test the questionnaire prior to preparing it for distribution to the target population. The final draft of the questionnaire consists of five sections which are described below.

The questionnaire consisted of 5 sections:
- HIV status and treatment
- Assistance & Treatment Usage and Needs
- Barriers to receiving assistance and treatment
- Health behaviors since becoming HIV positive
- Demographic information (i.e. race, age, & income level)

The majority of the questions are close-ended with the option for participants to add their own comments.

Sample Selection

The questionnaire was distributed to people living with HIV 18 years of age or older and live in Montana. Questionnaire participants were recruited through Ryan White Title II case managers throughout Montana’s five planning regions who were asked to offer the questionnaire to clients that were accessing services. Paper copies of the questionnaire were mailed in packets that included a cover letter, an informed consent form, a $10 incentive, a self-addressed

https://scholarworks.umt.edu/cgi/viewcontent.cgi?article=1295&context=etd
stamped envelope, as well as a link to the online version of the questionnaire. Case managers from each region were asked to mail the questionnaires to their clients during the six-week data collection period. Individuals receiving the packet could choose to take the questionnaire online or complete the paper copy and mail it directly to the researchers in the enclosed envelope. Case managers were asked to send follow-up reminders to their Ryan White clients two weeks and five weeks after the initial release of the questionnaire.

Research Procedures

Data Analysis

The framework used to organize the questionnaire data were the research questions guiding this project. This framework was preferred with two reasons in mind. First, the questionnaire was not designed with any theoretical framework in mind, making it impractical to implement a theory in retrospect. Second, the end goal of this project was to help guide the Montana Department of Health in meeting the needs of people living with HIV in the state. By organizing the paper through research questions, it allowed the state to quickly digest the data. Responses collected from the questionnaire were statistically analyzed using an SPSS computer program. Questionnaire analysis included descriptive statistics to report the demographics, risk behaviors associated with HIV transmission, perceived barriers to accessing and maintaining linkage to prevention and/or treatment services for HIV among people living with HIV in Montana. Frequencies were reported by actual count and sample sizes. Graphs and charts were used to illustrate the frequencies when appropriate.

Protection of Human Subjects

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

Demographics
Three hundred and twenty questionnaires were disseminated across the state of Montana by Ryan White case managers. One hundred and fifty-four were returned, resulting in about a 48% response rate. The table below shows the age breakdown of the questionnaire participants. The highest frequency of responses came from individuals in the 55 to 64 age group. Ninety percent of respondents were over the age of 35.

<table>
<thead>
<tr>
<th>Table 3. Age of Participants</th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>%</td>
<td>(n)</td>
</tr>
<tr>
<td>18 to 25</td>
<td>2.00%</td>
<td>(3)</td>
</tr>
<tr>
<td>26 to 34</td>
<td>8.00%</td>
<td>(12)</td>
</tr>
<tr>
<td>35 to 44</td>
<td>12.70%</td>
<td>(19)</td>
</tr>
<tr>
<td>55 to 64</td>
<td>30.70%</td>
<td>(46)</td>
</tr>
<tr>
<td>Over 65</td>
<td>8.70%</td>
<td>(57)</td>
</tr>
<tr>
<td>Total</td>
<td>100.00%</td>
<td>(150)</td>
</tr>
</tbody>
</table>

Over 80% of respondents identified as male. Two respondents identified as transgender.

<table>
<thead>
<tr>
<th>Table 4. Gender Identity of Participants</th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>%</td>
<td>(n)</td>
</tr>
<tr>
<td>Male</td>
<td>81.30%</td>
<td>(122)</td>
</tr>
<tr>
<td>Female</td>
<td>17.30%</td>
<td>(26)</td>
</tr>
<tr>
<td>Transgender (male to female)</td>
<td>1.30%</td>
<td>(2)</td>
</tr>
<tr>
<td>Total</td>
<td>100.00%</td>
<td>(150)</td>
</tr>
</tbody>
</table>
Approximately two-thirds (68%) of the respondents identified as gay or bisexual and over 25% identified as heterosexual.

<table>
<thead>
<tr>
<th></th>
<th>%</th>
<th>(n)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Heterosexual/Straight</td>
<td>29.50%</td>
<td>(44)</td>
</tr>
<tr>
<td>Gay</td>
<td>55.00%</td>
<td>(82)</td>
</tr>
<tr>
<td>Bisexual</td>
<td>12.80%</td>
<td>(19)</td>
</tr>
<tr>
<td>Other</td>
<td>2.70%</td>
<td>(4)</td>
</tr>
<tr>
<td>Total</td>
<td>100.00%</td>
<td>(149)</td>
</tr>
</tbody>
</table>

Employment status varied in the respondents with over half the respondents either being employed full time or on disability.

<table>
<thead>
<tr>
<th></th>
<th>%</th>
<th>(n)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Employed full-time</td>
<td>29.50%</td>
<td>(44)</td>
</tr>
<tr>
<td>Employed part-time</td>
<td>15.40%</td>
<td>(23)</td>
</tr>
<tr>
<td>Not employed</td>
<td>12.80%</td>
<td>(19)</td>
</tr>
<tr>
<td>Self employed</td>
<td>4.70%</td>
<td>(7)</td>
</tr>
<tr>
<td>Collecting disability</td>
<td>28.20%</td>
<td>(42)</td>
</tr>
<tr>
<td>Other (please specify)</td>
<td>9.40%</td>
<td>(14)</td>
</tr>
<tr>
<td>Total</td>
<td>100.00%</td>
<td>(149)</td>
</tr>
</tbody>
</table>
Most of the respondents were living below the poverty line with over 60% making less than $6,000.

### Table 7. Household Income of Participants

<table>
<thead>
<tr>
<th>Income Range</th>
<th>%</th>
<th>(n)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Less than 6,000</td>
<td>61.60%</td>
<td>(90)</td>
</tr>
<tr>
<td>6,000-10,000</td>
<td>8.90%</td>
<td>(13)</td>
</tr>
<tr>
<td>10,001-20,000</td>
<td>10.30%</td>
<td>(15)</td>
</tr>
<tr>
<td>20,001-35,000</td>
<td>9.60%</td>
<td>(14)</td>
</tr>
<tr>
<td>35,001-50,000</td>
<td>6.20%</td>
<td>(9)</td>
</tr>
<tr>
<td>50,001-75,000</td>
<td>2.10%</td>
<td>(3)</td>
</tr>
<tr>
<td>100,001+</td>
<td>1.40%</td>
<td>(2)</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td>100.00%</td>
<td>(146)</td>
</tr>
</tbody>
</table>

Over 80% of respondents reported no positive tests for STDs in the past two years.

### Table 8. Tested positive for STDs in the past two years

<table>
<thead>
<tr>
<th>Tested positive</th>
<th>%</th>
<th>(n)</th>
</tr>
</thead>
<tbody>
<tr>
<td>No</td>
<td>83.30%</td>
<td>(125)</td>
</tr>
<tr>
<td>Yes</td>
<td>16.70%</td>
<td>(25)</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td>100.00%</td>
<td>(150)</td>
</tr>
</tbody>
</table>

Over half of the participants did not receive housing assistance.

### Table 9. Participants Receiving Housing Assistance

<table>
<thead>
<tr>
<th>Assistance</th>
<th>%</th>
<th>(n)</th>
</tr>
</thead>
<tbody>
<tr>
<td>No</td>
<td>54.90%</td>
<td>(78)</td>
</tr>
<tr>
<td>Yes</td>
<td>25.40%</td>
<td>(36)</td>
</tr>
<tr>
<td>I’m not sure</td>
<td>1.40%</td>
<td>(2)</td>
</tr>
<tr>
<td>Doesn’t apply to me</td>
<td>18.30%</td>
<td>(26)</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td>100.00%</td>
<td>(142)</td>
</tr>
</tbody>
</table>
Over 90% of the participants did not have any dependent children living with them.

Table 10. Participants Living with Dependent Children

<table>
<thead>
<tr>
<th></th>
<th>%</th>
<th>(n)</th>
</tr>
</thead>
<tbody>
<tr>
<td>No</td>
<td>90.10%</td>
<td>(136)</td>
</tr>
<tr>
<td>Yes</td>
<td>9.90%</td>
<td>(15)</td>
</tr>
<tr>
<td>Total</td>
<td>100.00%</td>
<td>(151)</td>
</tr>
</tbody>
</table>

Nearly one hundred percent of the respondents were taking anti-retroviral drugs at the time of the questionnaire.

Table 11. Participants Taking Anti-Retroviral (ARV) Drugs

<table>
<thead>
<tr>
<th></th>
<th>%</th>
<th>(n)</th>
</tr>
</thead>
<tbody>
<tr>
<td>No</td>
<td>1.30%</td>
<td>(2)</td>
</tr>
<tr>
<td>Yes</td>
<td>97.30%</td>
<td>(146)</td>
</tr>
<tr>
<td>Don’t Know</td>
<td>1.30%</td>
<td>(2)</td>
</tr>
<tr>
<td>Total</td>
<td>100.00%</td>
<td>(150)</td>
</tr>
</tbody>
</table>
Research Questions Answered

**Research Question #1: What do individuals living with HIV perceive to be their greatest needs?**

Medical care, case management services and financial assistance with medications were the most frequently cited needs that are currently being met.

<table>
<thead>
<tr>
<th>Table 12. Services Most Needed and Currently Used</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
</tr>
<tr>
<td></td>
</tr>
<tr>
<td>Medical care (doctor, nurse, clinic, etc.)</td>
</tr>
<tr>
<td></td>
</tr>
<tr>
<td>Case management services</td>
</tr>
<tr>
<td></td>
</tr>
<tr>
<td>Financial assistance with medications</td>
</tr>
<tr>
<td></td>
</tr>
<tr>
<td>Help paying for health insurance</td>
</tr>
<tr>
<td></td>
</tr>
<tr>
<td>Dental care</td>
</tr>
<tr>
<td></td>
</tr>
<tr>
<td>Emergency financial assistance (utilities, food/groceries, meds, transportation, housing)</td>
</tr>
<tr>
<td></td>
</tr>
<tr>
<td>Mental health services</td>
</tr>
<tr>
<td></td>
</tr>
<tr>
<td>Referral services (i.e. non-medical case manage, rehab, or psychosocial services)</td>
</tr>
<tr>
<td></td>
</tr>
<tr>
<td>Enrollment into insurance</td>
</tr>
<tr>
<td></td>
</tr>
<tr>
<td>Treatment adherence support</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th></th>
<th>%</th>
<th>(n)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Medical care (doctor, nurse, clinic, etc.)</td>
<td>84.80%</td>
<td>(128)</td>
</tr>
<tr>
<td>Case management services</td>
<td>75.50%</td>
<td>(108)</td>
</tr>
<tr>
<td>Financial assistance with medications</td>
<td>73.30%</td>
<td>(110)</td>
</tr>
<tr>
<td>Help paying for health insurance</td>
<td>58.70%</td>
<td>(88)</td>
</tr>
<tr>
<td>Dental care</td>
<td>58.50%</td>
<td>(86)</td>
</tr>
<tr>
<td>Emergency financial assistance (utilities, food/groceries, meds, transportation, housing)</td>
<td>45.60%</td>
<td>(68)</td>
</tr>
<tr>
<td>Mental health services</td>
<td>41.70%</td>
<td>(60)</td>
</tr>
<tr>
<td>Referral services (i.e. non-medical case manage, rehab, or psychosocial services)</td>
<td>39.00%</td>
<td>(57)</td>
</tr>
<tr>
<td>Enrollment into insurance</td>
<td>35.40%</td>
<td>(51)</td>
</tr>
<tr>
<td>Treatment adherence support</td>
<td>30.60%</td>
<td>(45)</td>
</tr>
</tbody>
</table>
None of the services listed were reported as an unmet need by more than 15% of the respondents.

<table>
<thead>
<tr>
<th>Table 13. Services Most Needed and Cannot Get</th>
</tr>
</thead>
<tbody>
<tr>
<td>%</td>
</tr>
<tr>
<td>-----------------------------------------------</td>
</tr>
<tr>
<td>Dental Care</td>
</tr>
<tr>
<td>Buddy/companion volunteer support</td>
</tr>
<tr>
<td>Emergency financial assistance (utilities, food/groceries, meds, transportation, housing)</td>
</tr>
<tr>
<td>Legal services (excludes criminal defense and class-action lawsuits)</td>
</tr>
</tbody>
</table>
Research Question #2: What are the barriers to accessing HIV testing, prevention, and/or treatment services?

Overall the most significant barriers for testing were associated with interpersonal and logistical factors.

Table 14. Barriers to HIV Testing

<table>
<thead>
<tr>
<th></th>
<th>%</th>
<th>(n)</th>
</tr>
</thead>
<tbody>
<tr>
<td>I thought I was at low or no risk</td>
<td>15.80%</td>
<td>(29)</td>
</tr>
<tr>
<td>Too scared to find out the results</td>
<td>9.24%</td>
<td>(17)</td>
</tr>
<tr>
<td>I was in a monogamous relationship</td>
<td>6.50%</td>
<td>(12)</td>
</tr>
<tr>
<td>I didn’t know about HIV</td>
<td>6.00%</td>
<td>(11)</td>
</tr>
<tr>
<td>I was too scared to get the test done</td>
<td>6.00%</td>
<td>(11)</td>
</tr>
<tr>
<td>I was afraid of being discriminated against</td>
<td>5.43%</td>
<td>(10)</td>
</tr>
<tr>
<td>I was afraid of losing my job if HIV+</td>
<td>4.90%</td>
<td>(9)</td>
</tr>
</tbody>
</table>
The main barriers to obtaining and using HIV services were related to both mental health and logistics in terms of transportation and affordability.

<table>
<thead>
<tr>
<th>Table 15. Barriers to Obtaining and Using HIV Services</th>
</tr>
</thead>
<tbody>
<tr>
<td>%</td>
</tr>
<tr>
<td>My state of mind or mental ability to deal with treatment</td>
</tr>
<tr>
<td>Burn-out from dealing with talking about HIV</td>
</tr>
<tr>
<td>Not having transportation</td>
</tr>
<tr>
<td>Not having insurance coverage</td>
</tr>
<tr>
<td>My concern other people may see me when I go to get care</td>
</tr>
<tr>
<td>Not knowing what service or treatment is available to me/lack of services</td>
</tr>
<tr>
<td>The cost of attendance or treatment.</td>
</tr>
<tr>
<td>Not knowing who to ask for help.</td>
</tr>
<tr>
<td>The location of the organization providing services.</td>
</tr>
<tr>
<td>Lack of experience or expertise of the person providing the services to me.</td>
</tr>
</tbody>
</table>

Overwhelmingly, respondents who started HIV treatment continued to adhere to their treatment plan.

<table>
<thead>
<tr>
<th>Table 16. Participants who Decided to Discontinue Treatment Plan</th>
</tr>
</thead>
<tbody>
<tr>
<td>%</td>
</tr>
<tr>
<td>No</td>
</tr>
<tr>
<td>Yes</td>
</tr>
<tr>
<td>Total</td>
</tr>
</tbody>
</table>
Research Question #3: In what behaviors do individuals engage that may contribute to transmission of the virus?

Over two-thirds of the respondents knew about PrEP.

Table 17. Participants who Knew about PrEP

<table>
<thead>
<tr>
<th></th>
<th>%</th>
<th>(n)</th>
</tr>
</thead>
<tbody>
<tr>
<td>No</td>
<td>23.60%</td>
<td>(35)</td>
</tr>
<tr>
<td>Yes</td>
<td>67.60%</td>
<td>(100)</td>
</tr>
<tr>
<td>Unsure</td>
<td>8.80%</td>
<td>(13)</td>
</tr>
<tr>
<td>Total</td>
<td>100.00%</td>
<td>(148)</td>
</tr>
</tbody>
</table>

Over half the respondents knew about PEP.

Table 18. Participants who Knew about PEP

<table>
<thead>
<tr>
<th></th>
<th>%</th>
<th>(n)</th>
</tr>
</thead>
<tbody>
<tr>
<td>No</td>
<td>33.80%</td>
<td>(50)</td>
</tr>
<tr>
<td>Yes</td>
<td>55.40%</td>
<td>(82)</td>
</tr>
<tr>
<td>Unsure</td>
<td>10.80%</td>
<td>(16)</td>
</tr>
<tr>
<td>Total</td>
<td>100.00%</td>
<td>(148)</td>
</tr>
</tbody>
</table>

Overwhelmingly, participants said that viral suppression was very important to them.

Table 19. Importance of Viral Suppression

<table>
<thead>
<tr>
<th></th>
<th>%</th>
<th>(n)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Somewhat important</td>
<td>5.40%</td>
<td>(8)</td>
</tr>
<tr>
<td>Very important</td>
<td>94.60%</td>
<td>(139)</td>
</tr>
<tr>
<td>Total</td>
<td>100.00%</td>
<td>(147)</td>
</tr>
</tbody>
</table>
Approximately two-thirds of the participants expressed some level of comfort in sharing their HIV+ status with their sexual partner.

<table>
<thead>
<tr>
<th>Table 20. Comfort in Disclosing HIV+ Status to Sexual Partner</th>
</tr>
</thead>
<tbody>
<tr>
<td>%</td>
</tr>
<tr>
<td>-----------------</td>
</tr>
<tr>
<td>Very comfortable</td>
</tr>
<tr>
<td>Somewhat comfortable</td>
</tr>
<tr>
<td>Somewhat uncomfortable</td>
</tr>
<tr>
<td>Very uncomfortable</td>
</tr>
<tr>
<td>Total</td>
</tr>
</tbody>
</table>

More than half of the respondents reported using a condom when they engaged in sexual activity since becoming HIV positive.

<table>
<thead>
<tr>
<th>Table 21. Sexual Activity since becoming HIV+</th>
</tr>
</thead>
<tbody>
<tr>
<td>%</td>
</tr>
<tr>
<td>-----------------</td>
</tr>
<tr>
<td>Stopped having sexual relations (I am abstinent)</td>
</tr>
<tr>
<td>Never use condoms</td>
</tr>
<tr>
<td>Sometimes use condoms</td>
</tr>
<tr>
<td>Always use condoms</td>
</tr>
<tr>
<td>Total</td>
</tr>
</tbody>
</table>

Overwhelmingly, participants had not injected any substances within the past year.

<table>
<thead>
<tr>
<th>Table 22. Injection of Substances within the Past Year</th>
</tr>
</thead>
<tbody>
<tr>
<td>%</td>
</tr>
<tr>
<td>-----------------</td>
</tr>
<tr>
<td>No</td>
</tr>
<tr>
<td>Yes</td>
</tr>
<tr>
<td>Total</td>
</tr>
</tbody>
</table>
Research Question #4: What were the changes in barriers from 2012 to 2018?

While direct comparisons cannot be made between participants in the 2012 versus 2018 assessment, it is interesting to note that the percent of individuals reporting they encountered the barriers listed in the table declined substantially in all areas except for transportation.

<table>
<thead>
<tr>
<th>Table 23. Barriers to Obtaining and Using HIV Services from 2012-2018</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
</tr>
<tr>
<td>2018</td>
</tr>
<tr>
<td>---------------------------------------------------------------</td>
</tr>
<tr>
<td>%</td>
</tr>
<tr>
<td>My state of mind or mental ability to deal with treatment</td>
</tr>
<tr>
<td>Burn-out from dealing with talking about HIV</td>
</tr>
<tr>
<td>Not having transportation</td>
</tr>
<tr>
<td>Not having insurance coverage</td>
</tr>
<tr>
<td>My concern other people may see me when I go to get care</td>
</tr>
</tbody>
</table>
Again, direct comparisons between participants in each assessment cannot be made. It is interesting to note, however, the percent of individuals reporting they encountered the barriers listed below declined substantially in all areas.

<table>
<thead>
<tr>
<th>Table 24. Barriers to Testing from 2012-2018</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
</tr>
<tr>
<td></td>
</tr>
<tr>
<td>I thought I was at low or no risk</td>
</tr>
<tr>
<td>Too scared to find out the results</td>
</tr>
<tr>
<td>I was in a monogamous relationship</td>
</tr>
<tr>
<td>I didn’t know about HIV</td>
</tr>
<tr>
<td>I was too scared to get the test done</td>
</tr>
<tr>
<td>I was afraid of being discriminated against</td>
</tr>
<tr>
<td>I was afraid of losing my job if HIV+</td>
</tr>
</tbody>
</table>
Discussion

Portrait of the Participants

While the individuals living with HIV in Montana come from a variety of backgrounds, it is possible to distinguish key characteristics that comprise the respondents. The 154 respondents were overwhelmingly male, composing over 80% of the participants. Just over two-thirds identified as gay men or as bisexual (68%), showing consistency with national trends. Additionally, most of the participants self-identified as white (87.18%), with Native Americans being the second largest represented racial group (7.69%). This data on race and ethnicity closely matches Montana census data (Census, 2017). Many respondents were middle aged, with over half the participants being over 45 years old. Overwhelmingly, the respondents did not have dependent children living with them which may speak to the fact that over two-thirds of the respondents were gay or bisexual men. Over half the respondents were employed full-time. Over 25% were collecting disability benefits.

Following is a discussion of data collected quantitatively through a statewide questionnaire. The researchers examined perception of greatest needs, barriers to accessing HIV services, behaviors in which individuals engage that may contribute to transmission of the virus, and changes in the perceptions of HIV services from 2012 to 2018.

Perception of Greatest Needs

This research question was broken down into services most needed and used along with services that were needed, but not accessible. The results were mostly positive, meaning that goal four of the HIV/AIDS Strategy (2015): “achieving a more coordinated national response to the HIV epidemic,” is being met within the state of Montana. The most needed and used service for individuals living with HIV in Montana is medical care with 84% citing it as a used service. Case management was also a critical service with three-quarters of respondents indicating they both needed and used it. These statistics make sense because most individuals living with the illness are living long and healthy lives while managing their chronic conditions, assuming they receive treatment (Mahon, 2017). Furthermore, the HIV/AIDS Strategy (2015) has been focusing on how to increase widespread linkage to care, regardless of area of
residence. Case managers play a critical role in linking their clients to care, meaning that medical care is a highly used service now and in the coming years (National HIV/AIDS Strategy, 2015).

However, there is always more to do, and participants indicated there are currently services they need and cannot access. The top service needed was dental care with 15% of respondents indicating they were unable to access this service. The need for this service makes sense when one takes into account that when individuals are infected with HIV, they are more likely to develop tooth loss and pain in the mouth (Evans, 2009). Considering that Montana is a rural state, healthcare specialists such as dentists may not be easily accessible due to lack of transportation or distance between the individual and the provider (Nayar et al., 2013; Winbush & Crichlow, 2005).

The second most needed service was buddy/companion volunteer support. Older individuals living with HIV have high rates of loneliness which can lead to a variety of mental health issues (Greene, Hessol, Perissinotto, & Zepf, 2017; Moskowitz & Trykowski, 2017). Buddy programs can reduce these high rates of loneliness in HIV-positive individuals (Burrage & Demi, 2003). For instance, the Gay Men’s Health Crisis Buddy Program has reported a reduction in social isolation for the clients enrolled in the program (Moskowitz & Trykowski, 2017). Participants cited helpful aspects of the program such as “the fact that they didn't know each other beforehand, that they have a commitment to talk once a week, that they're there specifically to talk and not as a date” (Moskowitz & Trykowski, 2017). While the program was located in an urban area, a buddy program of a similar nature could do well in Montana.

The third most needed service was emergency financial assistance. The request for emergency funds makes sense when demographic information is considered. Most of the participants were gay or bisexual men, and LGBTQ individuals are more likely to live below the poverty line than heterosexual individuals (Fredriksen-Goldsen, Kim, Barkan, Muraco, Hoy-Ellis, 2013). Consequently, these individuals are less likely to have enough money to cover their living expenses, and they may need access to funds if an unexpected situation arises.

The fourth most needed service was legal services. Legal service providers can aid in tackling barriers to accessing and maintaining care among individuals living with HIV, making
these services important in reducing disparities for the population (Miyashita & Hasenbush, 2016). For this study, “legal services” was not specifically defined, meaning that participants may need legal services in a variety of areas such as housing, employment, and discrimination issues. Consequently, it is difficult to extrapolate specific reasons why individuals living with HIV are seeking legal services.

It is, however, important to note that none of the services were reported as inaccessible by more than fifteen percent of participants. It appears that Montana is doing a good job of providing services to this group of individuals living with HIV.

Barriers to Accessing HIV-Related Services
The second section of the questionnaire focused on barriers in relation to testing and prevention, and treatment. For testing, the number one barrier was the perception of low risk. However, it is important to note that many of the participants are in their late forties to late sixties, meaning they originally got tested in the 1980s and 1990s. During this time period, there was a significant amount of stigma surrounding the illness and a lack of knowledge concerning potential risks for contracting HIV. Consequently, these two factors may have affected the perceptions of barriers to testing.

In terms of prevention and treatment, the overwhelming majority said that once they started treatment, they had not discontinued. This lack of discontinuation from treatment may be attributed to greater accessibility of medication and coordination efforts with the state to help care for individuals living with HIV (CDC, 2018a). However, individuals still perceived some barriers with 27% attributing their mental mindset as an inhibitor to seeking out treatment and prevention. This barrier makes sense in light of previous research. Specifically, stigmatization aides in social distancing and avoidance (Kalichman et al., 2017). In essence, individuals take on the stigma that they perceived is attributed to them by society, it affects their mindset, and they distance themselves, leading to poorer health outcomes. Consequently, the biggest barriers were individual-based.
Behaviors Related to Transmission

Individuals living with HIV are engaging in generally positive behaviors that are reducing overall transmission. For instance, 67% knew about PrEP. That statistic is consistent with the national trend. Specifically, the number of adults prescribed PrEP increased by more than 300% from 7,972 in 2014 to 33,273 in 2015 (Wolitski, 2017). Furthermore, the participants of this questionnaire were contacted through Ryan White case managers, meaning they may have known about PrEP because of the organization’s support for the treatment (Cheever, 2016).

In terms of viral suppression, the questionnaire data shows that one hundred percent of participants thought that viral suppression was either “somewhat important” or “very important,” meaning that HIV-positive individuals are aware of how their illness affects both their own quality of life and others. This overwhelming statistic can be attributed to aggressive efforts by governmental and private organizations to spread awareness about the illness (National HIV/AIDS Strategy, 2015).

Changes from 2012 to 2018

Barriers to testing as well as obtaining and using services were greatly reduced from 2012 to 2018. In terms of barriers to testing, the reduction can be partially attributed to the attempts at normalizing testing. Currently, the Centers for Disease Control recommends that individuals between the ages of 13 to 64 get tested for HIV at least once as a component of their health care, and individuals who possess risk factors ought to get tested yearly (CDC, 2018).

In terms of barriers to accessing treatment, the top five concerns shifted. In 2012, the number one concern was lack of insurance coverage across participants in all five regions of Montana. In 2018, the number one barrier was the individual’s state of mind or mental ability to handle receiving treatment. This change in perception of barriers can be attributed to the implementation of the Affordable Care Act which has helped to increase coverage for individuals living with HIV without bankrupting these individuals (AIDS.gov, 2015).

The only barrier that has not greatly decreased is lack of transportation. Transportation barriers lead to missed appointments, delayed care, and missed medication use because individuals cannot obtain new prescriptions (Syed, Gerber, & Sharp, 2014). Ultimately, transportation issues can result in poor management of chronic illnesses and poor health.
outcomes (Syed, Gerber, & Sharp, 2014). Lack of transportation appears to be a long-term problem for individuals living with HIV in Montana. In part, this issue is perpetuated by Montana’s rural nature and the great distances individuals need to travel in order to access health care services. This barrier can potentially be reduced by lowering transportation costs through infrastructure improvements or increasing broadband access in rural areas to improve access to telehealth services (Watson, 2016).

Currently, Montana has the third lowest rate of HIV infection in the United States (CDC, 2018f). Public health officials continuing efforts to prevent transmission of the virus will ensure that this trend continues.

**Delimitations**

A number of delimitations exist in this assessment. First, the study was delimited to individuals living with HIV, who are age 18 or older, who reside in Montana, and have accessed a Ryan White Title II case manager. Second, the data was collected through an online and paper questionnaire from individuals who are living with HIV in Montana. Third, the data collected from participants was restricted to self-reports. Fourth, participants in the study were volunteers who may discontinue involvement at any time, at their own discretion.

**Limitations**

A variety of limitations were present in this needs assessment. Only opinions of 154 of the 595 individuals known to be HIV positive in Montana are reported in the data. Currently, 88% of the questionnaire participants have a case manager, and 96% of the participants stated they were currently receiving treatment. Participants were not randomly selected, and as a result, these individuals highlight a limited view of the types of people living with HIV in Montana.

Consequently, it is assumed that individuals who did not participate in the needs assessment depict a wide range of individuals living with HIV in Montana. These individuals may have access to the services they need to live a healthy life while other individuals may be isolated or impoverished to the point that they may not have knowledge or access to necessary HIV-related services.
In addition, most of the questionnaire participants have been living with HIV for more than 10 years. Since the nature of HIV prevention and treatment is constantly changing, the needs of recently diagnosed individuals can differ substantially from individuals who were diagnosed more than 10 years ago.

**Conclusion**

Individuals diagnosed with HIV can live longer lives due to the creation of effective treatments. However, a longer life expectancy does not necessarily mean a better quality of life. This needs assessment was an effort to examine barriers to treatment and care for individuals living with HIV in Montana. For this research project, 154 HIV-positive individuals completed a questionnaire. A majority of the participants had few economic resources, limited employment opportunities, and experienced health complications as a result of their diagnosis. Despite these inequities, results of this assessment reveal that many of the barriers to getting an HIV test and to obtaining needed services were greatly reduced from the 2012 assessment. In part, this can be attributed to the fact that 88% of respondents were connected to a case manager, allowing them the opportunity to receive help. Nevertheless, there is still a great deal that can be done to improve the quality of life of people living with HIV. By increasing awareness about HIV prevention and treatment along with addressing the social and economic inequities that often accompany a diagnosis of HIV infection, people living with HIV can live longer, healthier lives, thereby making the National HIV/AIDS Strategy vision a reality.

**References**


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Gellman, B. (2000, April 30,). AIDS is declared threat to security. *The Washington Post* Retrieved from https://www.washingtonpost.com/archive/politics/2000/04/30/aids-is-declared-threat-to-security/c5e976e4-3fe8-411b-9734-ca44f3130b41/?noredirect=on&utm_term=.4e5d8dcc7d9c


HIV.gov. (n.d.). *A timeline of HIV and AIDS*


Mahon, C. (2017, May 15). Life expectancy for people with HIV is now near-normal – but only


Appendix
Montana 2018 Health Needs Questionnaire

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

- The purpose of this survey is to clarify the health care needs of people living with HIV in Montana.
- Your participation in this study will help plan programs for you and others living with HIV.
- Your participation is VOLUNTARY.
- All responses are strictly ANONYMOUS.
- Please DO NOT put your name on this survey.

Please return this survey to your case manager or mail in the self-addressed stamped envelope as soon as possible.

THANK YOU VERY MUCH!
### PART 1: TELL US ABOUT YOUR HEALTH
(Your answers are strictly ANONYMOUS!)

1. In general, how would you rate your overall health?
   - [ ] Very good
   - [ ] Good
   - [ ] Fair
   - [ ] Poor
   - [ ] Very poor

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

3. How many years ago did you learn you were HIV+? ______

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

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

6. How long after learning you were HIV positive did you seek treatment?
   - [ ] I have not yet sought treatment
   - [ ] Less than one week
   - [ ] 1 week to 3 months
   - [ ] 3 to 6 months
   - [ ] 6 months to 1 year
   - [ ] More than 1 year
7. Do you currently take anti-retroviral (ARV) drugs?
   - [ ] No
   - [ ] Yes
   - [ ] Don’t Know

8. Do you know your current CD4 count and/or your viral load?
   - [ ] No
   - [ ] Yes

9. Have you had a CD4 count or viral load in the last 12 months?
   - [ ] No
   - [ ] Yes

10. Have you ever had a case manager?
    - [ ] I have one now
    - [ ] I no longer have one
    - [ ] I never had one

    **If you answered “no longer” or “never,” why not? (check all that apply)**
    - [ ] I don’t need services
    - [ ] I can get services myself
    - [ ] I didn’t know one was available
    - [ ] I live too far away
    - [ ] I’m worried people will find out I have HIV or AIDS
    - [ ] I don’t know how a case manager could help me
    - [ ] A different service provider helped me get services
    - [ ] They don’t speak my language
    - [ ] They don’t understand my culture
    - [ ] Use alternative therapy/standard medicine too harsh
    - [ ] Confidentiality
    - [ ] Other ____________________________

11. If you are receiving treatment, how did you get linked to treatment or related services?
    - [ ] I have never been linked to treatment or services for HIV
    - [ ] My personal doctor/health care provider connected me with treatment and services
    - [ ] I have an HIV positive friend/acquaintance who helped me find services
    - [ ] The person who did my HIV test referred me to a Ryan White case manager
    - [ ] The person who did my HIV test linked me to treatment services
    - [ ] I looked on the internet to find out where to get treatment and services
    - [ ] Other ____________________________
STEP 1:
On the following pages, you’ll find a list of assistance and treatment opportunities. For each opportunity listed, put a ✓ in one of the three boxes.

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

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

Some of the reasons other people have mentioned include:

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

Please feel free to mention other reasons.

EXAMPLE:

<table>
<thead>
<tr>
<th>Assistance/Treatment</th>
<th>Need and use</th>
<th>Don’t need</th>
<th>Need, can’t get</th>
<th>Why I can’t get it... (Please let us know so we can help!)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Dental care</td>
<td></td>
<td></td>
<td>✓</td>
<td>Can’t afford it</td>
</tr>
<tr>
<td>Support groups</td>
<td>✓</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
**MEDICAL AND RELATED ASSISTANCE & TREATMENTS**

<table>
<thead>
<tr>
<th>Assistance/ Treatment</th>
<th>Need and use</th>
<th>Don’t need</th>
<th>Need, can’t get</th>
<th>Why I can’t get it… (Please let us know so we can help!)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Treatment adherence support (help taking your HIV meds correctly)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Physical or Occupational Therapy</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Nutritional counseling</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Medical Equipment (wheelchair, etc.)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mental health services</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Financial assistance with medications</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Medical care (doctor, nurse, clinic, etc.)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Help paying for Health Insurance</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Dental Care</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Referral for substance abuse treatment counseling</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Other (please specify):</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

If you are currently using naturopathy, herbal medicine, Acupuncture or other non-Western therapies, do you consider this to be your primary form of medical care?

☐ NO  ☐ YES

**BASIC NEEDS AND ASSISTANCE & TREATMENTS**

<table>
<thead>
<tr>
<th>Assistance/ Treatment</th>
<th>Need and use</th>
<th>Don’t need</th>
<th>Need, can’t get</th>
<th>Why I can’t get it… (Please let us know so we can help!)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Emergency Financial Assistance (utilities, food/groceries, medication, transportation, housing)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Home delivered meals/Food bank</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Home Health Care</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Medical Transportation (assistance getting to/from HIV medical appointments)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Practical support (help with budgeting, cooking, cleaning, laundry, chores, moving, pets, etc.)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Other (please specify):</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
## COUNSELING, TREATMENT AND SUPPORT ASSISTANCE & TREATMENTS

<table>
<thead>
<tr>
<th>Service</th>
<th>Need ands use</th>
<th>Don't need</th>
<th>Need, Can't get</th>
<th>Why I can’t get it… (Please let us know so we can help!)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Case management services</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Referral services (i.e. non-medical case management, rehabilitation or psychosocial support services)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Child care</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Legal services (excludes criminal defense and class-action suits)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Enrollment into insurance</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Buddy/ Companion volunteer support</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Support groups/ peer counseling</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Spiritual support</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Other (please specify):</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

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

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

Did you obtain medical care for HIV and/or start anti-retroviral therapies and then decide to discontinue your care or your medications?

- [ ] Yes  
- [ ] No  
- [ ] I have never received medical care

Below is a list of possible problems that may arise when trying to obtain or when using HIV and AIDS services. Mark an X on the line beside each item to say if it has been a problem for you or not.

<table>
<thead>
<tr>
<th></th>
<th>Barrier</th>
<th>Not a Barrier</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Not knowing what service or treatment is available to me/ lack of services.</td>
<td></td>
</tr>
<tr>
<td>2</td>
<td>The location of the organization providing services.</td>
<td></td>
</tr>
<tr>
<td>3</td>
<td>My physical health.</td>
<td></td>
</tr>
<tr>
<td>4</td>
<td>The quality of assistance or treatment.</td>
<td></td>
</tr>
<tr>
<td>5</td>
<td>Not knowing what medical assistance or treatment I need to treat my HIV or AIDS infection.</td>
<td></td>
</tr>
<tr>
<td>6</td>
<td>My state of mind or mental ability to deal with the treatment (e.g. anxiety, depression or other mental illness).</td>
<td></td>
</tr>
<tr>
<td>7</td>
<td>Having a substance abuse problem.</td>
<td></td>
</tr>
<tr>
<td>8</td>
<td>Not having transportation.</td>
<td></td>
</tr>
<tr>
<td>9</td>
<td>Not knowing who to ask for help.</td>
<td></td>
</tr>
<tr>
<td>10</td>
<td>My concern that other people may see me when I go to get care or learn about my HIV infection (lack of confidentiality/stigma).</td>
<td></td>
</tr>
<tr>
<td>11</td>
<td>Discrimination I experienced by the persons or organization providing the services.</td>
<td></td>
</tr>
<tr>
<td>12</td>
<td>Lack of experience or expertise of the person providing services to me.</td>
<td></td>
</tr>
<tr>
<td>13</td>
<td>The hours when services were offered were unreliable or inconsistent.</td>
<td></td>
</tr>
<tr>
<td>14</td>
<td>The amount of time I had to wait to get an appointment to see someone.</td>
<td></td>
</tr>
<tr>
<td>15</td>
<td>The cost of assistance or treatment.</td>
<td></td>
</tr>
<tr>
<td>16</td>
<td>Not having insurance coverage.</td>
<td></td>
</tr>
<tr>
<td>17</td>
<td>Burnout from dealing with/ talking about HIV.</td>
<td></td>
</tr>
<tr>
<td>18</td>
<td>Other (please specify):</td>
<td></td>
</tr>
</tbody>
</table>

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

a) ____________________________________________

b) ____________________________________________
12. Which best describes your sexual activity since becoming HIV positive?

☐ Stopped having sexual relations (I am abstinent)
☐ Never use condoms
☐ Sometimes use condoms
☐ Always use condoms

If you use condoms “sometimes,” in what situations do you NOT use them?

☐ With my regular partner who is HIV+
☐ When my viral load is low or undetectable
☐ With any sex partner who is HIV+
☐ When my sex partner refuses to use condoms
☐ When I feel uncomfortable bringing up condoms
☐ Other _________________________________________

13. Do you know there is a pill that prevents HIV (PrEP)?

☐ No
☐ Yes
☐ Unsure

14. Do you know there is a pill that can be used after a possible exposure to HIV transmission to prevent infection (PEP)?

☐ No
☐ Yes
☐ Unsure

15. How important is viral suppression to you?

☐ not important
☐ somewhat important
☐ very important

16. If you have an undetectable viral load, do you think you still need to disclose your HIV status to potential sex partners?

☐ No
☐ Yes
☐ Sometimes
☐ Not sexually active

17. How comfortable are you disclosing your status to your sexual partner.

☐ Very Comfortable
☐ Somewhat Comfortable
☐ Somewhat Uncomfortable
☐ Very Uncomfortable
17. Have you tested positive for sexually transmitted diseases in the last two years?
   □ No
   □ Yes
   If “yes”, which did you test positive for? (check all that apply)
   □ Syphilis
   □ Genital warts
   □ Gonorrhea
   □ Herpes
   □ Chlamydia
   □ Other (specify):_____________________

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

19. Have you used substances in the past year?
   □ No
   □ Yes
   If “yes”, check all substances you have used:
   □ Alcohol
   □ Marijuana
   □ Crack
   □ Cocaine
   □ Heroin
   □ Meth/Crystal
   □ Downers
   □ Other (please specify):_____________________

20. Have you injected any substances in the past year?
   □ No
   □ Yes
   If “yes”, have you shared needles while injecting drugs in the past year?
   □ No
   □ Yes

21. Do you believe that your substance use is a problem?
   □ No
   □ Yes
   □ Not sure
22. Do you have emotional concerns which have caused a problem for you in the last 6 months?
- [ ] No
- [ ] Yes

If “yes”, what are your emotional concerns? (check all that apply)
- [ ] Stress
- [ ] Depression
- [ ] Guilt
- [ ] Suicidal tendencies
- [ ] Anger/resentment
- [ ] Anxiety/fear (concern about the future)
- [ ] Loneliness (isolating yourself)
- [ ] Other (please specify): ___________________

23. Are you receiving any treatment for emotional or stress related problems (depression)?
- [ ] No
- [ ] Yes

If “yes”, what treatment are you using? (check all that apply)
- [ ] Prescription medicine
- [ ] Alternative therapies
- [ ] Counseling
- [ ] Medical Marijuana
- [ ] Other (please specify) ____________________

24. Has becoming HIV+ caused problems in your close relationships?
- [ ] No
- [ ] Yes

If “yes”, what problems has it caused? (check all that apply)
- [ ] Stress or isolation in relationships with family
- [ ] Difficulties in relationship with spouse/partner
- [ ] Involvement with people who want to be infected (POZ chasers)
- [ ] Difficulties in relationship(s) with children
- [ ] Other (please specify): ____________________

25. What type of counseling do you prefer? (check all that apply)
- [ ] Individual (just a counselor and me)
- [ ] Group counseling (with other HIV+ people)
- [ ] Peer counseling (by other HIV+ people)
- [ ] Religious or pastoral counseling
- [ ] I am not interested in counseling
- [ ] Other (please specify): ____________________
**PART 5:**
**TELL US ABOUT YOURSELF**

<table>
<thead>
<tr>
<th>Question</th>
<th>Options</th>
</tr>
</thead>
<tbody>
<tr>
<td>26. What is your gender identity?</td>
<td>☐ Female</td>
</tr>
<tr>
<td>27. What is your race/ethnicity? (check all that apply)</td>
<td>☐ Native American/AK Native</td>
</tr>
<tr>
<td>28. What is your age?</td>
<td>☐ 18 to 25</td>
</tr>
<tr>
<td>29. How do you identify?</td>
<td>☐ Heterosexual/Straight</td>
</tr>
<tr>
<td>30. What is your current employment status?</td>
<td>☐ Employed full-time</td>
</tr>
<tr>
<td>31. What is your monthly household income?</td>
<td>☐ Less than 6,000</td>
</tr>
<tr>
<td>32. Where are you living now? (check all that apply)</td>
<td>☐ Your own house or apartment</td>
</tr>
<tr>
<td>33. If you are living in your own house or apartment, are you receiving housing assistance?</td>
<td>☐ No</td>
</tr>
</tbody>
</table>
1. What kinds of things may have helped you avoid infection with HIV? (check all that apply)
   - Being more aware that infection with HIV was a possibility for me
   - Being more knowledgeable about how HIV is transmitted
   - Knowing where to find clean needles or clean works
   - Getting treatment for depression or other emotional problems
   - Getting treatment for a substance abuse problem
   - Knowing how to bring up the subject of protection with a sex partner
   - Knowing the importance of talking to a sex partner about his or her HIV status
   - Other. Please describe any of the issues checked above in more detail or describe other things that may have been helpful to you.

   __________________________________________________________

2. What is the best way that the public health department and the Ryan White Care Program can get information about prevention, treatment, and services to you? (Check all you think would be helpful)
   - Billboards
   - Health care provider – doctors, nurses, etc.
   - Internet / health department website
   - Facebook, Instagram or Twitter (other) __________________________
   - Community educational events like health fairs
   - Movies/television clips/television commercials/magazines
   - Announcements on the radio (which stations are best?) ________________
   - Advertisements or articles in newspapers
   - Case managers
   - Peers and friends
   - Other ways that we can get information to you? ________________________
3. What is the single most important change you would suggest to improve the *quality of life* for individuals or families living with HIV?

______________________________________________________________________________

______________________________________________________________________________

______________________________________________________________________________

For contact information for a HIV medical case manager in your area, call 406-444-3565 or visit [http://dphhs.mt.gov/publichealth/hivstd/treatmentprogram](http://dphhs.mt.gov/publichealth/hivstd/treatmentprogram)

**THANK YOU!**