

Tennessee State University

College of Health Sciences

Department of Public Health, Health Administration, and Health  
Sciences

Collaboration with

The Community HIV/AIDS Partnership (CHAP) and the United Way  
of Metropolitan Nashville

2015 Needs Assessment

## Acknowledgements

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## **I. Overview**

The Community HIV/AIDS Partnership (CHAP) convened in 1994 and working collaboratively with the United Way of Metropolitan Nashville, continues to provide comprehensive outpatients health and support services within regions significantly affected by HIV disease.

The Tennessee Department of Health (TDOH), and the Middle Tennessee Ryan White Part B Consortium as mandated by Part B of the grant was tasked to conduct a 2015 needs assessment. The needs assessment catchment area included the following 26 Middle Tennessee counties: Bedford, Clay, Coffee, Cumberland, DeKalb, Fentress, Giles, Houston, Humphreys, Jackson, Lawrence, Lewis, Lincoln, Marshall, Maury, Montgomery, Moore, Overton, Perry, Pickett, Putnam, Stewart, Van Buren, Warren, Wayne, and White.

The goal of the Partnership is to improve the lives of individuals infected and affected with HIV/AIDS by providing grants to nonprofit organizations that provide HIV/AIDS treatment and prevention services. These funds must be used to develop effective and cost-efficient systems for the delivery of essential services to individuals with HIV disease and their caregivers and families. Community HIV/AIDS Partnership uses an inclusive definition of families (e.g., blood relatives, caregivers, significant others, etc.).

## II. Introduction

Ryan White Part B funding is allocated to cover HIV non-medical services for the 26 predominantly rural counties in Middle Tennessee outside of the Nashville TGA also called the 'Part B Consortium'. The Ryan White funding for the Middle Tennessee Part B Consortium is specifically targeted to individuals residing in the region who meet the federal poverty level income guidelines. As a recipient of Ryan White Part B funds, CHAP conducts a needs assessment for the 26 counties in the Part B Consortium. This annual needs assessment aims to define the population living with HIV disease (PLWH) in this area, determine the medical and non-medical support needs of this population and the resources currently available to them, and identify existing gaps in care services that should be addressed.

The research process began after the United Way of Metropolitan Nashville collaborated with Tennessee State University's Department of Public Health, Health Administration, and Health Sciences Research Team. The 2015 Community HIV/AIDS Partnership of Middle Tennessee Ryan White Part B Consortium Needs Assessment has been completed with efforts of the Part B Consortium members, the lead agency, evaluation consultants, volunteers and people living with HIV/AIDS.

The 2015 Community HIV/AIDS Partnership of Middle Tennessee Ryan White Part B Consortium Needs Assessment report consists of a literature review, an epidemiological data assessment from 2014 (the most recent completed year); findings from the Client Survey conducted among HIV service recipients; findings from a new Provider Survey, and findings from the Part B Consortium Needs Assessment/Focus Group sessions. The provider survey was developed and distributed to over 60 HIV/AIDS providers serving clients in the Part B Consortium area. A resource audit of the service providers was also completed during the study cycle.

### III. Executive Summary

The 2015 Part B Consortium Needs Assessment was conducted to define the epidemiologic profile of PLWH in the 26 Part B counties as well as to assess infected individuals' experiences and opinions related to the HIV care continuum from initial linkage, subsequent retention in HIV care and services, and through long-term adherence to HIV treatment. Additionally, current gaps in services, consumer needs and challenges that impact attrition along this continuum were evaluated. A new provider survey was administered to establish baseline data regarding the perceptions of medical providers who care for HIV/AIDS clients. Findings and recommendations from this Needs Assessment can be used to enable CHAP to most effectively direct planning and resource allocation towards the HIV/AIDS community needs and priorities, thus maximizing both individual and community benefit.

#### 1) Epidemiologic Profile of the Part B Consortium:

Defining the epidemiology of HIV/AIDS within the Part B Consortium is an essential first step to identify specific populations most heavily burdened by the HIV epidemic and those newly emerging with highest risk of new HIV transmission. The Part B Consortium is comprised of multiple counties from the three Middle Tennessee Health Regions, including the Mid-Cumberland Region (MCR, 4 counties), the South Central Region (SCR, 11 counties) and the Upper Cumberland Region (UCR, 11 counties) (Appendix Table 1). Key findings from 2010 to 2014 include:

- General trends:
  - The number of new HIV diagnoses increased between 2010 and 2014 (40 to 58 new HIV diagnoses), with a total of 264 new cases reported over the 5-year period (99 in MCR, 99 in SCR and 66 in UCR).
  - HIV prevalence in Part B also increased from 829 to 997 PLWH during this time.
  - Among PLWH in 2014, 37.5% resided in SCR and MCR each and 25% in UCR.
- Sex:
  - From 2010 to 2014, the proportion of new HIV diagnoses in the Part B Consortium was approximately three times higher for men, comprising 77.7% of the total reported (264 cases). Additionally, men remained three times more likely to be living with HIV disease during this period than women.
- Race/ethnicity:
  - At the end of 2014, non-Hispanic Whites (61.4%) comprised the largest racial/ethnic group living with HIV disease in the Part B Consortium.
  - Non-Hispanic Blacks made up 28.8% of the race/ethnicity living with HIV disease in the Part B Consortium. This percentage is disparate since non-Hispanic Blacks make up a little over 17% of the total population in TN. HIV disease continues to disproportionately impact minority groups in the Part B Consortium compared with the general population in Part B counties.

- Hispanics comprised 8.1% of the population which is an increase from 2013.
- Asians, Native Americans/Alaskan Indians, and Native Hawaiians/Pacific Islanders were classified as “other race/ethnicity.” The other races comprised a small number that has remained the same the last three years (2012-2014) at 15 each.
- Age:
  - The prevalence of HIV disease in Part B counties at the end of 2014 was highest among persons age 45-54 years (33%), followed by persons age >55 years (19.2%).
  - The people aged 25-34 years had a slight increase in the number of people living with HIV.
- HIV Transmission Route:
  - In 2014, nearly half of the HIV disease prevalence in the Part B Consortium occurred among men who reported transmission through sex with other men (44.2%) also called MSM. The proportions of each risk group’s contribution to overall prevalence have remained relatively stable over the past 5 years.

## 2) The 2015 CHAP Client Survey:

A survey was conducted among HIV positive individuals to evaluate their experiences with regards to HIV medical and non-medical services in the Part B Consortium, challenges or facilitators which impact their utilization of services, and their met and unmet service needs. Because of the low response rate in 2014, food and transportation questions were included in the 2015 survey.

### Description of respondents

- There were 89 HIV-infected respondents identified as people living with HIV/AIDS.
  - 43.8% were from MCR, 13.5% from SCR, 22.5% from UCR, 2.2% missing data, and 18% self-reported being from the TGA.
  - Respondents were predominantly age 20 to 74, white (56.2%), male (72%), homosexual-MSM (49%), heterosexual (39.3%), bisexual (5.6%), ‘other’ (2.2%), and transgendered (1.1%).
  - Approximately 39% had been diagnosed with AIDS.

### HIV Medical Care and Services

- Medical providers including doctors, nurses, and case managers were identified as being who gave the most information about HIV medical care and treatment by clients. Respondents self-reported at lower amounts that the internet and friends provided the most information about HIV medical care and treatment.
- Nearly all respondents (94.4%) reported receiving regular medical care, with the majority self-identifying the Vanderbilt Comprehensive Care Center (VCCC) or one of its satellite clinics in Springfield, Columbia, or Cookeville as the more frequented facilities. Most

also reported that they pay for their medical care through one or more federal funding sources, including Ryan White, Medicare, and TennCare.

- Over thirty-seven (37.1%) linked to HIV medical care within one month, and 31.5% of the respondents had last seen their provider within 3 months.
- Most respondents (95.5%) were currently receiving anti-retroviral treatment (ART) and reported adherence was high (>75%).
- Barriers reported as related to delayed linkage to HIV medical care or to inconsistent retention or adherence to care or treatment included did not know where to go to receive HIV medical care, too hard to get to medical care, fear of disclosure or discrimination, concern of how to pay for care, lack of transportation, and not understanding the importance of getting HIV care early or knowing where to go, and fear of HIV medical care among other reasons.

#### Non-Medical HIV Services

- Approximately 65% of survey respondents received non-medical support services within 6 months of HIV diagnosis. Lack of transportation was cited as one of the barriers to accessing HIV services. Other noted challenges were not knowing where to go, cost or ineligibility, and the waiting list.
- Respondents were asked which non-medical services that are currently provided are the most important. Transportation (49%), basic dental services (check-ups, fillings, and extractions) (48%) and food bank (41%) were reported as the most needed services, followed by non-medical case management (24%), psychosocial support (18%), and home delivered meals (10%).
- When asked which non-medical services that are NOT currently provided are the most important include transportation, food service, dental, residential services, and utility assistance.
- Lack of food services, food vouchers, and food bags were concerns of the respondents.

#### **2015 Needs Assessment Recommendations:**

1. Focus on special topics for future research including:
  - Research issues and challenges in the transgender population
  - Complete a transportation study
  - Replicate the Client Survey more frequently than every three years
  - Administer the Provider Survey.
2. Prioritize efforts and resources to address issues identified through the Client Survey:
  - Fear of unintended disclosure, stigma, or discrimination

- Concern about how to pay for HIV care
  - Lack of transportation
  - Lack of awareness of:
    - i. Importance of early treatment
    - ii. Where to get medical and non-medical services
  - Using non-medical sources to educate clients and raise awareness of available services
3. Prioritize resources (time, personnel, funding, services) to address the following specific barriers or challenges identified in the 2015 Client Survey and relating to the Cascade of Care (Continuum of Care):
    - Fear of unintended disclosure, stigma, or discrimination
    - Concern about how to pay for HIV care
    - Lack of transportation
    - Lack of awareness of importance of early treatment
    - Don't know where to get medical and non-medical services
    - Food insecurity, especially fresh foods (meat, produce, dairy products)
  4. Maintain or increase assistance for currently covered entities such as transportation, routine dental services, food bank, non-medical case management, psychosocial support, home delivered meals.
  5. Use the results of this Needs Assessment and other tools to seek additional resources to provide new assistance for uncovered services, including rent, utilities, eye care, support groups, housing, early intervention services (EIS), and substance abuse treatment.

## IV. Literature Review

HIV/AIDS has impacted the health of people globally. Olaleye, Ogwumike and Olaniyan (2013) studied the inequalities of HIV/AIDS in Nigeria and 3.3 million people were living with HIV/AIDS (PLWHA). Nigeria is ranked third in world for the most people living with the HIV/AIDS; Ethiopia and India are ranked first and second respectively. Additionally Olaleye, Ogwumike and Olaniyan (2013), indicated that poor and women living in rural areas were identified as being affected by HIV/AIDS in Africa. In contrast HIV/AIDS is just a prevalent in the United States.

Since the early 1980s, the United States has been influenced socially, economically, mentally, and physically. Although, there has been an increase in HIV education and health promotion prevention initiatives; stigma continues to affect people living with HIV/AIDS (PLWHA), families, and the effectiveness of treatment (Van Brakel, 2006). The prevalence of individuals living with HIV has been on the rise in the United States since the epidemic began. According to the Centers for Disease Control and Prevention (CDC), there are more than one million people living with HIV (PLWH) in the United States (U.S.).

The Centers for Disease Control and Prevention (2012) indicated in the U.S. by region, the Northeast and the South make up the highest rates of populations of PLWHs. “At the end of 2010, the South accounted for 45% of the estimated 33,015 new AIDS diagnoses in the 50 states and the District of Columbia, followed by the Northeast (24%), the West (19%), and the Midwest (13%)” (Centers for Disease Control and Prevention, p. 1). In 2004, 72% of individuals living with HIV were male. Other statistics noted were 37% were PLWHs between the ages of 40 and 49 and 48% were African-Americans. (Centers for Disease Control and Prevention, 2012).

Because the literature is replete with published research articles about various HIV/AIDS topics including Brakel (2006); Olaleye, Ogwumike & Olaniya (2013); & PRNewswire (2010), does not mean the literature is limited regarding studies completed on access to healthcare and barriers to healthcare for PLWHAs. Studies conducted within the last 10 years are limited that focused on PLWHAs and access to health care (Cornelius & Carrick, 2015; Darin, Scarsi, Klepser, Klepser, Reeves, Young & Klepser, 2015; Gerbert, Moe, Saag, Benson, Jacobsen, Feraios, Hill, Bronstone, Caspers & Volderding, 2007; Haochu, Li, Holroyd, Li & Lau, 2014; Kibicho & Owczarzak, 2012; Kim, Maulsby, Kinsky, Riordan, Charles, Jain, & Holtgrave, 2014; Li, Wu, Wu, Zhaoc, Jia & Yan, 2006; Macapagal, Valvano, Wairus, Wilson, West & Steplemen, 2014; Rosenquist, Best, Miller, Gilmer & Hirsch, 2010).

Being diagnosed with HIV/AIDS has been indicated to be a life-altering situation possibly affecting a person’s behavior and attitude. Stigma not only negatively affects PLWHA, however it also affects the community and health care professions. According to Macapagal, Valvano, Penwell-Wains, Wilson, West, & Stepleman (2014), a negative attitude when providing care promotes gaps in the PLWHA-provider relationship. The researchers developed a model in which health profession students in nursing, allied health, medical, mental health, and dental training programs in Georgia were tested on their attitudes toward lesbian, gay, bisexual, and transgender (LGBT) patients. Attitudes were also tested on clinical and classroom experiences relevant to sexual health. The measures developed to

identify provider attitudes were the Attitudes toward LGBT Patient Scale (ALTPS), and Attitudes toward HIV Scale (ATHS) (Macapagal, Valvano, Penwell-Wains, Wilson, West, & Stepleman, 2014). The study authors hypothesized that nursing and mental health students were less inclined to refuse the treatment of PLWH compared to the other disciplines. Students in the dentistry and medicine programs maintained the highest percentage of disciplinarians who did not want to work with patients with HIV/AIDS. The Nursing Students' Knowledge and Attitudes of LGBT Health Concerns (NKALH) survey identified a positive outlook in terms of HIV/AIDS treatment in the LGBT community.

Another study by Cornelius & Carrick (2015) who developed the Nursing Students Knowledge and Attitudes of LGBT Health Concerns (NKALH) sought to determine the knowledge and attitudes of nursing students in regards to LGBT healthcare. A 73-item survey was administered to 190 nursing students. The findings unveiled that, RN-BSN nursing students answered more questions correctly than the other students. Although, the members of the RN-BSN program had greater knowledge about HIV/AIDS, the results showed the medical professionals had more positive attitudes towards access to care and towards members of the LGBT community. This study also indicated that a more positive attitude would be obtained with the access to more HIV/AIDS health literacy. This study discussed that nursing schools need to incorporate a curriculum involving the knowledge base of HIV/AIDS and the LGBT community. Gerbert, Moe, Saag, Benson, Jacobsen, Feraios, Hill, Bronstone, Caspers & Volberding (2001) developed surveys to test the expertise level of medical physicians involved in HIV care.

The survey administered by Gerbert et al., 2001 assessed the participants demographic and practice characteristics, self-perceived HIV expertise, and level of confidence with rendering HIV care. The dominant three specialties, which dominated in having expertise rendering care of HIV, were infectious diseases, internal medicine, and family practice or general medicine. The majority of physicians ranked as experts. Conversely, confidence to provide HIV care was low. The results indicated there was a lack of confidence in published research that provided clear guidance, expertise was outside their own and traditionally followed by specialists, and research was not yet disseminated and/or the technology was not universally available. If the healthcare provider does not have an adequate sense of knowledge or assessment to render care to HIV individuals, the results were the patients felt neglected; and caused anxiety, depression, and a suicidal thinking.

In order to decrease the prevalence of HIV/AIDS, healthcare providers, should be the forefront of HIV/AIDS Prevention. A positive attitudes and knowledge should be obtained when it comes to family physicians' knowledge and attitudes in supporting patients that have the burden of HIV/AIDS. Torabi, Aguilon & Jeng (2000), utilized a cross-sectional survey design, which was given to five hundred rural and urban family physicians from Indiana State Medical Association membership directory. The data analysis indicated that 19% of the providers were practicing in urban areas, 29% in suburban areas, and 52% in rural. Per the ANOVA results, there was not significant difference of knowledge of HIV/AIDS between subgroup. Practice Questions indicated that there is still a lack of knowledge and education regarding HIV/AIDS prevention. When it came to asking patients questions concerning HIV/AIDS, concerning risk factors for HIV/AIDS, and risk factor reduction with patients, the percentage of responses for sometimes were 56.9%, 55.6%, and 57.6%. The

study made further indication that though advances have been made in regards to the treatment of HIV/AIDS within two decades, there is still a poor rate of knowledge between healthcare physicians. There is still an alarming rate of stigma associated with PLWHA globally.

Li, Wu, Wu, Zhaoc, Jia & Yan (2007) indicated that HIV-related stigma is prevalent in China. The researchers examined the individual and intuitional factors of healthcare discrimination towards PHLWHA. The Health Professional Survey (2007) consisted of 172 questions, which assessed the participants' demographics, medical training, experience, and attitudes/behavior of patients with a positive HIV status. The findings indicated that more institutional support of the providers deemed to be less discriminatory in the workplace toward individuals living with HIV/AIDS. If safety and occupational materials were provided at the worksite; such as rubber gloves, working autoclaves, and access to free HIV testing, individuals tended to be less anxious and discriminatory towards PLWHA; however, HIV training and HIV knowledge could also influence discrimination at work as well. However, if workers became culturally aware of HIV literacy, it would contribute to a positive change for PLWHA. Though HIV/AIDS is a chronic medical condition other health related diseases such as cardiovascular, diabetes, and hepatitis can complicate the health status of PLWHA.

Van Brakel (2006) developed a study, which reviewed the published reports in regards to stigma and discrimination of chronic diseases such as HIV/AIDS, leprosy, tuberculosis, mental health, and epilepsy. A literature study was composed with the International Consortium for Research and Action Against health-related Stigma (ICRAAS). There were five categories of stigma: 1) attitudes towards the people affected, 2) discriminatory and stigmatizing practices, services, legislation and materials, 3) experience of actual discrimination and/or participation restrictions, 4) perceived or felt stigma, and 5) self-or internalized stigma. The Explanatory Model Interview Catalogue (EMIC) (2006), was used to measure attitudes and perceptions for the various health conditions. Van Brakel (2006) also developed The Child Attitude Toward Illness Scale (CATIS) and the Participation Scale, which was used for children 8-12 and adolescents with epilepsy and asthma and the psychometric properties of terminology and conceptual framework respectively. The study revealed that stigma consequences are similarities in different health conditions, cultures, and public health programs. (Van Brakel, 2006).

It can be assumed from these literature reviews that there are still barriers in healthcare as it pertains to individuals who have been diagnosed with HIV/AIDS. Discrimination and stigma of healthcare providers towards PLWHA is prevalent within the HIV/AIDS community, though there has been medical advancement toward the study of the disease. If healthcare provider knowledge and attitudes are not increased within a two-decade frame, then mental, physical, and emotional mindset of people living with HIV/AIDS is not going to improve. I believe more longitudinal studies should be completed to fully understand the attitudes and knowledge of healthcare providers about HIV/AIDS.

## V. EPI Profile

### Methods and Limitations

This profile is based on data for the years 2010-2014 obtained from the Tennessee Department of Health (TDOH) HIV/AIDS/STD Section using surveillance data reported in Tennessee eHARS (HIV/AIDS Reporting System).

### Definitions:

- 1) Throughout this report, the terms “**HIV Disease**” and “people living with HIV disease (**PLWH**)” will be used to refer to three categories of cases:
  - a. Diagnoses of HIV infection only,
  - b. Diagnoses of HIV infection with later diagnoses of AIDS, and
  - c. Concurrent diagnoses of HIV infection and AIDS. Of note, laboratory-confirmed evidence of HIV infection is required to meet the Centers for Disease Control and Prevention (CDC) and TDOH surveillance case definition for HIV infection among adults and adolescents.
- 2) **HIV transmission** route, age, and race categories used in these analyses are also based on CDC surveillance standards also utilized by TDOH.
- 3) **AIDS** is defined according to the CDC as having laboratory-confirmed evidence of HIV infection in addition to a CD4+ T-lymphocyte count of  $<200$  cells/ $\mu$ L, a CD4+ T-lymphocyte percentage of total lymphocytes of  $<14\%$ , or diagnosis of an AIDS-defining condition. Note that once diagnosed, a person remains categorized as having “AIDS”, even though they can clinically and immunologically improve on effective combination anti-retroviral therapy (**ART**).
- 4) HIV/AIDS incidence or prevalence numbers of five (5) or less per county are suppressed in accordance with TDOH requirements.
- 5) **Acquired Immunodeficiency Syndrome (AIDS)** - A disease of the immune system due to infection with HIV. HIV destroys the CD4 T lymphocytes (CD4 cells) of the immune system, leaving the body vulnerable to life-threatening infections and cancers. Acquired immunodeficiency syndrome (AIDS) is the most advanced stage of HIV infection. To be diagnosed with AIDS, a person with HIV must have an AIDS-defining condition or have a CD4 count less than 200 cells/ $\text{mm}^3$  (regardless of whether the person has an AIDS-defining condition).
- 6) **Antiretroviral Therapy (ART)** -The daily use of a combination of HIV medicines (called an HIV regimen) to treat HIV infection. A person’s initial HIV regimen generally includes three antiretroviral (ARV) drugs from at least two different HIV drug classes.
- 7) **Human Immunodeficiency Virus (HIV)** -The virus that causes AIDS, which is the most advanced stage of HIV infection. HIV is a retrovirus that occurs as two types: HIV-1 and HIV-2. Both types are transmitted through direct contact with HIV-infected body fluids, such as blood, semen, and genital secretions, or from an HIV-infected mother to her child during pregnancy, birth, or breastfeeding (through breast milk).
- 8) **Men Sleeping with Men-** is abbreviated as MSM.
- 9) **Ryan White HIV/AIDS Program Synonym(s)-** The act is the largest federally funded

program providing HIV-related services to low-income, uninsured, and underinsured people with HIV/AIDS. The program's services are available in all 50 states and U.S. territories.

10) **Upper Cumberland Human Resource Agency-UCHRA**

11) **Viral Load (VL)** -The amount of HIV in a sample of blood. Viral load (VL) is reported as the number of HIV RNA copies per milliliter of blood. An important goal of antiretroviral therapy (ART) is to suppress a person's VL to an undetectable level—a level too low for the virus to be detected by a VL test.

**Limitations related to data collection and analysis:**

This report incorporates the most recent HIV/AIDS data available through Tennessee's HIV surveillance system. The Tennessee HIV/STD Surveillance and Epidemiology Program manages an HIV case surveillance registry, a population-based registry of all persons diagnosed with AIDS (since 1982) or HIV infection (since 1992) and reported to the Tennessee Department of Health (TDOH) according to standard Centers for Disease Control and Prevention (CDC) case definitions. The state's HIV case registry or eHARS contains demographic, HIV transmission, and clinical information on HIV-infected persons, as well as all diagnostic tests, CD4 counts and viral load tests reportable under Tennessee law.

We have incorporated the most recent and the most complete HIV/AIDS data available for this profile as provided by TDOH for the EPI Profile data range, January 1, 2014 through December 31, 2014. Please note that data is continually updated such that there are differences for the same periods for later reports. For example, data may not have been reported in a timely manner such that cases identified in March of 2014, may not become a part of reported data until a year later, making significant differences in the number of cases identified in the data. This is considered a data limitation and creates differences in each year of the epidemiologic profile publications (TDOH HIV/STD Program Manual May 2012).

The prevalence of undiagnosed individuals must be considered a limitation when identifying individuals within a community with HIV/AIDS [Chen et al, Prevalence of Undiagnosed HIV Infections Among Persons Aged  $\geq 13$  Years – National HIV Surveillance System, United States, 2005 – 2008. MMWR 2012; 61 (Suppl; June 15, 2012; p 57-64)]. Undiagnosed individuals are underrepresented because they cannot be included in those counted and reported. These individuals are calculated to represent more than 20% of HIV infected individuals with HIV/AIDS.

Data for years prior to 2013 are indicative of individuals with their initial diagnosis and risk data reported in Tennessee. Reported information reflects changes in data that are indicative of reporting changes by the state of Tennessee which identifies all prevalent or existing HIV diagnoses residing in Tennessee whether the diagnosis occurred within or outside of Tennessee.



## Middle Tennessee Population by Race and Ethnicity

Population estimates by race and ethnicity for Tennessee as a whole and the different Middle Tennessee sub-groups are shown in Table 2. The Part B Consortium has a smaller proportion of minorities compared to the TGA overall (16.9% vs. 26.2%), however the proportion of non-white minorities in the MCR of the Part B consortia (28.1%) is the highest compared to any area in Middle Tennessee or the state as a whole. MCR's large minority population is largely due to the population of Montgomery County (81.5% of MCR population), which is comprised of 19.6% black and 8.1% Hispanic residents.

Area	Total Population	Non-Hispanic Whites	All Minorities <sup>a</sup>	Blacks <sup>b</sup>	Hispanics
<i>Tennessee</i>	6,549,352	78.9%	25.1%	17.1%	5.0%
<i>Middle TN</i>	2,589,195	77.0%	23.0%	13.0%	6.3%
<i>TGA</i>	1,707,134	73.3%	26.7%	15.7%	6.9%
<i>Part B Consortium</i>	882,061	84.1%	15.9%	7.7%	5.3%
<i>MCR</i>	229,642	70.6%	29.4%	16.4%	7.9%
<i>SCR</i>	364,758	85.9%	14.1%	7.1%	4.5%
<i>UCR</i>	287,661	92.3%	7.7%	1.7%	4.2%

Note: Population data obtained from the U.S. Census Bureau, estimates for 2014 based on the 2010 Census. (<http://quickfacts.census.gov/qfd/states/47000.html>).

<sup>a</sup>All minority populations were calculated for each area by subtracting the number of non-Hispanic Whites from the total population.

<sup>b</sup>TDOH reports HIV/AIDS data using combined race and ethnicity categories in accordance with CDC methodology, whereas the U.S. Census Bureau reports race and ethnicity separately. Population percentages are published for non-Hispanic Whites and Hispanics but for non-Hispanic Blacks. Thus, calculation of non-Hispanic Black population is not possible. According to the 2010 Census Report, only an estimated 2.5% of Hispanics self-report as Black so the category for Black is used here for a rough estimate of the non-Hispanic Black population.

## Epidemiology of HIV Disease in the Part B Consortium

### Persons Living with HIV Disease in Middle Tennessee

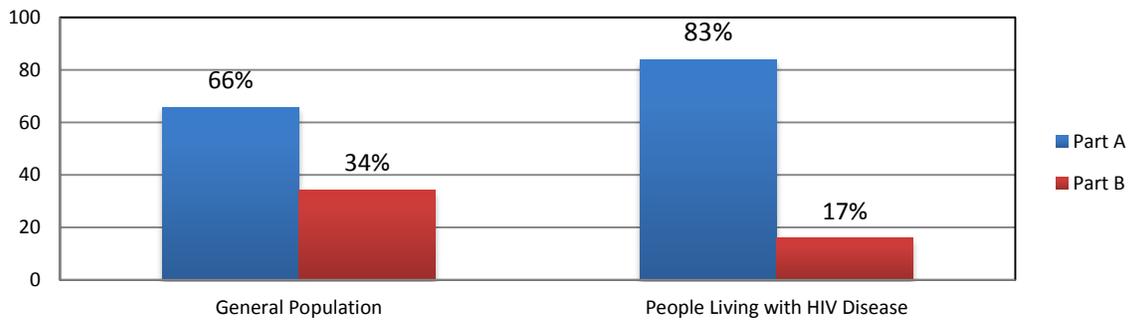
At the end of 2014, there were 5,972 PLWH in the 39 counties comprising Middle Tennessee, including 4,975 (83.3%) who resided in the TGA and 997 (16.7%) residing in a Part B county. Additionally, 1,460 persons were newly diagnosed with HIV infection in Middle Tennessee; 1,196 (82%) resided in the TGA and 264 (18%) in the Part B Consortium. Figure 2 demonstrates the disproportionately high population of PLWH residing in the TGA relative to the general population of this area (83% of PLWH versus 66% of the population). Although the total number of prevalent and incident cases of HIV disease is much smaller in the Part B Consortium, these cases are distributed over a large and diverse geographic area with generally fewer medical and support services available or HIV-infected persons, which poses an additional challenge for people living with HIV in Part B Consortium counties.

*Figure 2: People living with HIV in the Middle Tennessee region, a comparison of the general population.*

*Part A depicts individuals living in the TGA; Part B depicts individuals living in the Part B region.*

### HIV Incidence and Prevalence Trends in Part B Consortium, 2010 to 2014

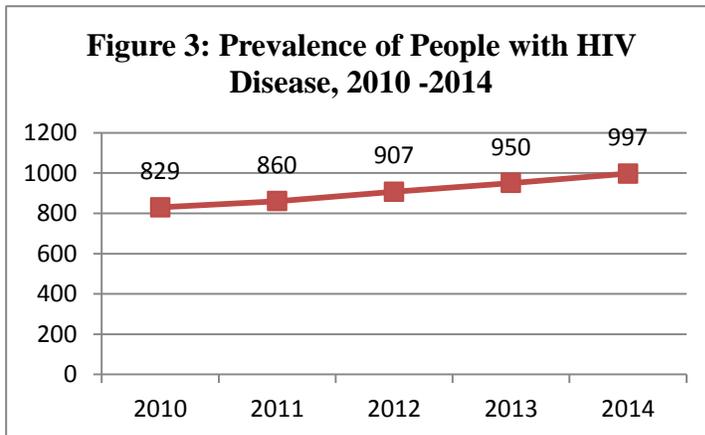
**Figure 2. People Living with HIV Disease in Middle Tennessee, 2014 (n=5,972)\*\***



\*\*The data analyzed, the results, and graphically depicted in all figures and charts was obtained from the data provided by the Tennessee Department of Health.

In this report, the term HIV prevalence is used to describe how many people are living with HIV disease at a given time, regardless of when HIV infection was diagnosed. Incidence typically measures the occurrence of new cases of disease in a specified time period, but since it is not possible to measure the actual rate of *new HIV infection*, the rate of *new HIV diagnosis* is used as a surrogate measure in this report. HIV disease prevalence data indicate what the overall burden of care would be if all infected persons

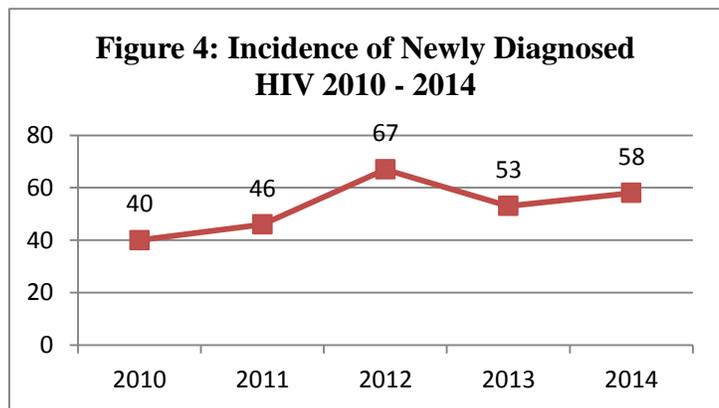
were engaged in the health care system, and is thus useful for determining the quantity of services that may be needed within a health jurisdiction and for allocating resources and funding. HIV incidence data indicates recent changes in specific groups or areas and can be used to identify areas of ongoing or increased HIV transmission in the community. Evaluation of prevalence and incidence data within the Part B Consortium can facilitate identification of population or geographic “hotspots”, and thus can inform decision makers of the types of interventions needed to decrease HIV transmission and improve health outcomes.



Among Part B Consortium counties, the prevalence of HIV disease has continued to rise over the past five years, increasing from 829 to 997 PLWH (Figure 3). This increase prevalence is a result of both an increase in newly reported HIV disease as well as improved survival of persons already infected. From 2010 to 2014, there were 206 individuals who were newly

diagnosed with HIV in Part B counties, and the total per year with a significant increase between 2011 and 2013 (Figure 4).

Over the past decade, significant progress has been made in HIV treatment and prevention, such that HIV is now considered a chronic disease as infected persons are living longer and experiencing improved health, with the caveat that such persons are aware of their HIV status, engaged in HIV care and services and adherent to combination antiretroviral therapy (ART) (Gupta, 2013). Despite this, a total of 356 persons with AIDS in the Part B Consortium have died, though this includes deaths from causes unrelated to HIV.



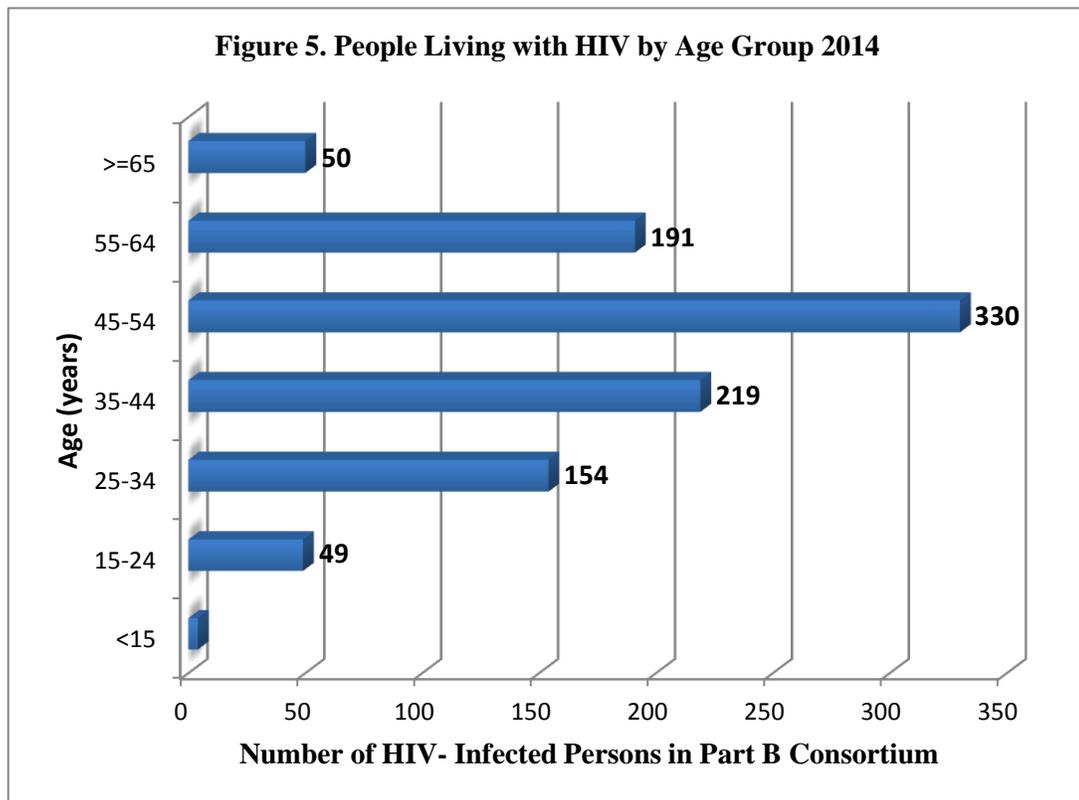
Because the number of new HIV diagnoses at the county-level can be small, 5-year compiled incidence is reported instead of one-year data (2014). Of the 997 PLWH in Part B counties at the end of 2014, 424 were reported in SCR (42.5%), 302 in MCR (30.3%) and 271 in UCR (27.2%). At the county level, geographic “hotspots” for higher HIV prevalence exist in Montgomery (n=273) Maury (n=129), Putnam (n=87), Bedford (n=54), Giles (n=45), Coffee (n=53) and Cumberland (n=43) counties. With regards to

incidence from 2010 to 2014, 264 persons were newly diagnosed with HIV, including 99 (37.5%) in MCR, 99 (37.5%) in SCR, and 66 (25%) in UCR.

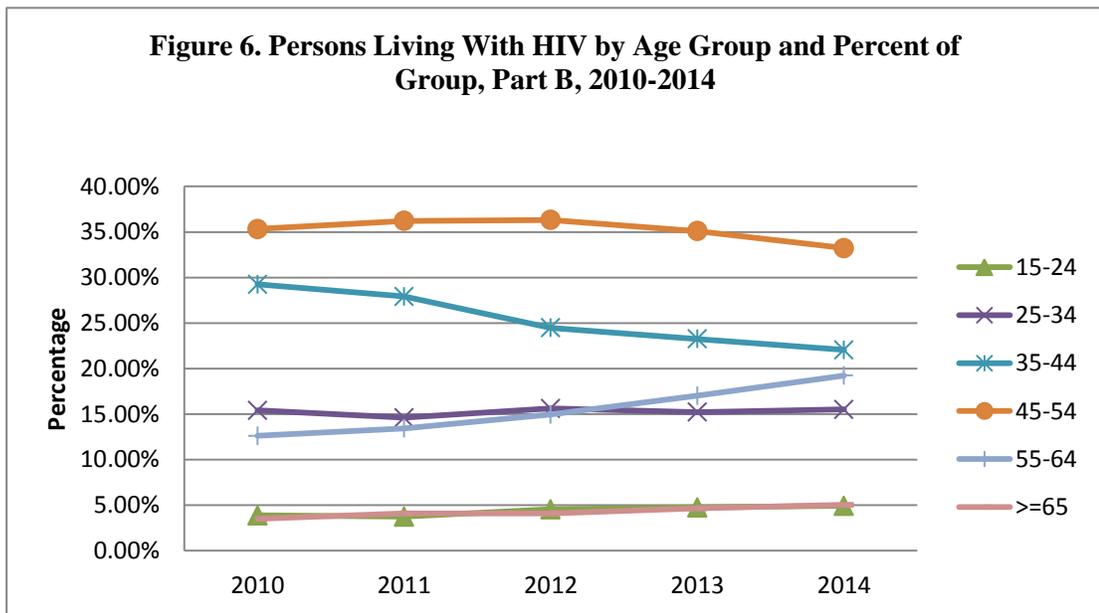
## HIV Disease Prevalence

### Age

The distribution of all PLWH in the Part B Consortium in 2014 by age is shown in Figure 5. HIV disease prevalence was highest among middle-aged persons age 45-54 years (33%), followed by age 35 -44 years (22%) and 55-64 years (19%). A very small number of children with HIV disease resided in the area.

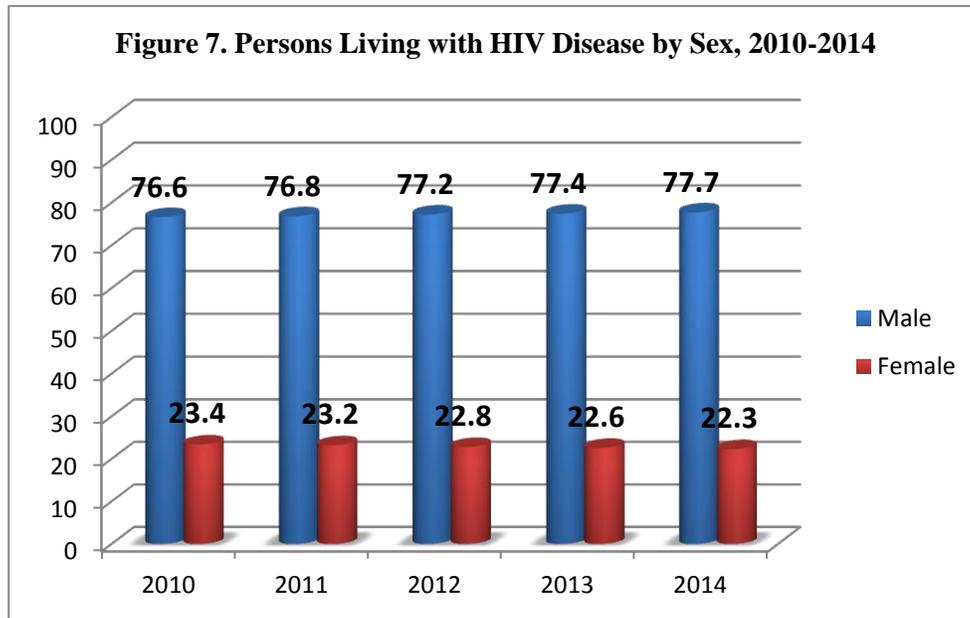


HIV disease prevalence trends by age group from 2010 to 2014 are shown in Figure 6. The highest proportion of PLWH consistently occurred among adults age 45-54 years and remained relatively stable over the five-year period (35.3% to 33.23%). The reported percentage among adults age 35-44 years decreased (29.3% to 22%) during this time while increasing among 55-64 year olds (12.6% to 19.2%). Fewer PLWH were ages <34 years and ≥65 years, and the number of children <15 years living with HIV has remained extremely small.



## Sex

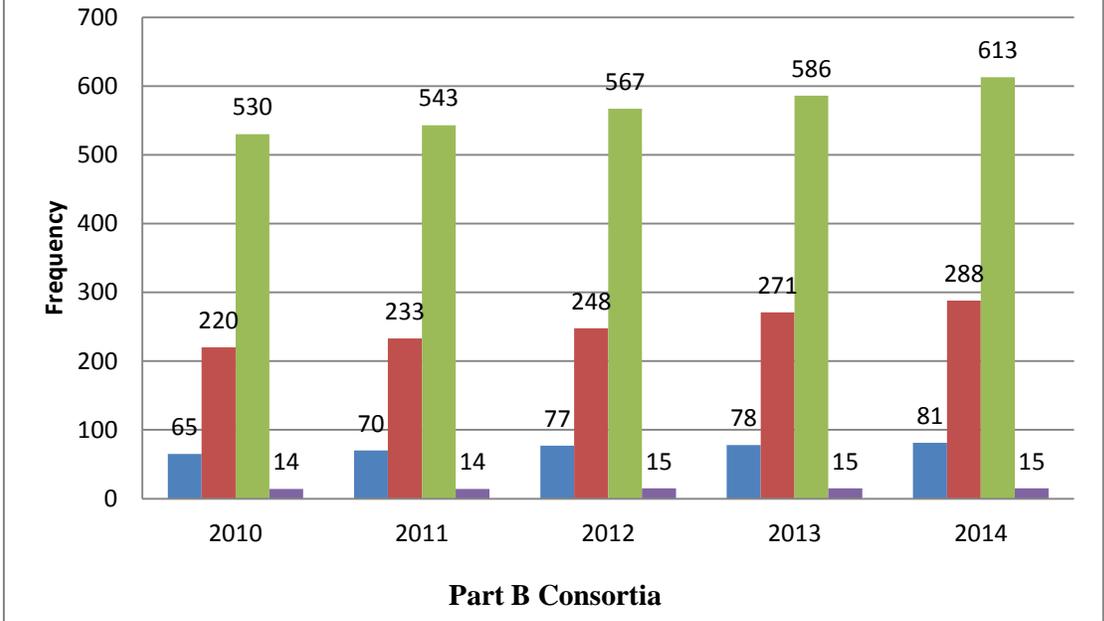
As of December 2014, three quarters of PLWH in the Part B Consortium were male, a trend that has been consistent for at least the last five years (Figure 7). No PLWH who identified themselves as “transgender” were reported in eHARS as residing in the Part B consortium.



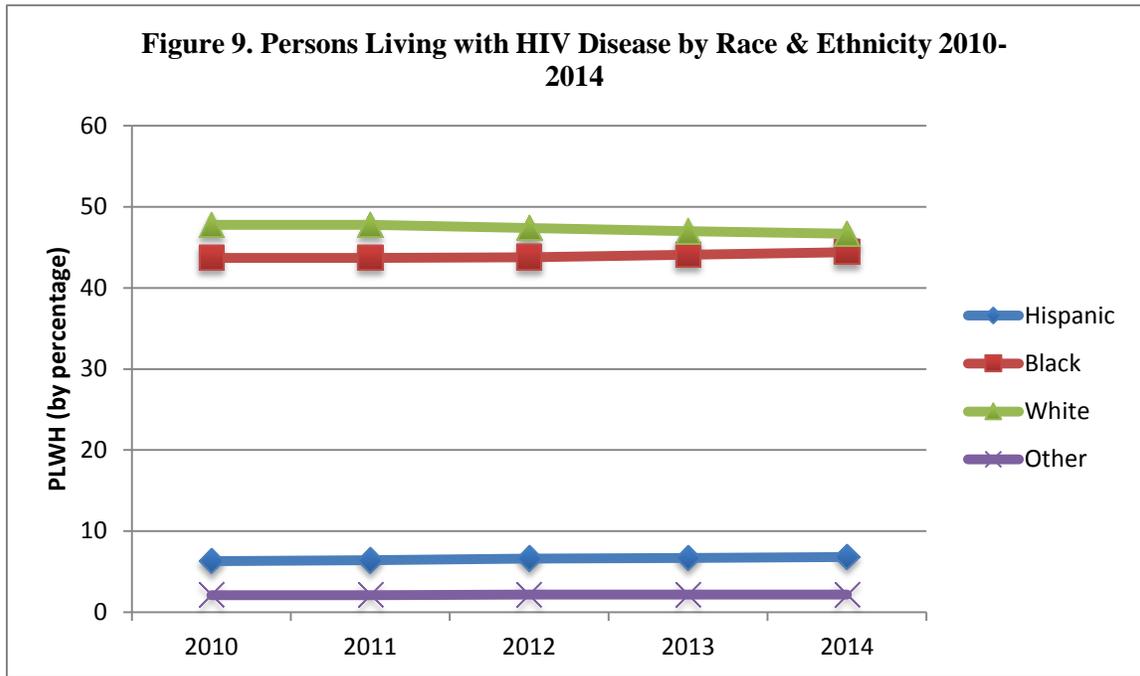
## Race and Ethnicity

At the end of 2014, non-Hispanic whites (61.4%) comprised the largest racial/ethnic group living with HIV disease in the Part B Consortium, followed by non-Hispanic Blacks (28.8%), and Hispanics (8.1%) (Figure 8). Asians, Native Americans/Alaskan Indians, Native Hawaiians/Pacific Islanders are included in “other race/ethnicity”, which comprised a very small group. Figure 9 shows that PLWH, by race/ethnicity, has continued to increase over the last five years (2010-2014) as indicated in Figure 9.

**Figure 8. Persons Living With HIV Disease by Race/Ethnicity, 2010-2014**

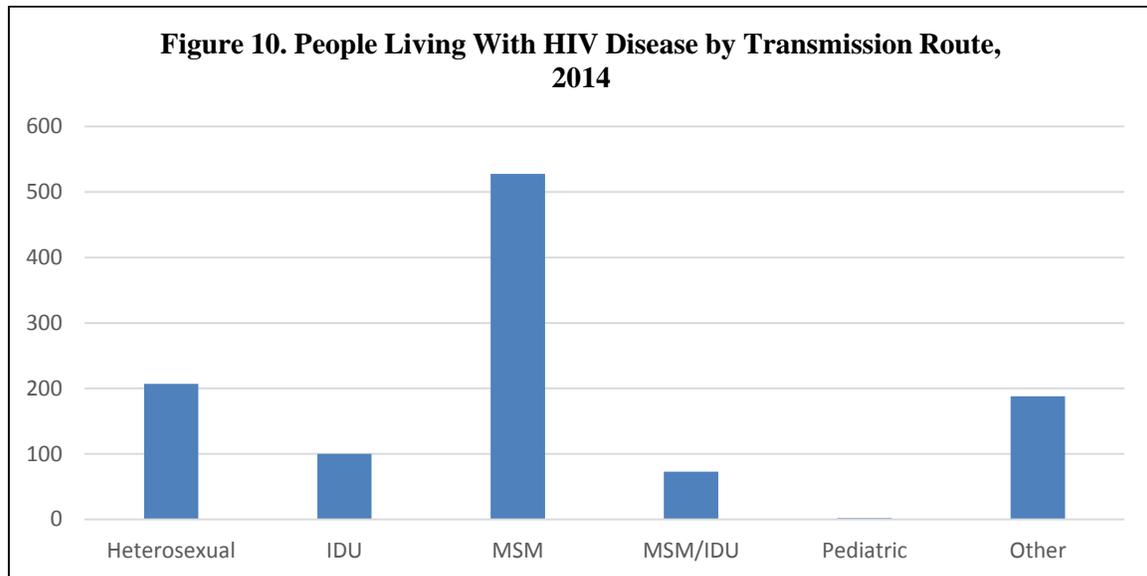


**Figure 9. Persons Living with HIV Disease by Race & Ethnicity 2010-2014**

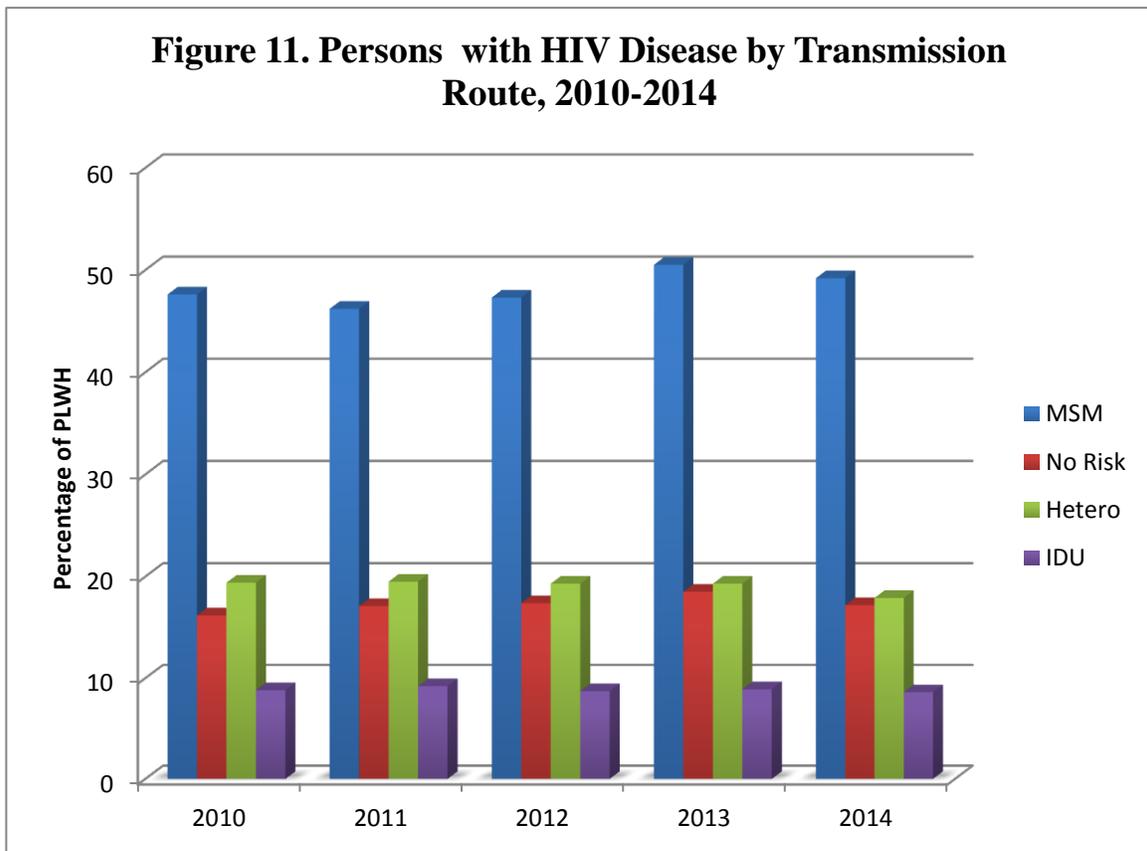


## Mode of Transmission

In 2014, nearly half of the HIV disease prevalence in the Part B Consortium occurred among men who reported transmission through sex with other men (MSM) (44.2%) (Figure 10.) Heterosexual HIV transmission accounted for 18% and injections drug use (IDU) for 8.6%. HIV transmission through both MSM and IDU was less than 1% of the 2014 HIV disease prevalence and pediatric exposure (perinatal mother-to-child transmission route (PMTCT) or unknown risk) was only even lower.



Prevalence trends indicate that these proportions have incurred minimal changes over the past five years as shown in Figure 11 and in the Appendix Table 3. The prevalence rates for people living with HIV disease by transmission route, for 2014, are as follows: Heterosexual (18.9%), IDU (9.1%), MSM (48.1%), MSM/IDU (6.6%), Pediatric (.2%), and Other (17.1%).

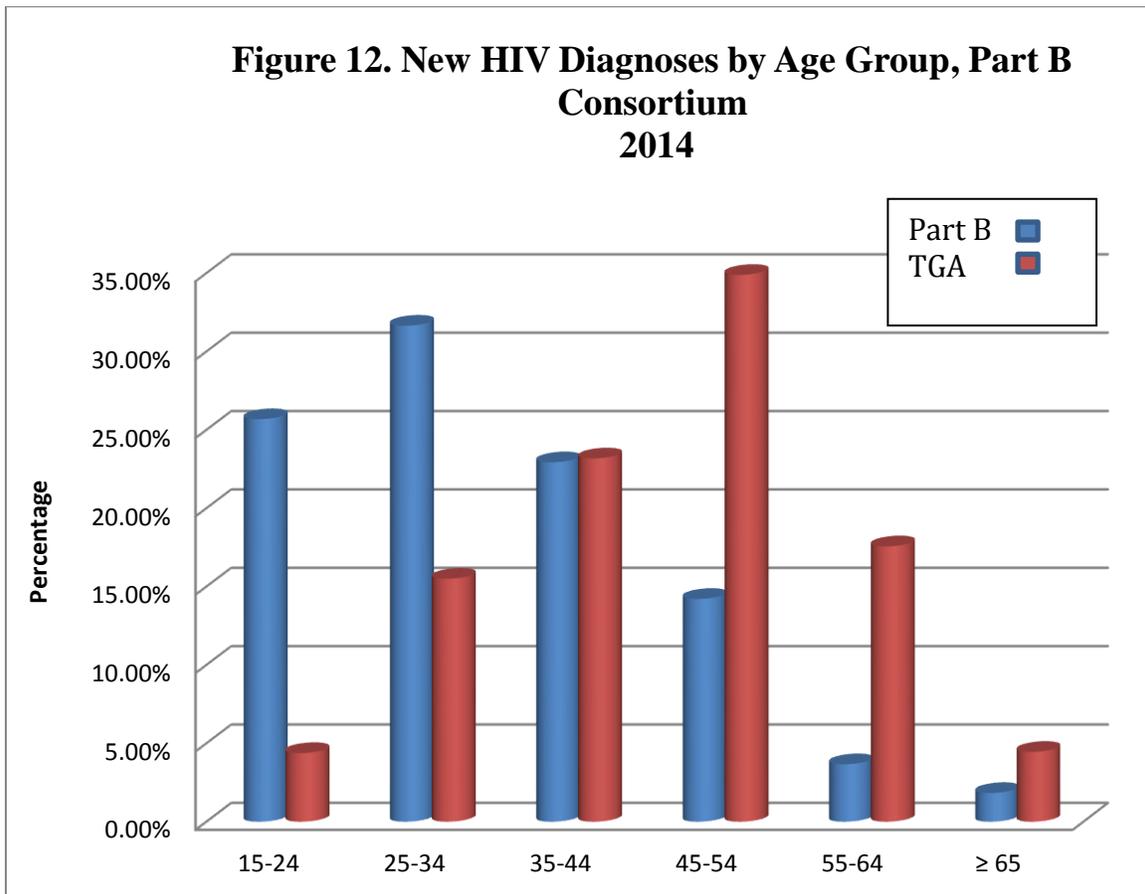


**Figure 11: Persons with HIV Disease by Transmission Route in Part B Consortium, years 2010 to 2014.**

## Incidence of New HIV Diagnosis

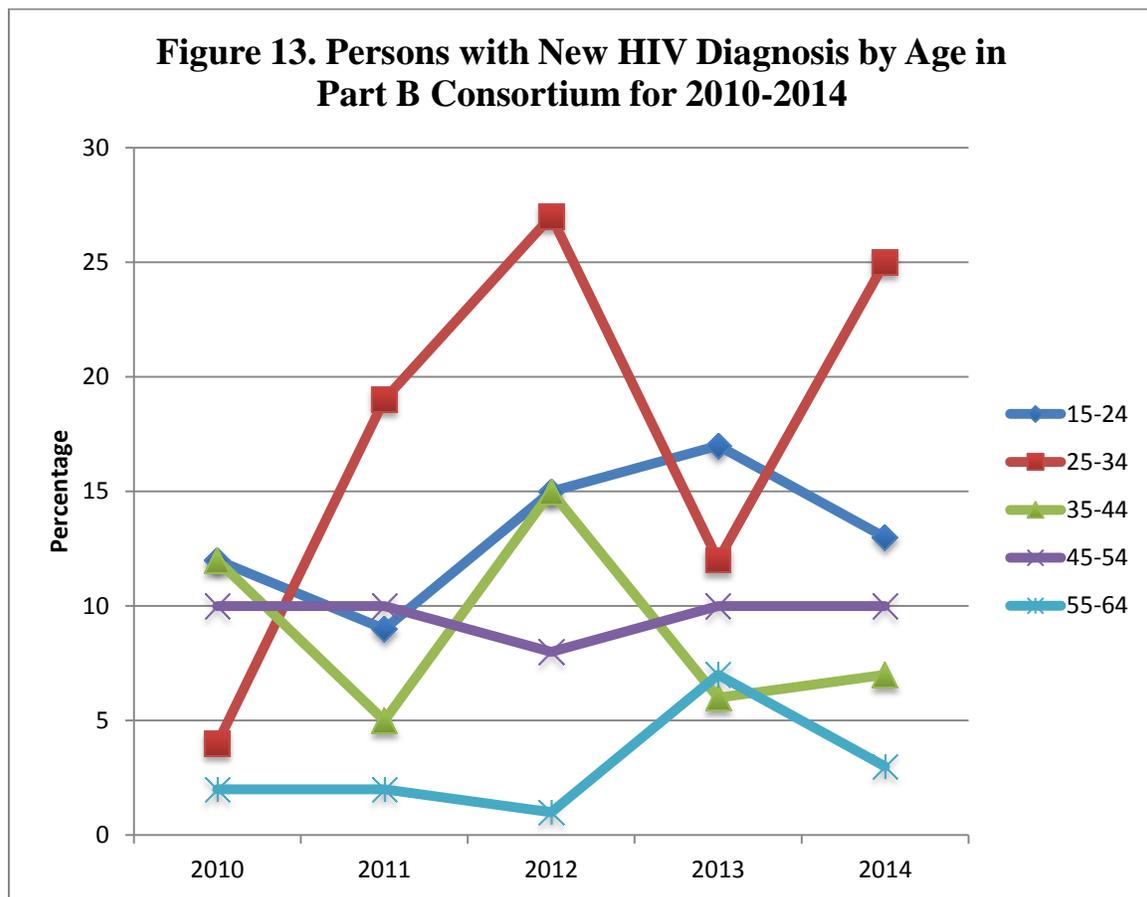
### Age

In 2014, the number of persons newly diagnosed with HIV disease in the Part B Consortium was highest among 25 to 34 year olds, followed by 15-24 year olds, and 35-44 year olds (Figure 12). Compared to the TGA, which has ages 45-54 as the highest ranking category of new diagnoses. A very low percentage of new HIV diagnoses were reported in persons over age 65.



**Figure 12. New HIV Diagnoses by Age Group, Part B Consortium 2014**

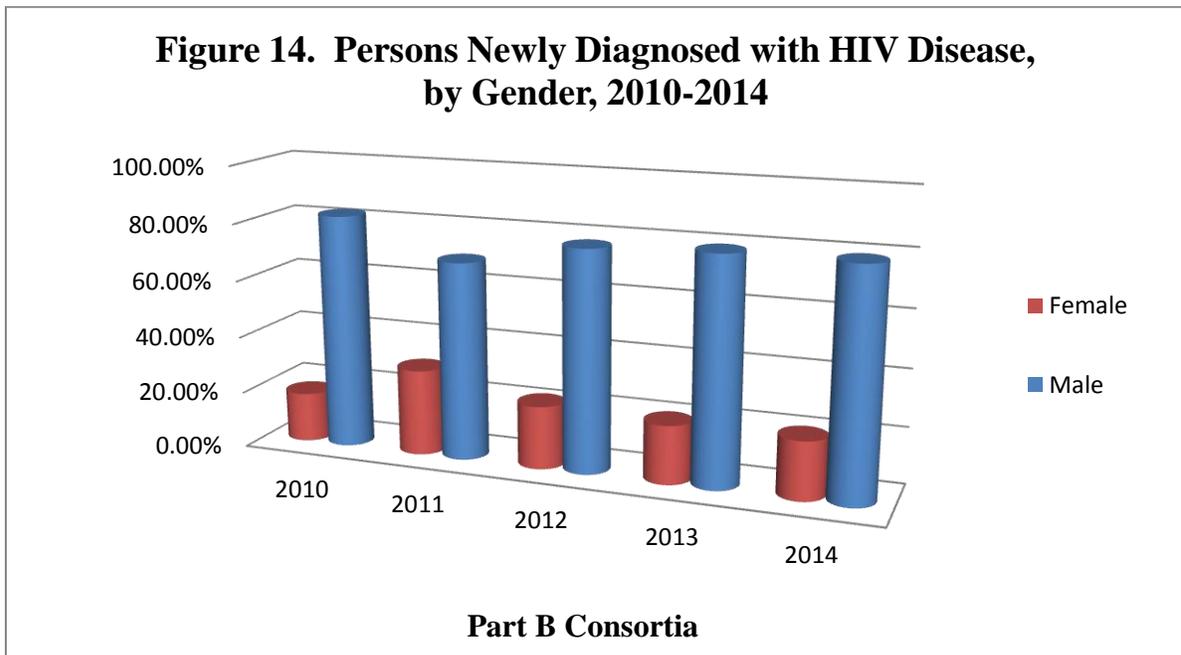
Because of the small number of new HIV diagnoses occurring in all age groups each year between 2010 and 2014, even minimal changes in the year-to-year incidence in each category appear as significant fluctuations in the trend line and should be interpreted with caution (Figure 13). Overall, the HIV incidence was lowest among persons less than 15 years and older than 65 years, and consistently higher among the most economically and socially productive ages of 15-54 years. Very few newly diagnosed HIV infections were reported among children younger than 15. Significant differences are seen in 2013, which may be reflective of reporting changes, but should be monitored in subsequent years for reporting follow-up.



**Figure 13: Persons with New HIV Diagnosis by Age in Part B Consortium for the years 2010 to 2014.**

## Sex

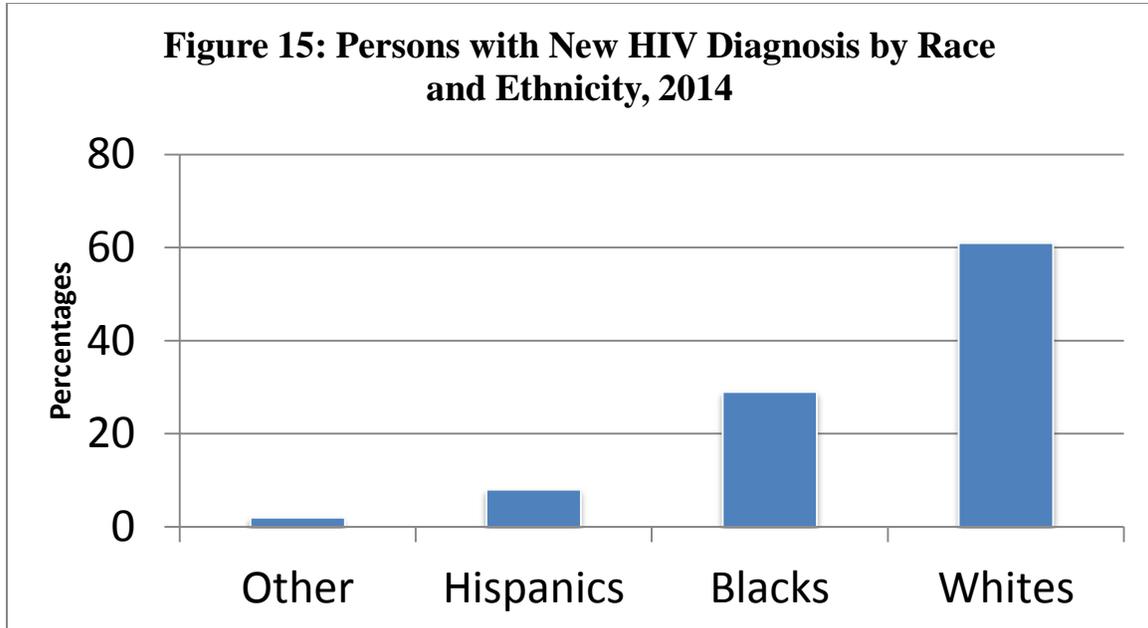
As with prevalence, the proportion of new HIV diagnoses among men in the Part B Consortium from 2010 to 2014 was consistently more than double that of women (Figure 14), ranging between 82.5% in 2010 and 79.3% in 2014.



**Figure 14: Persons Newly Diagnosed with HIV Disease by Gender in Part B Consortium.**

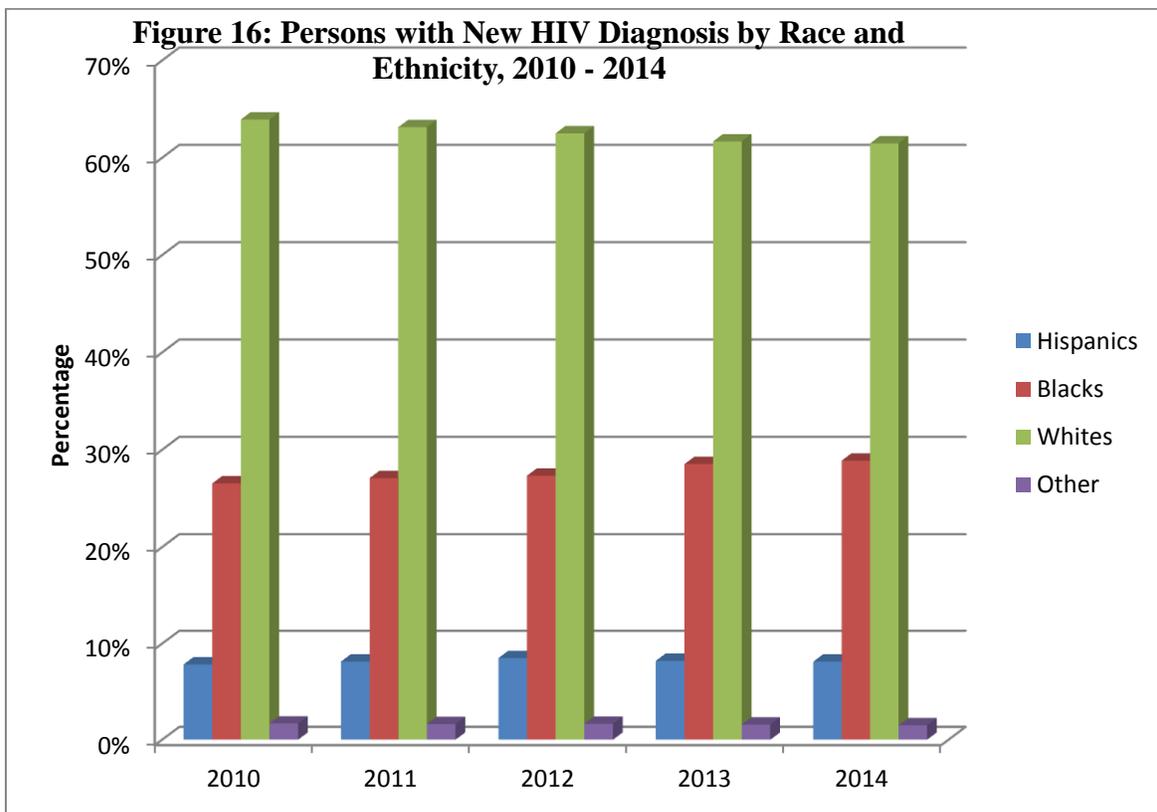
## **Race and Ethnicity**

In 2014, the incidence of new HIV diagnosis was highest among non-Hispanic whites (61%), followed by non-Hispanic blacks (29%) and Hispanics (8%) (Figure 15). When considering the five year incidence trends shown in Figure 16, there was a slight decrease in new HIV diagnosis among non-Hispanic whites (64% in 2010 to 61% in 2014). In contrast the proportion of new HIV diagnosis for blacks increased continually from 27% in 2010 to 29% in 2014. New Hispanic diagnosis hovered around 8% for all five years (2010 to 2014).



**Figure 15: Persons with New HIV Diagnosis by Race and Ethnicity, 2014**

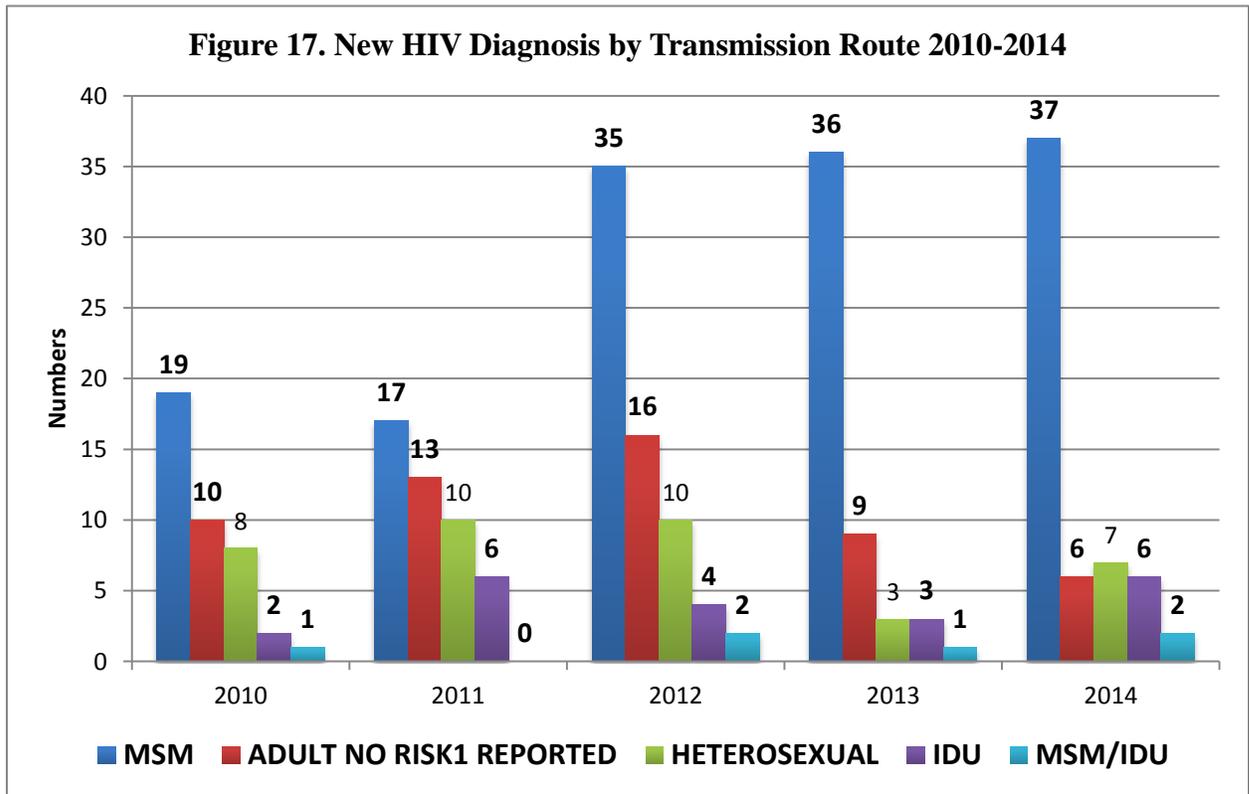
When considering 5-year incidence trends (Figure 16), there was an increase in new HIV diagnosis among non-Hispanic whites. Data was limited for sub-categories including gender of males and females by race.



**Figure 16: Persons with New HIV Diagnosis by Race and Ethnicity, 2010 to 2014.**

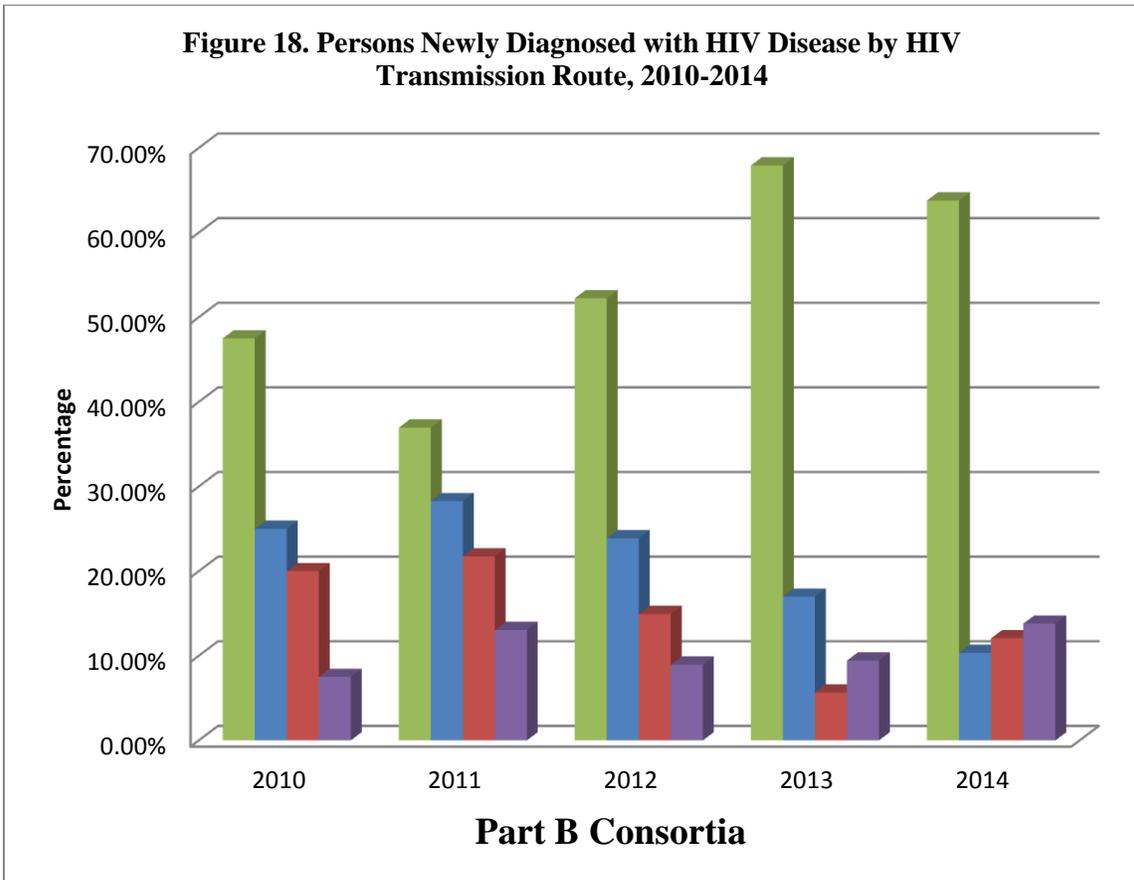
**HIV Transmission Route**

In 2014, the highest number of new HIV diagnoses occurred among the group MSM (63.4%) (Figure 17). “Other” HIV transmission route accounted for 13.8%, heterosexual transmission was 12%, and ‘No risk’ reported categories were 10.3.



**Figure 17: New HIV Diagnosis by Transmission Type; 2010 to 2014.**

With regard to 5-year trends in HIV incidence (Figure 18), the MSM transmission route has remained the most common route of infection, increasing from 47.5% to 63.8% with some fluctuation during the period. Concurrently, the proportion of persons reporting unknown or no HIV risk increased in 2011 and decreased in 2014, possibly reflecting more successful efforts by public health staff to obtain information from clients or increased comfort among clients to disclose their HIV risk behaviors. Heterosexual transmission accounted for 20% in 2010 decreasing to 12% in 2014, whereas the proportions among persons reporting IDU and both MSM/IDU remained low.



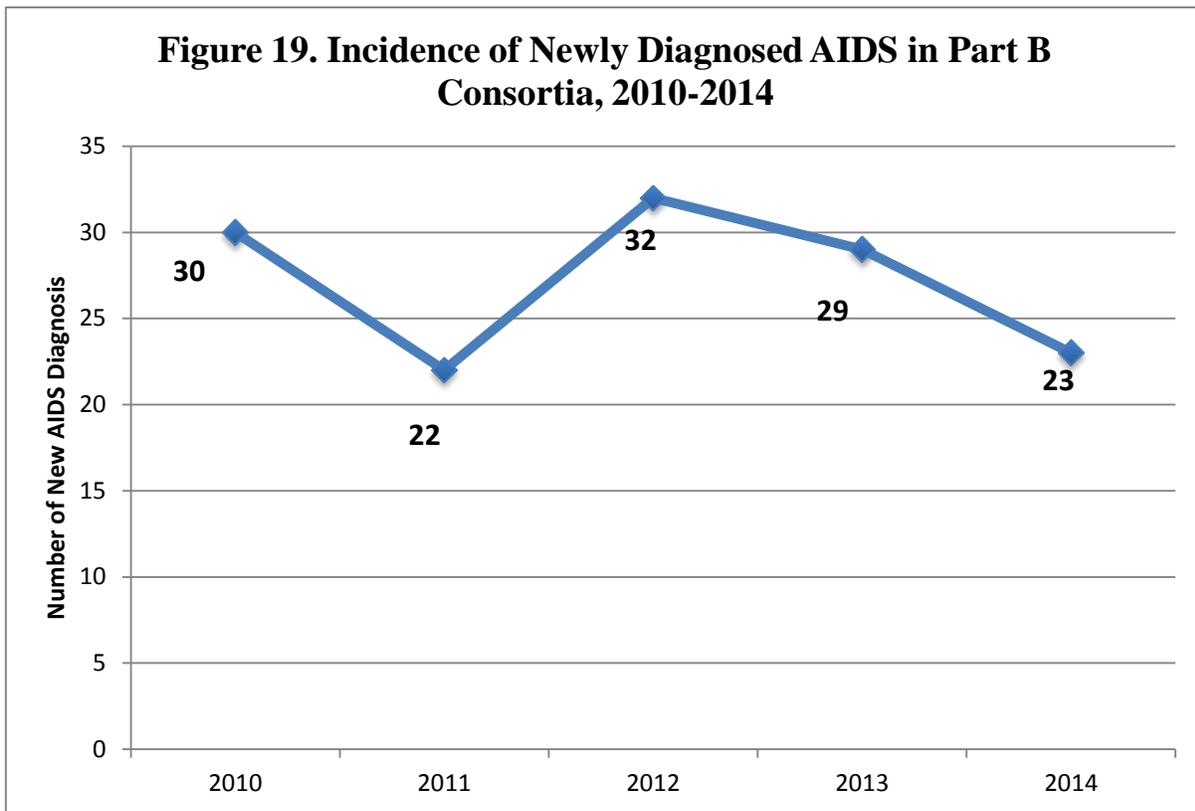
**Figure 18: Persons Newly Diagnosed with HIV Disease by Transmission Route, 2010 to 2014.**

**AIDS**

The annual incidence of new AIDS diagnosis within the Part B Consortium fluctuated between the years 2010 to 2014 (Figure 19) for a total of 136 persons being newly diagnosed with AIDS over this period. The distribution of new AIDS diagnoses within the Part B sub-regions included 30% in MCR, 40% in SCR, and 30% in UCR. With regards to 2014 year incidence, 29% of persons with newly diagnosed AIDS were ages 25 to 34 years old and 29% were ages 45 -54 years. 8.8% were reported as 55 to 64 years and 6.6% were reported as 15 to 24%.

**AIDS**

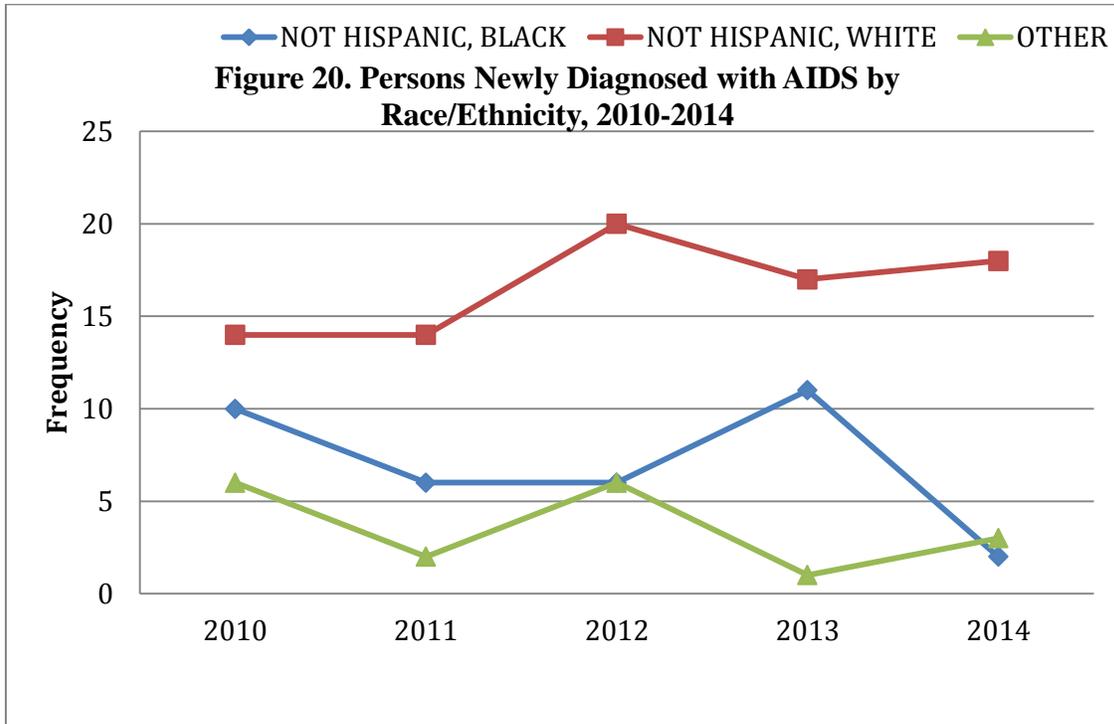
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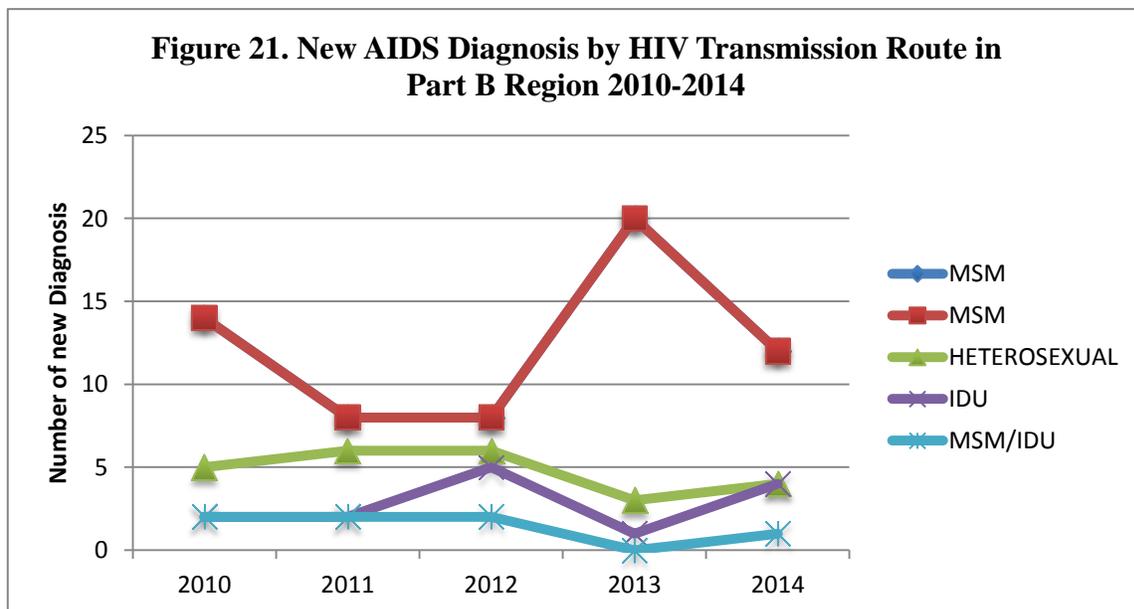
**Figure 19: Incidence of Newly Diagnosed AIDS in Part B Consortia 2010 – 2014.**

More than half occurred among non-Hispanic whites (61%). Less than a third (26% Blacks) occurred among non-Hispanic minorities and 11% among Hispanic minorities, with more than half among males (74%). HIV transmission through MSM accounted for 45.5% of new AIDS diagnoses over the five year period with heterosexual route of transmission accounting for 17.6% with IDU transmission accounting for 10.3% and IDU/MSM accounting for 5.1%.

Similar to trends related to HIV incidence, new AIDS diagnosis has increased overall among non-Hispanic whites and among non-Hispanic blacks (Figure 20). The number of Hispanics remained near or below 20% of the new cases from 2010 to 2014, though total numbers were consistently too small to draw meaningful conclusions. Among transmission categories, the proportion has been highest among MSM (46% to 45%, Figure 21.) There was an overall decreasing trend among heterosexuals and persons reporting “other risk” despite some fluctuation. The number of persons in the remaining categories remained relatively low.



**Figure 20. Persons Newly Diagnosed with AIDS by Race/Ethnicity, 2010-2014**



**Figure 21. New AIDS Diagnosis by HIV Transmission Route in Part B Region 2010-2014**

## **VI. 2015 CHAP CLIENT SURVEY**

### **Methods and Data**

The Institutional Review Board (IRB) at Tennessee State University approved the application to conduct the research project in July 2015. The CHAP Client Survey was distributed via mail to the clients in the Part B service area by the United Way in July and August 2015. The survey was distributed with a very short turn-around time period. Specific questions on the 2015 Client Survey focused on the following:

- Socio-demographic description of respondents (with response categories matching the Ryan White Services Face Sheet)
- Receipt of HIV medical care
- Use of HIV non-medical services
- Challenges and facilitators to accessing/using medical and support services
- Provision of and adherence to anti-retroviral therapy (ART)
- Sources of HIV information
- Met and unmet HIV medical and non-medical service needs
- Questions about discrimination and stigma surrounding the transgendered population, which are critical in impacting the Cascade of Care and the HIV disease (Reif, et al., 2014)

The respondents were asked the following questions:

### **SERVICE AVAILABILITY, UTILIZATION, ACCESS**

1. Are you currently accessing HIV/AIDS medical care and/or support services?
2. What agencies or types of services are you currently obtaining services from? (For example, AIDS service providers, community-based organizations providing social services, neighborhood clinics, hospitals, etc.)
3. What are the most important HIV-related services/care you are using now or have used in the last year? (Prompt: medical care, perinatal services, case management, transportation, mental health, substance abuse counseling, support groups, etc.)
4. Have you ever not accessed care for a period of 12 months or more? If yes....
  - a. What caused you to stop accessing care?
  - b. What could have kept you in care?
  - c. What made you want to access care again?

### **SATISFACTION WITH SERVICES/QUALITY OF SERVICES**

5. What services are you most satisfied with in the current system of care and why?  
(Prompt: medical care, case management, transportation, mental health, substance abuse counseling, support groups, etc.) Why/why not?
6. What services are you least satisfied with in the current system of care and why?  
(Prompt: medical care, case management, transportation, mental health, substance abuse counseling, support groups, etc.) Why/why not?
7. If you could change one thing in the HIV/AIDS system of care what would it be?
8. Are there any services you need but can't get or aren't offered in your area?

### **BARRIERS**

9. Are there any barriers that you have experienced while trying to access services in your community?  
Probe: (unhelpful attitudes, behaviors, travel a great distance to receive service, transportation problems, inconvenient hours of operation, having to pay a fee for services, unmanageable waiting time to get an appointment or to see a provider once you are there, hassle by staff or other clients, child care, language/cultural barriers)
10. Are there instances when you have felt particularly unwelcome, uncomfortable, discriminated against at an agency?

### **UNMET NEED**

11. What services or care do you need, but are unable to get?  
Probe: (transportation, food, coordinated appointment schedules, prescription Drugs/medication, insurance coverage, benefits.)
12. What concerns do you have about getting services or care for you in the future?

Data from returned surveys were entered into the Statistical Package for the Social Sciences (SPSS) database. The dataset was then analyzed. The survey questions were analyzed individually. Some respondents did not answer every question on the survey, and thus missing data varied for each question. Percentages were calculated as frequencies. The results provided were the findings from the data collected and entered into SPSS. The percentages have appeared to be identical to the previous study in 2014, however the numbers can be completely different. As verified by the statistician,

percentages/rates should not change significantly across one year unless there has been an epidemic or outbreak.

## **2015 CHAP Client Survey Results**

### **CHAP Client Survey Respondents**

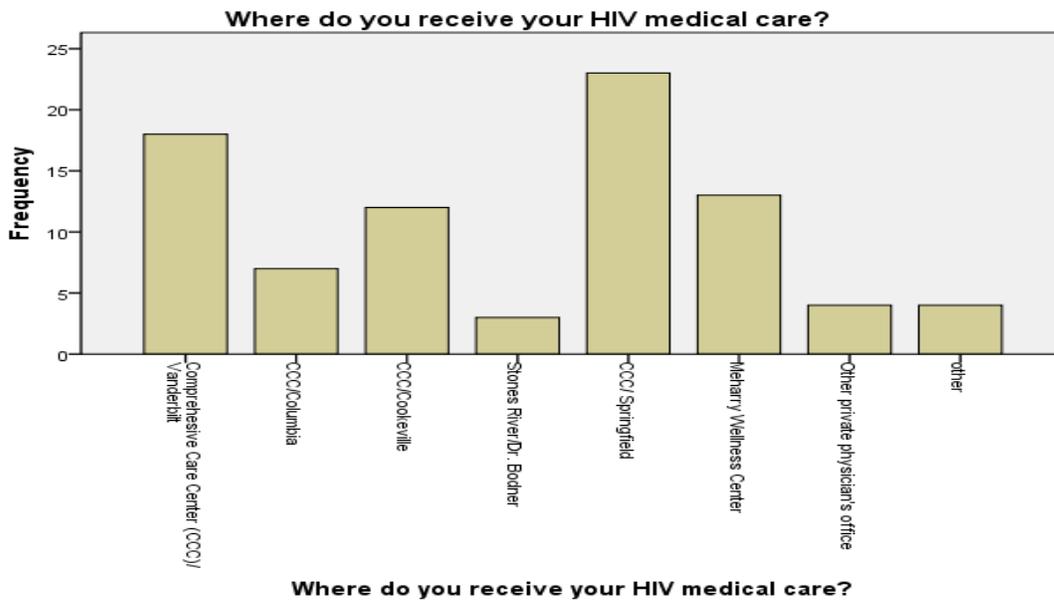
Eighty-nine HIV positive participants voluntarily completed and returned the Client Surveys. Of the 89 participants 39 (43.8%) were from MCR, 12 (13.5%) were from SCR, 20 (22.5%) were from UCR, and 16 (18%) were from the TGA.

The characteristics of the survey respondents are listed in Appendix Table 4. Respondents were predominantly male (71.9%), English-speaking (96.6%) and born in the U.S. (94.4%). Their ages ranged from 20 to 74 years of age, with a median of 46 years. Whites represented the majority of people completing the survey (56.2%), followed by blacks (40.4%), and Hispanics (1.1%). Most respondents reported their sexual orientation as heterosexual/straight (39.3%), whereas bisexual orientation was less common (5.6%), and two (2.2%) reported self-reported as transgendered. When asked about how the participants thought they were likely infected with HIV, most reported through MSM contact (61.8%), heterosexual contact (9.0%), and IDU (7.9%). Few reported transmission through MSM/IDU (2.2%) or receipt of transfusion with blood products (2.2%). Over ten percent (10.1%) reported “unknown” or “other” route. Among survey respondents, most (89.0%) were diagnosed with HIV disease for more than 2 years and more than one third (39.0%) reported they had been diagnosed with AIDS, which remained the same from the 2014 Needs Assessment findings.

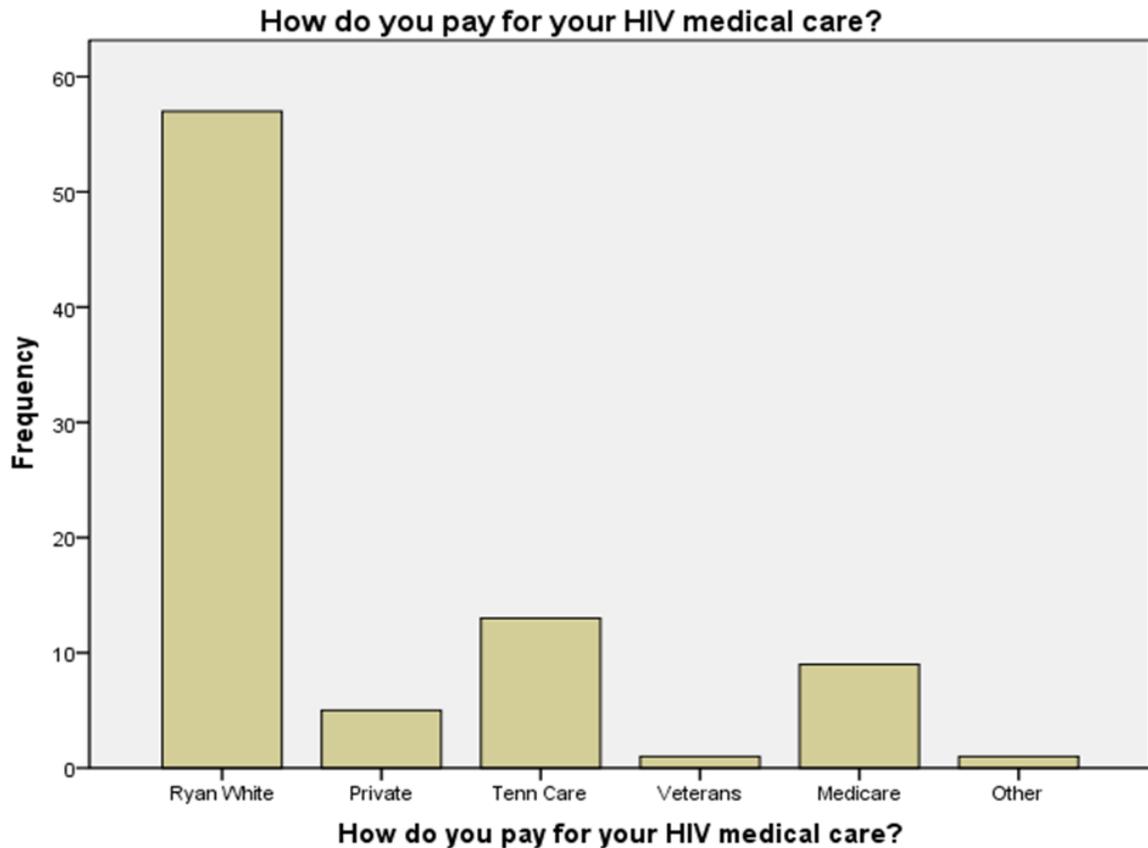
Other findings, from the Client Survey, were that only 14 (15.7%) self-reported using illegal drugs in the past year; 13 (14.6%) self-reported as being homeless in the past year; nine percent (9.0%) self-reported as having been in jail or prison in the past year. While 82.1% of respondents completed vocational, some high school, or at least some college education, 15.7% did not complete high school.

### **HIV Medical Services**

Among Part B Client Survey respondents, most received care at the Vanderbilt Comprehensive Care Center (VCCC) or one of its satellite clinics in Springfield, Columbia, or Cookeville (Figure 22). Few indicated they receive care at private physician’s offices or the Meharry Wellness Center. Participants self-reported receiving medical care from doctors not located in Tennessee, and from Chattanooga Cares. Most respondents reported that they pay for their medical care through one or more federal funding sources, including Ryan White, Veterans (VA), Medicare, and TennCare. Few reported using private insurance (Figure 23).



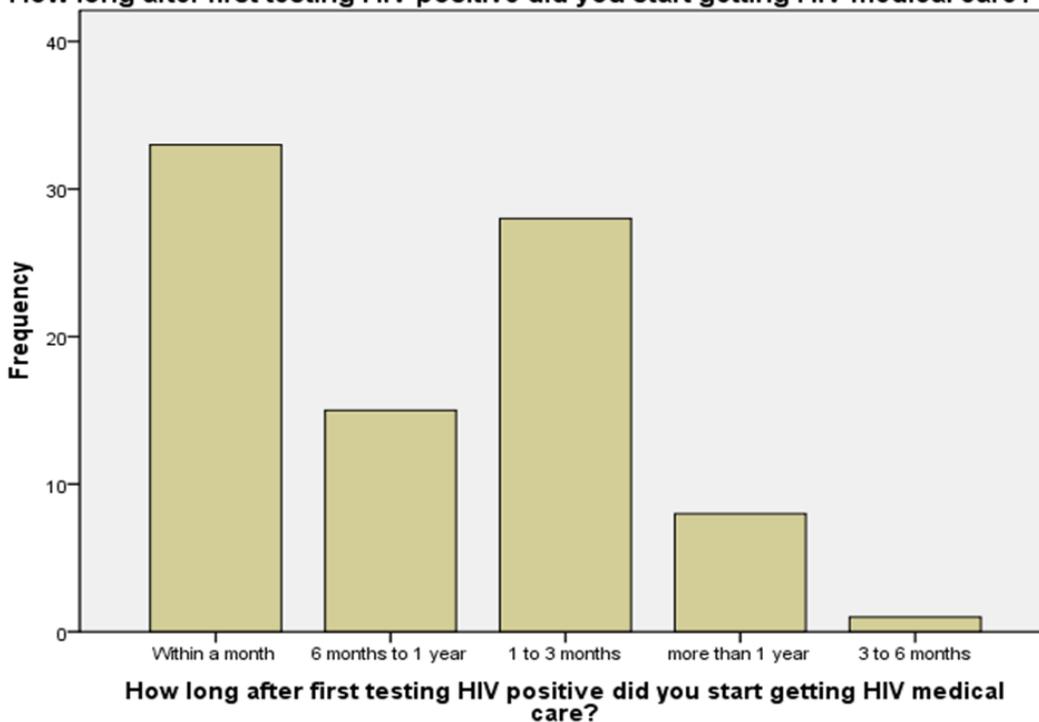
**Figure 22. Where Do You Receive HIV Medical Care?**



**Figure 23. How Do You Pay for Your HIV Medical Care?**

When survey participants were asked how soon after diagnosis they first linked to HIV medical care, the majority (68.5%) reported within 1-3 months, while 25.9% reported waiting 6 months to more than a year to seek medical care after first testing HIV positive (Figure 24). Challenges that impact early HIV care seeking are listed in Table 5 below. As identified in the limitations of the study, the finding of a high linkage to care rate should be considered to determine who are less likely to seek care when needed, which is directly related to the Cascade of Care (Kilmarx, P.H., & Mutasa-Apollo, 2013; and Konkle-Parker, Erlen, & Dubbert, 2010).

**How long after first testing HIV positive did you start getting HIV medical care?**



**Figure 24. How Long After First Testing HIV Positive Did You Start Getting HIV Medical Care?**

**Table 5. What Reasons Kept You from Seeing Your HIV Medical Provider?**

	Frequency	Percentage
I was afraid someone would learn I have HIV	5	5.6%
I was worried about how I would pay for my care	5	5.6%
I didn't have transportation	5	5.6%
I didn't know where to get HIV medical care	3	3.4%
I was not comfortable with the HIV provider	3	3.4%
I use drugs or alcohol	3	3.4%
I was in jail or prison	1	1.1%
I was not ready to deal with HIV/AIDS	5	5.6%
I felt too sad or worried to go to an HIV provider	3	3.4%
I was homeless/no stable place to live	5	5.6%
I have to take care of others	1	1.1%
I worry more about getting food or work	2	2.2%

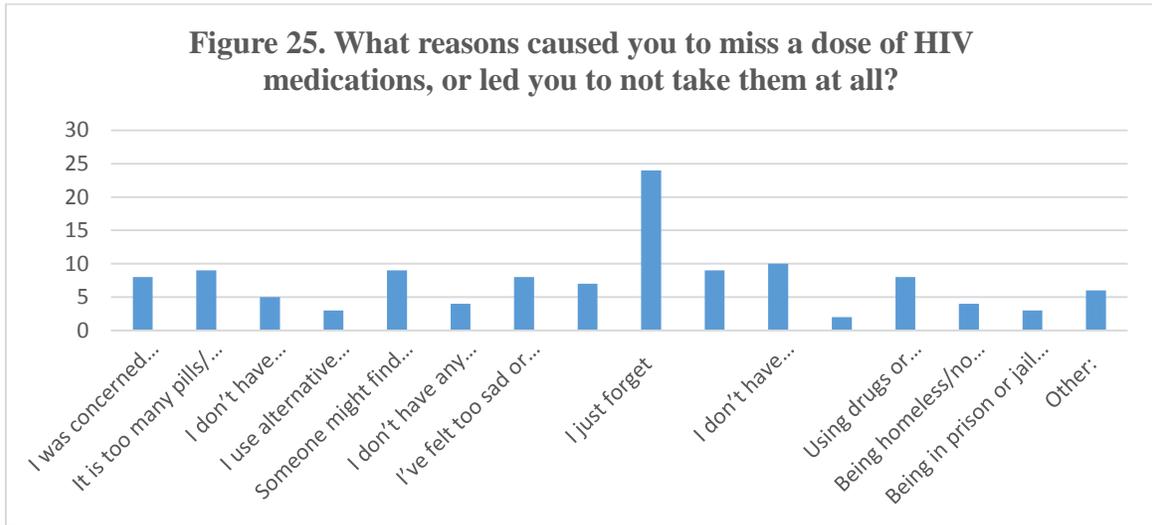
Note: This question allowed respondents to select more than one answer.

Over 80% (84.3%) of the Client Survey respondents self-reported they had received care within the last year, and most had received care within the last 6 months (Table 6). Although, the majority of the respondents self-reported receiving medical care in the last six months to a year, 15.8% either reported as not receiving medical care or not providing any information.

**Table 6. When was the last time you saw your HIV Medical Provider?**

	Frequency	Percent
Never	1	1%
Within 6-12 months	11	13%
Within the last 3 months	56	64%
Within 3-6 months	19	22%
Total	87	100%

Most respondents also reported currently being prescribed combination ART (95.5%), and self-reported adherence was high. Twenty-four (27%) self-reported they just forgot to take their HIV medication. Adherence is important for long-term positive health outcomes, according to Konkle-Parker, Erlen, & Dubbert (2010). Reasons individuals might have missed taking their HIV medications are displayed in Figure 25.



Factors listed as influencing why individuals might not seek medical care from an HIV provider in more than a year are listed in Table 7. When survey respondents were asked who gave them the most information about HIV medical care and treatment, individuals self-reported receiving the most information from health facilities, such as providers (73%), case manager or social workers (9%), and other health care workers like nurses (4.5%) (Table 7). Support groups (3.4%), friends (2.2%), the Internet (1.1%) and other sources (3.4%) were identified as information sources.

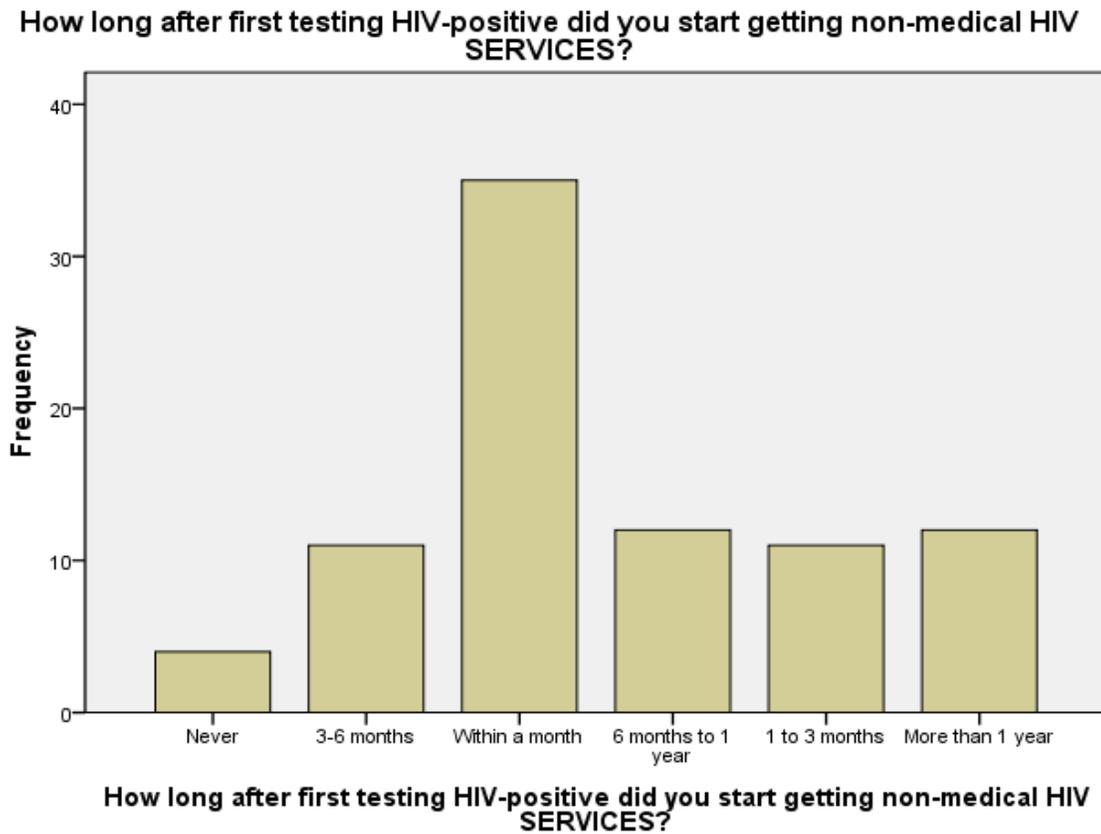
**Table 7. Who gave you the most information about HIV medical care and treatment?**

<b>Source of Information</b>	<b>Frequency</b>	<b>Percent</b>
Doctor/Nurse Practitioner	65	73.0
Case Manager/Social Worker	8	9.0
Nurse/Other healthcare worker	4	4.5
Support Groups	3	3.4
Other	3	3.4
Friends	2	2.2
Internet	1	1.1
Missing	3	3.4
<b>Total</b>	<b>100</b>	<b>100.00</b>

**HIV Non-Medical Support Services**

Among 89 respondents, 75 (84.3%) have seen their HIV medical provider at least twice in the past year. The majority of respondents (77.6%) self-reported after being diagnosed as accessing non-medical services. Over thirty-five percent (39.3%) first accessed HIV non-medical services within one month of initial HIV diagnosis, 24.8% first accessed those services between 3 and 12 months after diagnosis, and 13.5% delayed more than 1 year to access non-medical services (Figure 27). Lack of transportation was cited as the most common barrier to accessing HIV services (Table 8).

**Figure 27. How Long After First Testing HIV-Positive Did You Start Accessing Non-Medical HIV Services?**



**Table 8. During the past YEAR, have you had any difficulty getting HIV services for the following reasons?**

	<b>Number of Respondents</b>	<b>Percentages</b>
No transportation to HIV services	13	14.6%
I did not know where to go for HIV non-medical services	19	21.3%
Cost of HIV services/ did not qualify for assistance	11	12.4%
I worry about getting food/spend my time making sure I/my family can eat	4	4.5%
HIV service providers were not convenient (location, long wait time)	7	7.9%
I was afraid of discrimination because of my race/ethnicity	3	3.4%
I was afraid someone would learn I have HIV	11	12.4%
I had to take care of others (children, others with HIV, etc.)	2	2.2%
I was afraid of discrimination because of my sexual identity	5	5.6%
I have been in prison or jail	2	2.2%
I am homeless/no regular place to live	2	2.2%

Note: This question allowed respondents to select more than one answer.

**HIV Non-Medical Service Needs**

Respondents were asked which three services already provided through Ryan White Part B they considered most important and which three not currently provided are most important. The top services currently offered were (1) non-medical case management, (2) Psychosocial support, and (3) transportation (Table 9).

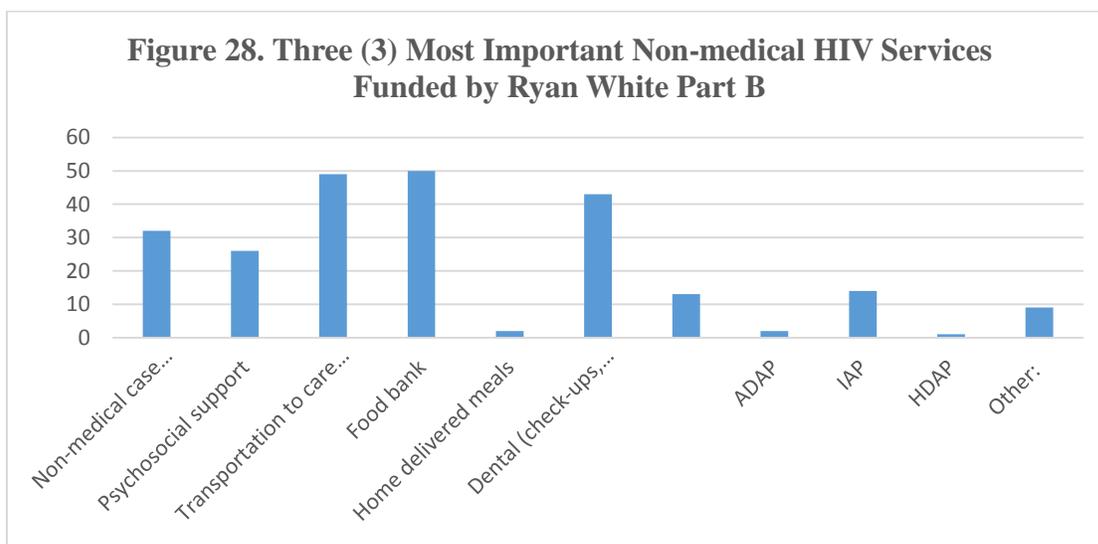
**Table 9. Most Important Non-Medical Services Currently Offered**

	No. (%) Respondents		Rank
Non-medical case management	32	36%	1
Psychosocial support	29	18%	2
Transportation	39	24%	3

The top services not currently offered were (1) eye care, (2) support groups, and (3) rent/utility assistance (Table 10). Other currently offered services that are considered as important were having a food bank, receiving home delivered meals, dental services, and IAP as evidenced in Figure 28.

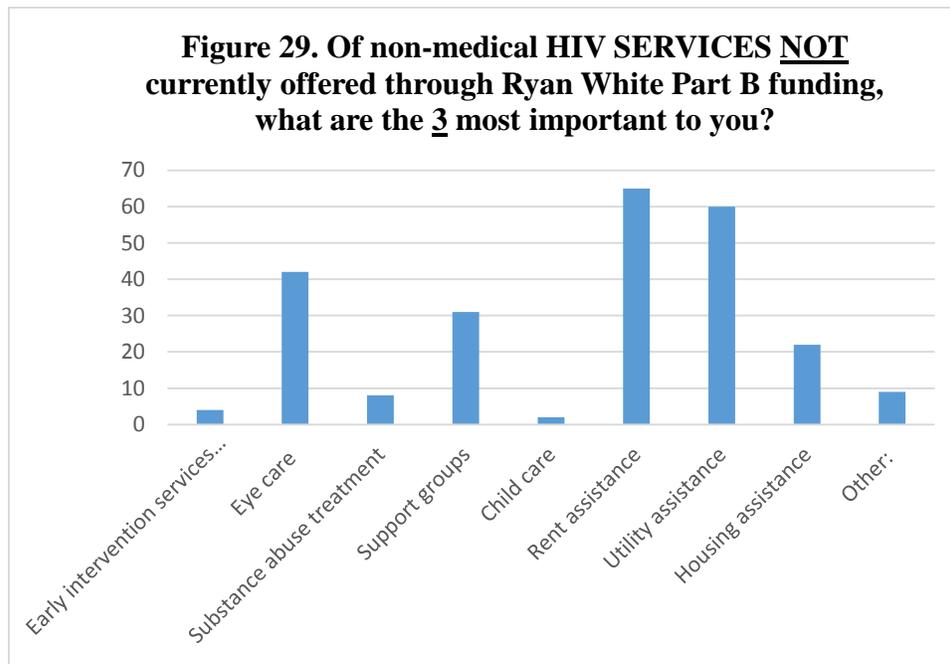
**Table 10. Most Important Non-Medical Services Not Currently Offered**

	No. (%) Respondents		Rank
Eye Care	39	43.8%	1
Support Groups	17	19.1%	2
Rent/Utility Assistance	17	19.1%	3



**Figure 28. Three (3) Most Important Non-medical HIV Services Funded by Ryan White Part B**

Other non-medical HIV Services not currently offered through Ryan White Part B funding that were identified as most important included Early Intervention Services (EIS), substance abuse treatment, child care, and other (i.e. food cards, gas cards, housing assistance, transportation, and not applicable). The rankings are depicted graphically in Figure 29.



**Figure 29. The Most Important Non-Medical HIV Services Currently Not Offered Through Ryan White Part B Funding**

Any respondent self-identifying as transgendered was asked new questions related to stigma and discrimination. According to Macapagal, & et al., (2014); Reif, et al., (2014), clients and health professionals are benefitted by enhanced awareness and improved training to mitigate negative attitudes and negative behavior toward HIV/AIDS patients and exhibited by health professionals. Of the two respondents identifying as transgendered, one (1.1%) self-reported worrying that behaviors will be judged or viewed stereotypically. At the time of this survey, the transgendered individuals did not self-report instances of discrimination or perception of being treated unfairly.

The respondents (N=45, 50.6%) self-reported needing help from someone to deal with sadness, stress, or other emotional issues in the last year. Eighteen respondents (20.2%) self-reported needing to speak to a member of the clergy or a pastor in the last year.

## Cascade of Care/Continuum of Care

The Cascade of Care is a set of steps and measures that may be used to assess HIV/AIDS prevention initiatives by determining a client's plan of care from diagnosis to acquiring viral suppression. The State of Tennessee used the CDC's guidelines to develop baseline objectives to accomplish in the continuum. Definitions were created using the CDC's guidelines, located in a Tennessee Department of Health 2010 White Paper as follows:

**Diagnosed:** Persons diagnosed with HIV infection.

**Linked to Care:** Persons newly diagnosed with HIV infection in Tennessee, who sought medical care within three months after the initial diagnosis.

**Retained in Care:** Persons diagnosed with HIV infection who sought medical treatment at least two times within a three month period on an annual basis.

**Achieved Viral Suppression:** Persons diagnosed with HIV infection who achieved HIV viral suppression.

Although, research findings showed that the majority of the clients are compliant in seeking medical care and follow-up treatment with the continuum of care, there are challenges to overcome as long as barriers exist for accessing health care.

## **VII. Needs Assessment/Focus Group**

The 2015 Ryan White Part B Funding mandated a focus group be completed as a component of the funding requirements. The PHHAHS research team in collaboration with the United Way of Metropolitan Nashville and CHAP updated the Client Survey, modified the Focus Group Survey items, scheduled the Focus Group sessions, and provided the incentive gift cards for the voluntary participants.

A focus group is a type of qualitative research method. The focus group requires interviewing the willing participants. The identified participants are considered a sample of convenience, because the participants are not randomly selected. Focus groups are used in qualitative studies to obtain meaningful data on a particular issue or problem. Therefore, this study was targeted to glean whether there are gaps in medical care, services, and resources in the Part B consortium.

There were a total of 54 people that volunteered to participate in the study. The focus group sessions were conducted over three days in July and August 2015. Sessions took place on July 30, 2015 in Clarksville, TN at the Trinity United Methodist Church (Nashville CARES HIV/AIDS Support Group); on August 6, 2015 in Columbia, TN at the Riverside United Methodist Church (Columbia CARES HIV/AIDS Male Support Group), and on August 7, 2015 in Cookeville, TN at the Upper Cumberland Regional Health Center HIV/AIDS Support Group). All participants were part of a convenient

sample. Therefore, the research team could only collect data on the participants attending the support group on the assigned date. The focus groups were conducted in two hour sessions each day. Informed consent was obtained from all participants. All data collected were anonymous and the demographic quantitative data were collected before the focus group session began. A 12-item focus group questionnaire was used to gather information and feedback. Permission was obtained from the volunteer subjects. Confidentiality statements and full-disclosure were read to the subjects. The ice-breaker was conducted and the two-hour sessions began.

From the three focus group sites, 54 people participated in the sessions. There were 32 participants in the Clarksville group, 16 in the Columbia group, and 6 participants in Cookeville. Forty males and 14 females participated in the focus groups. The average age of the participants was 50 years. The lowest person's age was 27 years and the older person was 59 years of age. Race was reported as:

- 36-Caucasian/White (Not-Hispanic)
- 16-African American/Black
- 2-American Indian

The respondents self-identified as either homosexual, heterosexual, bisexual, transgendered, or other. Of the focus group participants, 32 (36%) self-identified as 'homosexual' (MSM). Of the focus group participants, 16 (18%) self-identified as 'heterosexual' (straight). Of the focus group participants, 4(4.5%) self-identified as 'bisexual'. Two (2.2%) focus group participants self-identified as 'other (non-specified)'. None of the focus group participants self-identified as transgender.

Forty-four respondents self-reported having sex with a man (MSM) was the most likely way they were infected with HIV/AIDS. Two self-reported having sex with a women was the most likely way they were infected with HIV/AIDS. Two self-reported having sex with someone who shares needles was the most likely way they were infected with HIV/AIDS. Four group participants self-reported "other (oral sex)" was the most likely way they were infected with HIV/AIDS.

## **Themes**

Common themes were found from the focus group data using the qualitative software Atlas.ti7. The main themes were derived from the 12-item questionnaire. The themes were service availability, utilization, access, satisfaction with services, and quality of services, barriers, and unmet need. The main items listed under service availability were dental, Nashville CARES, Vanderbilt Comprehensive Care Center (CCC), and local health departments. An insurance subtheme was determined under service availability. The participants self-reported that they were currently obtaining services from the Insurance Assistant Program (IAP). One overarching response from the focus group was:

*“Comprehensive care center. They've been there for me since the beginning of time, until I started trusting my doctors. The ones that were people persons and not looking at me uh say like a person with a disease. That made things better. They are helpful.”*

The feedback responses for the utilization theme included support groups, mental health services, dental services, and utilization of available transportation as the most important HIV related services/care you are using now or have used in the last year. Responses from the Columbia Cares' focus group were:

*“Support Group, Columbia Cares, Nashville C.A.R.E.S, Ryan White Insurance and Dental Program.” Response 2: “Ours through the Health Department (Maury County Health Department)”*

Under the access theme, respondents self-reported experiencing financial difficulties (i.e. no insurance, signing up for insurance/waiting period, no income, relocation costs, cost of living changes, and lack of local resources [improved transportation]) as the reasons care was not accessed for 12 or more months. One response provided in a focus group sessions was:

*“Yes, I did not have insurance when I moved to Tennessee. Because I had no insurance, I had no medical care.”*

The feedback responses for satisfaction with services were Nashville Cares, pharmacy, private primary physicians, and the Vanderbilt Comprehensive Care Center (CCC). A response from the Cookeville focus group was:

*“We are very satisfied with the dental services and Walmart cards and gas cards provided to me from the UCHRA.”*

Under the satisfaction with quality of services' theme, respondents identified change in transportation services, recertification steps, and access to primary care as the things that would be changed if the clients were permitted. The same items were listed for services needed but cannot get or are not offered in your area. Responses regarding satisfaction with services are:

*“I don't have AIDS, but I've been sitting here and I've been listening to everybody I think they need some more doctors here.”*

*Response 2: Clarksville- “Lack of medical care, physicians, and quality of care with health facilities [Gateway].”*

*Response3: Cookeville - "The providers need more cultural competency training. They need more training provided to medical professionals about how to care for HIV/AIDS patients."*

Discriminatory practices and being discriminated against were listed as barriers to accessing services. A response from one of the focus group session was:

*"...the only helpful ones are the HIV/AIDS agencies...."*

Subthemes from the barrier theme were listed as being discriminated against for housing; discriminated against when on interviews for jobs; being discriminated against while on-the-job, and experiencing difficulty in being able to obtain a job. One response from the focus group was:

*Response: "I had a job in Nashville; let me explain something really quickly, and I had to quit because I had no housing and I was living at the mission and I was losing sleep and I had to quit that job. I stop my medication 2 months ago I want to get back on it I relocated here because someone offered to give me a helping hand. If it wasn't for Jim I wouldn't be setting here today because I would have taken my life. That is how low my life was and has been for the last seven months."*

The last identified theme was unmet need. Participants listed the following unmet needs: lack of local access to primary care, lack of transportation, nutritional needs not being met, unsure of resources, only having a nurse practitioner providing primary care services instead of a doctor, and the long waiting time to see nurses and doctors.

*Response: "My concern of issues happening for me to continue to better my health and in the future is my insurance stopping, because if my insurance stop I can't pay for Atripula (HIV medication). If my insurance stop I can't go to my doctor's visits every 6 months to check up on my viral load and my CD4 so insurance stopping, it's not being able to access the services that are at Nashville CARES, it's not being able to have Mr. Jim here twice a week. It's those things fading out and stopping. Because that is what is going to stop me from bettering my health for the future, so it's something of that nature for me."*

One unmet need subtheme from the Clarksville focus group session was indicated 'no food pantry was available in Clarksville.' A copy of the rough draft transcripts is available in the appendix section.

## **Limitations**

Some limitations of the research study are provided to assist with the interpretation of the findings. Because the survey was distributed among a convenient sample, the findings are not generalizable. Another limitation of the study was that the clients were not monitored while completing the survey. In addition, the survey was again distributed primarily through the main Part B Consortium community agencies; so that individuals who are not clients of these agencies as well as those not currently engaged in HIV medical care or services might not be aware of the opportunity to participate.

Two other limitations inherent to any survey likely add some degree of bias that should also be considered. First, responses are largely subjective and reflect the personal experiences and opinions of the survey respondents, and therefore might not represent those of the entire population of PLWH in the Part B Consortium area. Second, the potential pool of participants was limited to those individuals currently in medical care and the results cannot be generalized to all PLWAs other than those who completed the survey and volunteered for the focus groups.

Other limitations include challenges posed to the Continuum of Care. Challenges in linkage and retention include barriers due to the Ryan White eligibility requirements, issues of co-morbid care, transportation, mental health issues, and lack of access to services, stigma, discrimination, low income, food insecurity, and homelessness. Challenges for ART and viral suppression include fear of toxicity, cost, drugs for co-morbidities, and lack of education about benefits.

Additionally, limitations of the study were low response rates on the surveys, short promotion about the study, which affected the sample size. There is potential bias of the study, because of PLWH who are not yet diagnosed. The Epi data might be underestimated. Those that are undiagnosed or lost to care were unable to participate in the Client Survey. The Epi data and Client Survey were assessed in accordance with HRSA and TDOH guidance.

## VIII: Summary and Recommendations

### **General Recommendations:**

The fight to defeat HIV/AIDS is an ongoing effort globally, nationally, and in the State of Tennessee. The Tennessee Department of Health (2010) created goals for 2015 to increase access to care and improve the health outcomes for people living with HIV. The goals are:

- Reduce HIV transmission rate to 3.5 per 100,000
- Reduce late stage diagnosis (proportion of AIDS within one year of diagnosis) by 20%
- Increase proportion linked to HIV medical care within three months of diagnosis to 80%
- Increase proportion retained in HIV medical care to 64%
- Increase proportion achieving viral suppression to 51%

These goals are only achievable if the service and coverage gaps can be closed. Therefore, continued research is necessary to collect comparison data and build upon the established baseline studies.

### **National evidence-based recommendations supporting the fight against HIV/AIDS**

#### **1. Screening efforts should be improved**

- a. More studies should be conducted to determine community interest in alternative medical providers offering screenings and to evaluate potential barriers and facilitators to HIV screening in the community (Darin, Scarsi, Klepser, Klepser, Reeves, Young & Klepser, 2015; Grade ‘A’ USPSTF recommendation, 2013).
- b. Comprehensive guidelines to improve engagement in HIV care and services and ensure long-term retention in care and adherence to therapy have been published (Thompson, M.A., 2012; Chi, B.H., and Stringer, S.A. 2010).

#### **2. Creative strategies need to be developed in the South to address HIV**

- a. According to Reif, et. al., (2014) determined there is a disproportionate impact of HIV in the South (i.e. higher HIV diagnosis, prevalence rates, and greater HIV mortality).

In summary, the 2015 findings concur that CHAP and Part B Agencies should consider how improvement and the increase of medical and non-medical services might enhance the HIV care cascade, increasing individuals who are tested and learn their HIV status (social networks of those currently living with HIV), link HIV-positive persons to care soon after initial diagnosis, remain consistently in HIV care, accept and adhere to ART to achieve viral suppression. This will have a profound individual impact by decreasing morbidity and mortality, as well as a significant community impact through treatment as prevention of transmission to others.

## **Summary of specific findings and recommendations for CHAP and Part B-funded Agencies**

1. Focus interventions, funding and resource allocation on the following high **priority populations** identified through this Needs Assessment:
2. Prioritize resources (time, personnel, funding, services) to address the following specific barriers or challenges identified in the 2015 Client Survey:
  - Lack of transportation
  - Concern about how to pay for HIV care
  - Lack of awareness of importance of early treatment
  - Don't know where to get medical and non-medical services
  - Food insecurity, especially fresh foods (meat, produce, dairy products)
  - Concerns about discrimination and stigma
3. Maintain and increase assistance for currently covered entities such as transportation, routine dental services, food bank, non-medical case management, psychosocial support, and home delivered meals.
4. Provide new assistance for uncovered services (may require new funding sources), including rent, utilities, eye care, support groups, housing, early intervention services (EIS), and substance abuse treatment.

## IX. Provider Survey Results

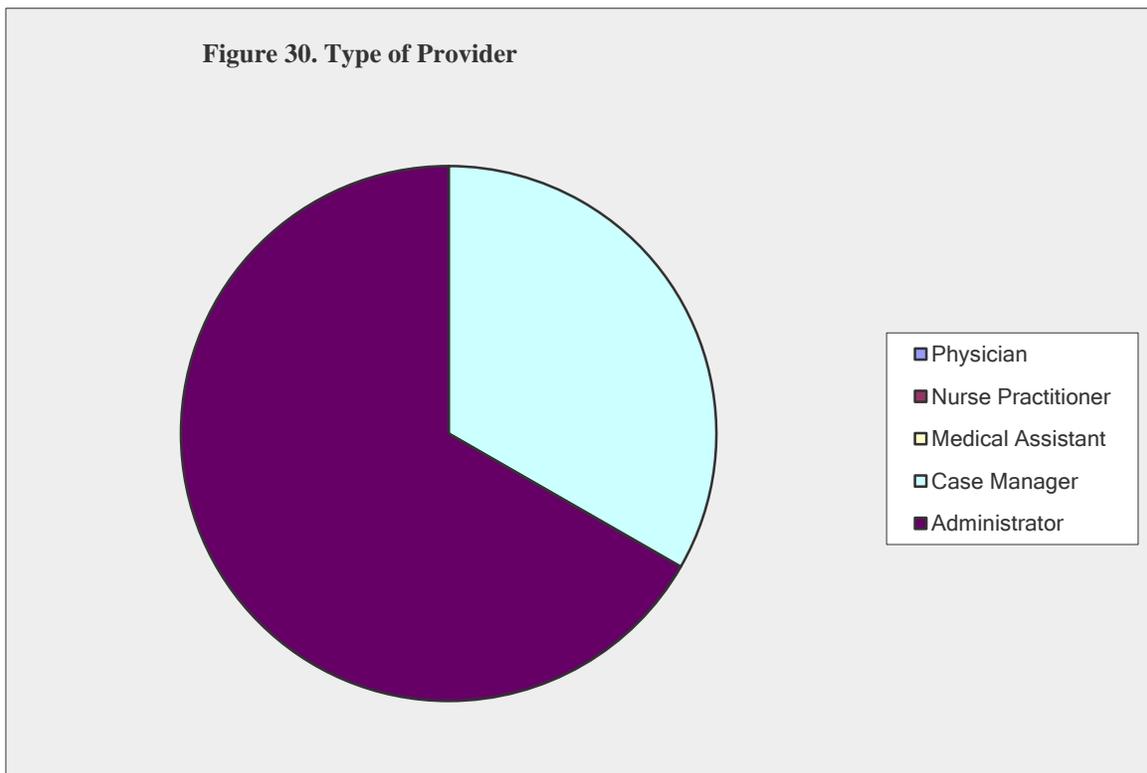
A new provider survey was developed to determine if there are gaps in service areas necessary for the comprehensive care of individuals diagnosed with HIV/AIDS and for their families. Determining the perceptions and attitudes of providers servicing the designated population, will contribute to enhanced customer service and possible improved services, from the feedback. The feedback could also help to build and promote growth of the service providers and patient relationships. Additionally, providers could improve communication skills to relate more effectively to impact quality of care and decisions of clients to utilize services or to remain with providers. Participating in the survey process gives you a voice in the planning for HIV and AIDS treatment services and assisting with the identification of gaps of service(s) throughout Tennessee.

The survey consisted of six questions as follows:

- 1) Please tell us which of the following describes you best:
  - a. Physician
  - b. Nurse Practitioner
  - c. Medical Assistant
  - d. Case Manager
  - e. Administrator
  - f. Other \_\_\_\_\_
- 2) Have you ever participated in any training related to HIV/AIDS stigma and discrimination?
  - a. Yes
  - b. No
- 3) Have you given health care service for Transgender persons living with HIV/AIDS in the last 6 months?
  - a. Yes
  - b. No
- 4) What additional resources and/or materials do you feel you need to provide services for Transgender persons living with HIV/AIDS?  
\_\_\_\_\_
- 5) What type of training do you feel you need to provide services for Transgender persons living with HIV/AIDS?  
\_\_\_\_\_
- 6) Do you fear contracting the HIV/AIDS virus?
  - a. Yes
  - b. No

The survey questions were loaded into Survey Monkey and a survey link was created. An introduction coversheet was prepared for the survey and the survey link created. The link was sent to the identified providers servicing the Part B Consortium. The survey was sent to more than 60 providers. Only nine providers participated in the survey, which is a very low response rate. Because the response rate was low, the results and findings are not generalizable for the purposes of the study. While the research is limited in generalizable findings, there was relevant information discovered from the nine respondents. The data was entered into an Excel Spreadsheet and analyzed using the same software. The information provided is demographic in nature. Only percentages and frequencies are provided.

Question one which inquired how the providers identified themselves, produced six (66.7%) self-reporting and identifying as administrators. Three (33.3%) respondents self-identified as case managers, and one self-identified as other as graphically depicted in Figure 30.



**Figure 30. Type of Provider**

Question two asked the providers if they had participated in any training related to HIV/AIDS stigma and discrimination. Eight (88.9%) self-reported having received training. One (11.1%) indicated no training had been received. The third question inquired as to whether the providers had provided health care to transgendered persons living with HIV/AIDS in the previous six months. Four (44.4%) providers had cared for transgendered patients. Five (55.6%) respondents self-reported as not providing care to transgendered PLWHAs patients. The fourth and fifth questions were open-ended. Question four asked the respondents to provide the additional resources or materials needed to serve the transgendered population. Five respondents indicated the resources needed as follows:

1. *Training*
2. *Booklets*
3. *Information materials*
4. *Proper training*
5. *'I would like to know what resources are available in the community'*

The fifth item asked the respondents to provide feedback as to what type of training is felt to be needed to provide offer services to transgendered PLWHAs. Four providers responded as follows:

1. *Unsure*
2. *Cultural competency and HIV health related to transgender issues and how to deal with personally.*
3. *Cultural sensitivity and awareness relating to that population*
4. *'I do not feel I need additional training at this point'*

The last question reaped an interesting finding, because as the literature showed that stigma and discrimination continue to impede an effective response for treatment and care for PLWHA worldwide (Li, Wu, Wu, Zhaoc, Jia, & Yan, 2009). In question six providers were asked if they feared contracting the HIV/AIDS virus, where eight (88.9%) responded no to being fearful of HIV/AIDS contraction. However, one (11.1%) indicated being afraid of contracting HIV/AIDS from providing care. The findings confirm the recommendation by Torabi (2000), regarding the need to continue to educate physicians, conduct more research on physicians' knowledge, attitudes, and practices of HIV/AIDS, and the trends monitored.

## X. Resource Audit

A resource audit was conducted on the services provided to and for the PLWHA in the Part B consortium. The resource audit was conducted to assess the services offered to PLWHA clients and patients residing in the 26 counties of the Part B Consortium. The data entered into an Excel spreadsheet was used to assess the services. The information was used to compile a comprehensive guidebook containing listings of available resources and services in the 26 county area.

Overall, more than 2,000 services are provided in the 26 counties. The counties offering the most services are listed alphabetically as follows: Bedford, Coffee, Cumberland, DeKalb, Lawrence, Marshall, Maury, and Montgomery. Counties offering the least amount of services are Houston, Moore, Perry, and Stewart. The resource audit presented findings confirming the focus group respondents' indication of service gaps in some counties. Data were entered by county with the agencies coded by the type of services offered. The counties' service agencies offering more than n=13 ( $\geq 50\%$ ) of HIV/AIDS resources were as follows listed alphabetically:

- Abuse counseling - 13
- Adolescent youth counseling – 18
- Career development – 15
- Child care expense assistance – 18
- Child health and disability prevention exams – 24
- Children's protective services – 18
- Commodity supplemental food program – 25
- Community economic development – 18
- Community mental health agencies – 14
- Comprehensive job assistance – 14
- Congregate meals – 13
- Cooking (extension offices) – 22
- Donated specialty – 15
- Elections – 29
- Families with children counseling – 15
- Food pantries – 33
- Food production support – 24
- Food stamps – 23
- Formula/baby food – 26
- Foster homes for dependent children – 15
- GED/High school and local schools – 38
- General clothing provisions – 14
- General counseling services – 23
- General medical care – 21
- General paratransit – 15

- Group counseling – 14
- Home barrier evaluations – 15
- Home delivered meals – 13
- Home health care – 16
- Home management instruction – 21
- Homemaker assistance – 30
- Hospice care – 14
- Immunizations – 15
- Individual counseling – 14
- Intensive family reunification services – 27
- Job search/placement – 31
- Job training formats – 22
- Juvenile detention facilities – 13
- Marriage counseling – 16
- Motor vehicle registration – 13
- Multipurpose centers – 16
- Municipal police departments and sheriffs – 54
- Neonatal care – 22
- Nutrition education – 38
- Parenting programs – 43
- Peer-to-peer networking – 17
- Personal care – 15
- Physical therapy – 14
- Post-partum care – 22
- Pre-job guidance – 29
- Psychiatric services – 29
- Public official offices – 16
- Social Security Services – 13
- Substance abuse programs – 19
- Residential treatment facilities – 13
- TANF (Families First) – 24
- Tax collection and tax information – 18
- Utility service payment – 42
- Vocational program – 25
- Welfare to work - 20
- WIC – 25
- Youth agricultural programs – 24
- Youth programs – 16

Out of those services coded for offering the majority of resources, there are several services that are limited in the 26 counties. The focus group respondents further confirmed the services that are lacking in the provider area. The limited services are childcare providers, dentists, disability services, domestic violence interventions, expectant mother programs, health insurance providers, HIV/AIDS testing/screening sites, homeless shelters, medical care, local transportation, safer sex education, services for sexual assault (see Table 11), suicide prevention, transit to health care, tuberculosis screening sites, unemployment insurance, veterans' assistance, VITA programs, and worker's compensation assistance.

**Table 11. Sexual Assault Services by County**

<b>County</b>	<b>Agency</b>	<b>Service Code Category</b>
Bedford	Centerstone - Bedford County - Shelbyville - Sexual Abuse Treatment	Sexual Assault Counseling
Coffee	Centerstone - Coffee County - Tullahoma - Sexual Abuse Treatment	Sexual Assault Counseling
Cumberland	Avalon Center - Domestic Violence / Sexual Assault Survivor Counseling	Sexual Assault Counseling
Giles	Centerstone - Giles County - Pulaski - Sexual Abuse Treatment	Sexual Assault Counseling
Lawrence	Centerstone - Lawrence County - Lawrenceburg - Sexual Abuse Treatment & Kids Place	Sexual Assault Counseling
Lewis	Centerstone - Lewis County - Hohenwald - Sexual Abuse Treatment	Sexual Assault Counseling
Lincoln	Centerstone - Lincoln County - Fayetteville - Sexual Abuse Treatment	Sexual Assault Counseling
Marshall	Centerstone - Marshall County - Lewisburg - Sexual Abuse Treatment	Sexual Assault Counseling
Maury	Centerstone Associates - Maury County - Columbia - Sexual Abuse Treatment	Sexual Assault Counseling
Putnam	Upper Cumberland Child Advocacy Center - Child Abuse / Trauma Counseling and Genesis House	Sexual Assault Counseling
Warren	Children's Advocacy Center - Warren & Van Buren Counties - Forensic Interviews	Sexual Assault Counseling
Wayne	Centerstone - Wayne County - Waynesboro - Sexual Abuse Treatment	Sexual Assault Counseling
Cumberland	Avalon Center - Crisis Intervention	Sexual Assault Hotlines
Putnam	Genesis House, Inc. - Domestic Violence Hotline	Sexual Assault Hotlines
Maury	Maury County Center Against Domestic Violence - Domestic Violence and Sexual Assault Shelter	Sexual Assault Shelters
Lawrence	A Kid's Place - Child Advocacy Center	Sexual Assault Treatment
Montgomery	Montgomery County Child Advocacy Center - Our Kids Center	Sexual Assault Treatment

## **XI. Recommendations for the next CHAP Part B Needs Assessment**

1. Replicate the Provider Survey
2. Replicate the Client study more frequently than every three years.
3. Increase the Client and Provider Survey response rate.
4. Conduct a transportation study.
5. Conduct special studies to assess populations residing in Part B Consortium that are not currently well-defined, such as the incarcerated, homeless, substance abusers, people who identify as transgender, and veterans.
6. Define the impact of co-morbid medical conditions such as sexually transmitted infections, diabetes, cardiovascular disease, viral hepatitis, tuberculosis, etc. among persons residing in Part B Consortium counties.
7. Continue to coordinate needs assessment planning with the Ryan White Middle Tennessee TGA, community partners, academic institutions and TDOH so that collaborative interventions can be implemented to make the assessment process more effective, efficient and informative.

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<b>Table 1. Middle Tennessee Consortium Counties</b>			
<b>TGA Counties (N=13)</b>	<b>Part B Counties (N=26)</b>		
	<b>Mid-Cumberland Region</b>	<b>South Central Region</b>	<b>Upper Cumberland Region</b>
Cannon	Houston	Bedford	Clay
Cheatham	Humphreys	Coffee	Cumberland
Davidson	Montgomery	Giles	DeKalb
Dickson	Stewart	Lawrence	Fentress
Hickman		Lewis	Jackson
Macon		Lincoln	Overton
Robertson		Marshall	Pickett
Rutherford		Maury	Putnam
Smith		Moore	Van Buren
Sumner		Perry	Warren
Trousdale		Wayne	White
Williamson			
Wilson			

<b>Table 3. Prevalence of HIV Disease by HIV Transmission Route, 2009-2013</b>					
<b>Part B Counties</b>					
<b>HIV Transmission Route</b>	<b>2010</b>	<b>2011</b>	<b>2012</b>	<b>2013</b>	<b>2014</b>
MSM	47.9%	47.1%	47.4%	48.4%	48.1%
Heterosexual	19.1%	19.1%	19.0%	18.3%	18.9%
IDU	9.1%	9.4%	9.2%	9.0%	9.1%
MSM/IDU	5.3%	5.0%	4.8%	4.8%	6.6%
Pediatric <sup>†</sup>	1.2%	1.2%	1.1%	1.1%	.2%
Other risk <sup>‡</sup>	17.4%	18.2%	18.5%	18.5%	17.1%
<b>Total</b>	<b>100%</b>	<b>100%</b>	<b>100%</b>	<b>100%</b>	<b>100%</b>

<sup>†</sup>Pediatric category includes those <15y with a reported HIV transmission route of perinatal mother-to-child and those with no reported transmission route.

<sup>‡</sup>“Other risk” includes occupational exposure, recipient of transfusion with blood products, and no risk reported.

<b>Table 4. Comparison of 2014 and 2015 CHAP Client Survey Respondents</b>				
<b>Characteristic</b>	<b>2014 Client Survey Respondents</b>		<b>2015 Client Survey Respondents</b>	
	<b>N</b>	<b>%</b>	<b>N</b>	<b>%</b>
<b>Total</b>	164	100	89	100
<b>Race/Ethnicity</b>				
Non-Hispanic White*	106	65%	50	56.2%
Non-Hispanic Black	56	34%	36	40.4%
Latino/Hispanic	9	6%	1	1.1%
Other race/ethnicity <sup>†</sup>	7	5%	1	1.1%
<b>Sex</b>				
Male	108	66%	64	71.9%
Female	56	34%	22	24.7%
Transgender	0	0%	2	2.2%
<b>HIV Transmission Route</b>				
MSM	56	40%	55	61.8%
Heterosexual	52	32%	8	9.0%
IDU	11	9%	7	7.9%
MSM/IDU	3	2%	2	2.2%
Pediatric <sup>‡</sup>	1	<1%	0	0%
Other risk <sup>*</sup>	30	19%	17	19%

NR=Not reported.  
<sup>\*</sup>The survey asked individuals to self-report race and ethnicity separately from race. Individuals who marked “Hispanic/Latino” ethnicity were included only in that category (all of those individuals also considered themselves “white”).  
<sup>†</sup>“Other race/ethnicity” includes Native American/Alaskan Indian, Asian, Pacific Islander/Native Hawaiian, and unknown.  
<sup>‡</sup>Pediatric category includes those <15y with a reported HIV transmission route of perinatal mother-to-child and those with no reported transmission route.  
<sup>\*</sup>“Other risk” includes occupational exposure, recipient of transfusion with blood products, and no risk reported.  
Note that survey respondents could report more than one transmission category and these data are based on self-report and not confirmed in eHARS.

## **APPENDIX: Focus Groups Transcripts**

Needs Assessment for HIV/AIDS

Clarksville, TN, Transcript Recording A

Data Collector- Kelsey Burton

Key

Interviewer, Dr. Elizabeth Brown (EB), Charles Brown (CB), and Owen Johnson (OJ)

Responders (R1)

Icebreaker-56.67

Question 1- 10.56

EB- Are you currently accessing HIV/AIDS medical care and or support services?

R1- Yes

R2- Yes

R3- Yes

R4- Yes I do

R5- Yes

R6- Yes

R7- Yes

R8- Yes

R9- Yes

Question 2 - 11.45

EB- What agencies or types of agencies are your currently obtaining services from? For example

R1-Nashville Cares

R2-Nashville Cares

R3-Nashville Cares

R4-Nashville Cares

R5- Nashville Cares

R6-Nashville Cares and PAN Physician Assistant Network

R7-Vanderbilt 100 Oaks

R8- the Springfield Health Dept.

R9- Comprehensive Care Center at 100 oaks

R10- Clarksville Health Dept.

R11-Clarksville Health Dept.

Question 3 - 12.58

EB- what are the most important HIV related services care you are using now? Or within the last year?

R1. 100 oaks mall

R2. Comprehensive Cares

R3. Nashville Cares

R4. Doctors unit

R5. Nashville cares

R6. Robertson county health Department

R7. Nashville Pharmacy

EB what did you say one more time?

R7. Nashville Pharmacy

EB. Nashville Pharmacy? Ok

EB. I will let you all speak and I will repeat some of this information to make sure we get it recorded. Ok so we have medical care, Robertson county health department, Nashville cares, Columbia, 100 oaks and then Springfield Health department.

R8. And Dr. Vincent is the local physician who is not.....

EB. Ok, Dr. Vincent

R8. Yes, he takes blue cross blue shield and of course APA

EB. So he's private

R8. Yes, he's the only one in Clarksville

EB. Only one in Clarksville? And then you indicated pharmacy as one of the most important services

R1. No, doctors unit

EB. Didn't someone say pharmacy?

R7. Hmm Nashville Pharmacy.

EB ok thank you, anything else? Again that was for the most important services for HIV services and care.

Question 4

EB- Have you ever not accessed care for a period of 12 months or more?

R1. Yes, ma'am

R2. What was the question again?

EB. Has there been a time when you have not access care for a period of 12 months or more?

R2. Yes

R3. No

R4. No

R5. No

R6. Yes

EB-. May I ask for those that did if yes, what caused you to stop accessing care?

R1. I gave up

R2. I was afraid

R3. I didn't have insurance

R4. No doctor

Phone Rings

EB- For those who did, if yes, what could have kept you in care?

R1. Mental health

R2. Financial

R3. Better financial assistance

R4. Local access

EB. Local access?

R4. Yes, it's an all-day event to go to a physician

R5. Yes and all the traffic and they keep you out all day

R6. I left at 7o'clock in the morning; it wasn't until the next morning when I got back. They left me at Nashville cares all day, by 100 oaks mall. I was there all night long till 7o' clock the next morning. I had to hitch hike a ride. I hitch hiked back to Clarksville; because they still wouldn't come back and get me.....they left me there

EB. This was the transportation.

R6. Yes

OJ-so the problem is more pronounced when you have to leave Clarksville to go somewhere else.

R1. Yes

R2. Yes

OJ. Because right. No local access. So how much local access do we have? Is it a whole lot? Is it getting better?

Discussion (cannot comprehend)

R1. It's never...

R2. It's not

- R3. No, it's one doctor
- R4. It's none in Clarksville
- R5. There's nothing
- R6. It's nothing here in Clarksville period
- R7. For medical care one private doctor
- R8. Yea, you either have to Nashville or Springfield
- R9. The city bus goes out here or mid ways to take you to Nashville. I suggest you go to the train station and get you a pass. It's an all-day adventure but at least you can get there. You still have to be patients. It cost 4 dollars one way. You can go back and forth to Nashville with 8 dollars.....sometimes people don't have that I didn't years ago
- R10. Not everybody has the money to do that either
- R11. and besides when you go to Nashville, a lot of the providers assume your local and basically just pretty much dismiss the concept of, well just come back tomorrow, not realizing what an effort that is to come back at all, and they don't realize exactly how much we're going through to go to these appointment, and they aren't responding in a light fashion when we get there to focus on how much we actually did go through to get there
- R12. And in some cases it's not convenient because for someone to have to go all the way to Nashville or all the way to Springfield, there's family, there's job. I mean so it's not an easy access thing for someone to have to go spend all day somewhere else for some care or for their health issues or something. But if it was something more local, you can make you an appointment, and you can go to your appointment and be in and out go take you family go to work and everything else, but to have to travel somewhere that's a whole day. You can't go to work that day because you have to go so far and if you do go you have to stay so long. I mean you got make babysitter arrangements and everything else. So it's an inconvenient to not have local services in some cases and at sometimes.
- R13. Or going to Dr. Vincent, sometimes things with him it's about... and um...discussion about misunderstand (cannot comprehend)
- R14. I refused to ride with Mid-Cumberland. I'll never ride with Mid-Cumberland ever again
- CB- we can't hear, please speak louder
- R15. I asked for a different transportation besides Mid-Cumberland. My insurance said that they did change it, but Mid-Cumberland wind up coming to get me anyway.
- R16. Murray county transportation Montgomery County so Tenn. care want pay for double transportation
- R17. I've been on there one time and they kept me form 7 o'clock in the morning to 7 o'clock in the evening and that just ridiculous. For me to have be gone 12 hours of riding around and they going off into different towns picking up people from way off.

Spontaneous those call come in. It's like I want to go home. If I get done at 10 I shouldn't have to get home at 7 when I can get home at 12 or 11. It terrible.

R18. You have to call 3 days in advance to get a ride too.

EB. You have to call 3 days in advance to get ride that might leave you for 12 hours.

R1. Yes

R2. Yes

Discussion about transportation (can't comprehend)

R3. One time they left at Kroger's pharmacy when I only asked for a drop off. He left me up there and told me to get someone to take me. I had no money. I had waited for him to wait for this lady who was in a pharmacy in Springfield. He waited a whole hour till she got out of there. She didn't just do a drop off she went in for her medicine. When we made it back to Clarksville he left me at the Kroger's and told me this was as far as he could take me. I had to hitch a ride home. And I have an 8 year old son.

EB- So, for those of you that indicated yes again, what made you want to access care again? After these obstacles and barriers?

R1. You got to have your state of mind

R2. You got to have your medication

R3. That's the only way you can get to a doctor

R4. Mental health

R5. You got to get it the best way you can

R6. For better health

R7. Finally got my insurance back.

OJ. So there's two issues? There's 1 seeing the doctor and 2 medication? Or are those two separate things? Transportation for both those things.

R1. Yup

R2. Yes

R3. Yes

R4. I have to have transportation for my doctor.

R5. I have to have transportation for my doctor and my medication.

Mumbling

Other Dr. Brown- when you talk about insurance are you talking about particular insurance carrier?

R1. Yes. I didn't have nothing. It was just gone. So, recently within this year I got the uh Obamacare. So it's something.

R2. Now for me I relocated and when I relocated it was a while before the insurance kicked in, in order for medication to start back and for healthcare to start back. So it was a relocation process that took place too that caused a break in the insurance

OJ- So in terms of your local access medication is more of a transportation problem right now, accessing pharmacy? Am I correct?

R1. Transportation access? Access is more medical care. We still access pharmacy, pretty much if we can get on the bus or we have to.

OJ. It more accessing medical care.

Question 5-

EB. What services are you most satisfied with in the current system of care and why?

R1. Nashville cares

R2. I like my doctor

R3. Nashville cares

R4. My doctor

R5. My physician

R6. Nashville pharmacy

R7. I like my doctor, and my pharmacy and Nashville cares

R8. My pharmacy and my doctor

R9. Comprehensive care center. They've been there for me since the beginning of time. Until I started trusting my doctors. The ones that were people persons and not looking at me uh say like a person with a disease. Uh that made things better.

R10. That's also the one he was talking about. These doctors are specialist. All of them. These doctors are specials and they are more in detailed about what they are doing.

EB- so you like them at the comprehensive care center because their specialist?

R1. Right

EB. And because they care?

R1. they care

R2. They care

OJ. And if I'm correct all of these medical comments are out of Nashville.

R1. Yes

R2. Yes

R3. Yes

R4. And Springfield

R5. Except for mine

R6. Columbia and Clarksville

R7. And Nashville and Springfield

R8. Just to be clear Dr. Vincent doesn't take anything Ryan white.

Mumbling

EB. So being clear, that in Clarksville there is only one doctor, that's Dr. Vincent, as indicated by you all the participants. And he does not take any Ryan white.

R9. right and Dr. Vincent doesn't follow the law very well, because he will discuss your problem with two doors open if two people are in the .....And he'll just talking about you and the doors are open. There's a code for it and you have to tell him to close the door.

R10. He refused to see me. He wouldn't see me at all. He told my family he didn't want me in his office. He closed the door on me. Wouldn't let me in the office. That's why I went to Nashville and see Dr. Betty and I love her to death. I've been seeing her for over 4 years now.

Question 6-

OJ. So what are some things that you don't like about your services?

R1. Transportation

R2. Transportation

R3. Every so often you get a doctor that has bit of an attitude and you got to sit there and you got to deal with it because your like ok, I need this help, but yet I don't want to snap on this person because I'm not going to get the help I need. So that's really frustrating dealing with doctors you have to go see and they have an attitude.

Discussion (can't comprehend)

R4. I have one. Having to have to have a new doctor. You get comfortable with one doctor and then you go in for another appointment and another doctor walking in. and your like well who you are. Now you have to get a report all over again with the new doctor. Having to have to change doctors and get a new doctor sometimes that can be real uncomfortable.

R5. I have a problem with 6 months recertification. Recertification doesn't qualify as medical appointment there for does not qualify for transportation. Every 6 months and we're required to go to Nashville and back and forth every 6 months. And everyone calling in and saying you need come in to set an appointment and not explaining the fact you know we're coming 65 mile out or better.

R6. Look. Comprehensive center sometimes they have students come in and I don't like being put on the spot like that. Sometimes they will bring them in and say well do you mind if they're in here. I'm like why didn't you ask me first before bring them in. sometimes things are really personal. Sometimes you can look up my robe. I don't want nobody else looking at it. Its real personal and you putting me on the spot.

OJ. Sometimes you have to say no.

R6. I have said no and tell them don't bring them back down here.

R7. We argued and fought in his office, because at the pinnacle hour of him writing a prescription and he refused to write that I was already taking. He refused to write it and said you need to go see a therapist again. And I'm like. you sitting there saying you're going to be a primary care, you going to refill all these prescription and at the pinnacle hour I have to go see somebody else. And you're fine at 4:00 in the afternoon. It really hard to get to Nashville that's why Dr. Vincent is the local doctor, but that the type of personnel you going to get. And he doesn't just do civilians he does military as well so he's got some serious issues. It's not convenient

R8. Before they switched my doctor to the one I have now. Every time I would have a disagreement, like he said with people coming in the room. And when I would get mad or how you would say vent out, he would go down the hall get the psychiatrist he would come in like I had a problem. And I'm like did I ask to see you. Well you acting out your doing this. He would do that a couple of times and then they had uh was trying to give me something one day and it almost killed me and I thought my doctor was trying to kill me. When I ended up in the ambulance and had to go to Vanderbilt uh bout time I got out of there they switched me to Dr. R. and ever since him everything's been peaceful I ain't had no problem. I don't have problems with transportation. They come and get me sometimes yea, I have to spend all day up there, but it doesn't bother like other people that have something to do. I don't have anything to do. So that like a vacation.

Question 7

EB. If you could change one thing in the HIV/AIDS system of care what would it be?

R1. Finding a cure

R2. More people that care

R3. Local access

R4. Change attitudes

R5. More support for people that are HIV positive

R6. I don't have AIDS, but vie been sitting here and I've been listening to everybody I think they need some more doctors here.

R7. Yes

R8. Yes

EB. More doctors here. Local access?

R9. Most doctors, they do not care. There not there for the patients. I went to dr..... office and waited 45 minutes and they tell me oh he's not here this afternoon. Why?

OJ. So do you get referred to a doctor or do you pick your doctor.

R1. Referred

R2. I had been referred

R3. Referred

R4. Referred

R5. I got referred

R6. I picked mine

R7. Referral

R8. I got mine at the hospital.

Question 8

EB. So as it relates to satisfaction with services you answered it potentially, but I wanted to ask it. Are there any services you need but can't get or aren't offered in your area?

R1. Better quality food

R2. Most HIV patients are diabetics. Mainly because of the medication they were given. You have to stay away from so many things that's processed, but that's all that's available. I mean do you get this rice with fat or so on. But it's all process and fat and it's not good for us to eat.

R3. Better housing. And the services like Nashville cares offer, like they'll pay your 1st months' rent and your deposit if you don't receive your SSI check. And most people just get there SSI check which is 700 dollars. Where do find a place to live for 300 dollars a month? It's very hard

R4. I wanted to mention volunteers for life house keeping

Question9

EB. So barriers. Even though I know you all have mentioned some. Are there any other barriers that you have experienced while trying to access services in your community? Unhelpful attitudes, behaviors, these are examples, travel great distance to receive services, transportation problems, inconvenient hours of operation, and so forth.

R1. Finding housing

R2. All of the above

R3. Yea (with laughter)

R4. Yea (with laughter)

CB. So what can we add to the list?

EB. Is there anything else you haven't expressed so far because you've expressed this in many different ways in reference to the transportation the doctors, the food, nutrition, housing anything else?

OJ. What about finances and jobs?

R1. Oh yea.

EB. Employment, is that an issue?

R1. No one really wants to hire anybody and if they know you have HIV

R2. They want hire you if they know

R3. Yea they don't

R4. Don't put it on the application or anywhere else. Just don't mention it.

R5. But if you don't do that then ... want cover you, and they really can't hire you because of that

R6. It's a law that says we do have to tell people that we do have....

Discussion (can't comprehend)

R7. I had a job in Nashville; let me explain something really quickly. And I had to quit because I had no housing and I was living at the mission and I was losing sleep and I had to quit that job. I stop my medication 2 months ago I want to get back on it I relocated here because someone offered to give me a helping hand. If it wasn't for him I wouldn't be setting here today because I would have taken my life. That how low my life was and has been for the last seven months.

R8. A lot of people, once they find out you are diagnosed they treat you differently and I think that is really unfair.

R9. They really want hire you if they know

R10. mumbling-cannot understand respondent

R11. Same thing here. I mean some days in going to work, by the time I get home from work the neuropathy in my foot hurt so bad. That all I can do is prop my feet up. I'm so stressed and drained that its bothering with my hip but then if I don't work I don't have the finances to able to maintain so lack of finances to be able to continue to maintain, paying all your bills, taking care of kids and everything is a problem as well as well as the job situation. It goes hand in hand.

R12. Umm my brother who was on SSI and he was only allowed to work some many hours or they would cut his SSI.

R13. That also means you're medical. They'd cut your medical. You could get that much medical attention anymore and that's the most important thing you need.

R14. I had a problem with my family. They had told a lot of people that I had HIV. and so....it was hard for me to get a job because people knew me and I was from Clarksville, so with them knowing that it kind of cringed on me to where uh I wasn't able to work or get a job. So I left it alone and then me and my family stopped getting along.

R15. My husband is HIV positive and he tried to get disability and they continuously turn him down.

R16. They told me I was too healthy.

R15 how does it supposed to work? Tell me that

R17. I thought it was automatic

R18. NO

R19. NO

R16. I got dementia... (Cannot hear participant)

R20. My ex he had a doctor that refused to go into the hospital. He would not walk into the room where he was at. He asked from the door way was he alright and wouldn't go in.

Question10

EB. Are there instances when you have felt particularly unwelcome, uncomfortable, discriminated at any agency?

R1. Walgreens' pharmacy in Clarksville

R2. Gateway hospital in Clarksville

R3. Hospital in Clarksville

R4. basically discriminated against because, when they walked in there they had their mask on and their hands covered, the whole nine yards and then after me going there for while there was one doctor he I guess basically stood up for me and said there is no need for all of that. He said you can't even catch that way. After while I kept getting the same doctor and basically no other besides him will see me.

R5. There was a pharmacy. I was on a certain medication and they wouldn't refill me. They gave me some big story, this medicine not supposed to go with this medicine. And had taken it for 15 years so I just went another pharmacy.

R6. Sometimes when I go to her appointments with her. I have heard the nurse and say, you know she has AIDS, you have to be careful when you go in there. I don't know if my girlfriend heard it, but it kind of upset me and if you want to get technical she doesn't have AIDS she's just HIV positive. I said if you're going to say something make sure you know the difference of what you say.

R7. Gateway is actually horrible

R8. It sure is

R9. I have a problem with the nurses not wanting to do their job.

R10. It's a lot of ignorance

Discussion (can't comprehend)

R11. You sit in there all night long

R12. Or they'll ship you to Vanderbilt

R13. Vanderbilt, skyline

R14. St Thomas

R10. I know from experience because that what they kept doing with my brother.

R15. They'll send you to a hospital doesn't have any medicine.

OJ. Again this is local

R1. It's for profit

### Question 11

EB. So the unmet need, what services or care do you need but are unable to get.

R1. I would like to ... transportation. If we could get bus passes and get around and shop and do general every day, besides appointments. Again... does not qualify for transportation

R2. I just think Clarksville needs another hospital.

R3. Or the...needs to be updated

Discussion (can't comprehend)

R4. The reason why I say that, you go to Nashville you got 3 to 4 hospitals that you have a choice of. Unfortunately Gateway (hospital in Clarksville) to hell is the only place we got to go.

R5. I'll say financial services, because the question said what other services you need. I say financial service, better or more, or better budget of services we are able to access in assistance in rent or something of that nature.

R6. Transportation to be re certified

R7. Jim needs an assistant

R8. Yes

R9. Yes

R10. Yea

R11. He's only here 2 days a week

R12. Here at the church (trinity episcopal in Clarksville)

R13. Complete holistic care in services

### Question 12

R1. A cure for HIV/AIDS, or at least having to take one pill instead of 5, 6, 7, or 8.

R2. I take one pill and they have like 3 different medications in them. Those 3 different medications have totally different side effects.

R2.i take one pill a day to the side effects are pitiful.

R1. I take a whole hand full of pills every day. (Responders listed the types of medication) and I have to take it all at one time.

R3. My concern of issues happening for me to continue to better my health and in the future is my insurance stopping, because if my insurance stop I can't pay for atripula (HIV medication). If my insurance stop I can't go to my doctor's visits every 6 months to check up on my viral load and my CD4 so insurance stopping, it's not being able to access the services that are at Nashville CARES, it's not being able to have Mr. Jim here twice a week. It's those things fading out and stopping. Because that is what is going to stop me from bettering my health for the future. So it's something of that nature for me it is.

R4. If there was a way the medications could be a little more affordable. That would help. I know it's a big mission, but it seriously it would help. Because some of the pills are like 100 dollars per. and that's just crazy.

R5. I'm on SSI and it's a catch 22 because if I get off SSI and go to work, which I wish I could do, I could lose my insurance and the medication is too expensive and I could get very sick and die.

R6. Like everybody else my concern is the insurance. And in 2016 they're clearing up disability and social security, and they're talking about cutting their checks 13%. On top of that they are wanting to cut Medicare back, for Medicare they'll pay up to 80% to 90% and they want to cut it back 40 to 50%. What am I going to do? I can't pay for the medication

R7. Even if we do get jobs we lose our current insurance, and as soon as the new job has new insurance to offer, we're still going to have a gap before that insurance kicks in and we're going to be doing without. So where is the incentive to get a job?

R8. That was their whole thing about cutting their checks back 13%. For people to go back to work, but if you're not able to work you're not able to work.

R9. What scares me is the funding being cut back. I've been up to DC the past 3 years in a row and all I hear is sequester, cut, repeal affordable care act. Sequester, cut backs, repeal affordable care act. Again, they're trying to come up with a new way to repeal the affordable care act. Even though the Supreme Court said no. And they're trying to wrap around legislation to be around that. As opposed to what are we going to do; CARES lost a millions dollars in federal funding.

OJ. What about Medicaid expansion? You guys concerned about that?

R1. Do we want to get it?

OJ. Right?

R1. if it can't get passed the committee it want get voted on. They won't be able to discuss it.

R2. Now don't forget, don't cut out the food bags, because I look forward to mine every month. If they cut them out, then I'm going to be like hey. I need my food.

**Transcription Columbia, TN**  
**Data Collector- Kelsey Burton**

Key

Interviewers, Dr. Elizabeth Brown (EB), Charles Brown (CB), and Owen Johnson (OJ)

Responders (R1)

Question9

EB. Are there any barriers that you have experienced while trying to access services in your community?

R1. In my community? I don't get any services in my community.

R2. I would say that everything on that list applies to this community

R3. It's sad but it's true.

R4. Can I ask a question? Why is there no legal advice people in this area for AIDS in this community, because we can only go through legal aid? Actually I just went to legal aid a couple of weeks back here because I live here and have heard once from them, I haven't heard back. They don't seem to want to talk with me about this situation because it involves discrimination for HIV and once they hear that word HIV they shut down here. So, what I'm asking is why we don't have that through Nashville Cares were we can actually talk with someone who can help us with our problems.

R5. I have some success with ACCOU

R6. I called them and got a referral. I actually sent a letter to the attorney general of this state and to the state congressman.

R5. I'm very vocal too. I get a letter almost every month.

R6. I want stop until this changes. That's just the type of person I am, but I mean you know when you're not receiving medical attention. I have to get medical attention 3 day a week or I die, and to have someone kick you out of an office and not allow you to go anywhere in the state is a pain in the butt, and they should never be able to do that, for an argument that some nurse started with me. And so I'm going through legal services trying to get that fixed. Taken literally too the courts to find out why they did that and how they got away with that. Because they put me at risk to die and that was not a very good place for me and so I wanted to get legal advice for that and there was nowhere. I went through the state, I've gone through the.....

R7. They haven't responded at all?

R6. They respond in the fact, we're working on it. Just like I told you I gone through the.....every years there's like a place you send letters too for like grievances. I sent the letter, it was like April of 2012 I think it was, that I went into the doctor's office to get a doctor and he kicked me out, he didn't even face me, he kicked me out and he had his nurse kicked me out. Now we all know that's against the law. We all know we have rights and that they're not allowed to do that today. He actually signed a letter stating that he did that and have sent all of this to state and they've done nothing, and every time I

call, they're working on it. I call about every 6 months. They're nice, but they're working on it. They have better cases.

CB. In terms of barriers in the community. Are there any other barriers anyone else would like to add?

#### Question 10

What services and care do you need but are unable to get? (prompt)

R1. So there are certain benefits for certain income levels. Which it always amazes me in its self because you're looking at different types of people and different cost of living. Why is that, I don't mean this offensively at all, but when your lower income you get everything paid, everything, because I was there once and when you make a certain amount of money your just cut off like zero amount of money. You can make one dollar over and lose all those benefits. So co pays get very expensive. I mean co pays can be very, very expensive. Just one hospital visit this year for me this year was almost 2000 dollars out of my pocket. Plus with Medicare, out of pocket, I almost have to pay 43000 dollars out of my pocket when I am only making a certain amount of money. By the time they take all of that money out of my money, I making less than the fourteen thousand six hundred.

CB. Just to clarify, you're speaking in reference of being employed?

R1. No I'm talking about if you're on Medicare and you make less than a certain amount, you get extra help that pays for almost all your copays, except maybe 2 or 3 dollars for prescriptions. Where I have health insurance, I don't get extra help. My co pays were on my drugs a lot of money and they still are just like. For non HIV drugs. Plus doctor visits are 40 to 45 dollars a time that you go and when you're sick you have to go to the doctor a lot especially when you have multiple illnesses. Um plus I go to dialysis and I wish I had one of those bills to show you what the co pays are. So I qualify. I mean there are different programs available through outside of there that I qualify like the kidney foundation it's always a battle trying to figure out where I'm going next to get somebody to pay something. Whereas if I was under this income I wouldn't have to do this at all. I wouldn't have to worry about losing my home because I had to pay a bill. So it makes it very difficult for somebody who is just an income over that. I mean I make.....plus the fact I'm a little resentful because I paid into a system to get extra money.

EB. So are you indicating gaps in coverage? Based upon poverty levels.

R1. Right, there's no place per say, you don't qualify at all. Where there is no stages. You either make it or don't....

R2. There's no graduated system. There's a number they go over it, because you're not talking about employment issues.

R3. No, I was so lucky to have enough money in life to buy things like health insurance and disabilities insurance and those things. I was lucky enough to have those but I feel like I'm being penalized for having them, because now that I have them I don't qualify for anything. So all that money I put out to buy those programs to make me more comfortable in life are being taken away from me. Because I not qualify for any of those program, or some of those programs. I shouldn't say all of them some of them. So I have to put out a lot more money than others... (Hard to hear)... I don't know of how many others are. And so I do thank god for all of the services I have I think it could be better and I think it could be fairer.

#### Question 12

EB. What concerns do you have about getting services or care in the future?

R1 I'm worried our congress is going to eliminate all funding for AIDS research and programs

R2. Basically being cut off

R1. I mean they seem to be taking all of the money out of the system and they could care less about the poor anymore.

OJ. What about job or employment? Is there an issue there? How does that play into?

R1. I don't work

R2. I'm self-employed and so it's tough. Um because it's basically just the two of us. And with everything, health wise that I've been going through we've had to juggle things around. We've had to tell people sorry we can't help you because you know I got doctors' appointments treatments and everything else I've been having to go through. That I've had to turn people away, which is really hurt my income this year. It's been really really difficult and uh you I know I can't afford to hire someone else to replace me when I'm not there. And I can't go anywhere without Travis because he needs to drive because I can't drive right now. You know so we're kind of stuck you know. We have some great customers we can move around here or there but I can't attend any more customers because I can't physically do it anymore.

CB. In terms of mental health services, any concerns?

R1. Well the Ryan White doesn't offer any of that, from what I know of.

R2. Well CCC has one on staff.

R1. They do

R2. Yea they have I psychologist.

R3. Yea, well they have 1 psychiatrist and 2 psychologist

R2. Yea, they have 2

R4. Where is that?

R2. It's at CCC in Nashville

R1. And see that's the problem, that's in Nashville.

R2. Like I said I have to go up there an hour and half every day. It concerns me, because what happens when I'm not the only little gay boy with HIV in Lincoln county. What happens then? They won't see you

R5. There's no other people

R4. No they won't see you

R6. So there's no one?

R2. Not that I know of.

EB. So even at the CCC for all of these counties, there's 2 places?

R1. They can go to see a health professional that can be in Maury County or Vanderbilt, for mental health

R2. For mental health? Yea.

Discussion among participants (can't comprehend)

R3. Everything is getting farther and farther away. Which is really difficult because you know for me, just getting over cancer. I still have problems, you know I still have neuropathy and so forth. I cannot sit in the car for an hour's long drive to Nashville every time I need some kind of service. Uh so you know we get out of the car and I can't walk. Because I'm messed up.

Discussion about his doctor

R3. With all this traveling, you know everyone is like oh go up to Nashville, well that's not quite as easy as you think it is.

R4. Especially when your 51 years old and has AIDS, you got neuropathy, bottom half of your body will go to sleep. I mean I thought I was stroke out one time when I came back. My whole right side went floppy on me and I thought I was having a stroke.

R5. Something I didn't hear people complain about, but what I hear people complain about is about the doctor out here in Columbia. And have an appointment in the morning and don't get out until the afternoon. So there's no consistency with appointments.

OJ. What about substance abuse services?

R1. No

R2. No I'd not have a problem with that

R3. No not an issue here

R4. Never had to deal with that

R5. I'm not sure, I mean it's the same problems as everything else out here, but I don't know if anyone here is in need of that.

R6. I have a friend that's straight who is a substance abuse user and he has problems finding a place to go, so I doubt there's a place for HIV and something like that

OJ. So in closing I'm going to ask us to go around the table and say that one service, that one thing that you know in a perfect world you would like address in terms of your own individual situation.

R1. Distance to the doctor

R2. I don't have anything

R3 better services closer to home

R4. I think this would solve all the problems, if we had one person we could go to, to guide us into a direction to figure out what to do next in our lives. Somebody that not, where I'm not doing all the work and no response and who can help me and see this and do something about it.

OJ. A centralized location?

R1. Yes, someone who can sit there with me and shake their head in disbelief and do something about it. And maybe have some common place to go to fix this problem, because it's not just one thing its many many things. I'm ready to move because of it. I mean I'm traveling 3 hours a day for dialysis.

Discussion about where he goes for dialysis, and why he can't get help in Columbia

R2. Basic information, we were diagnosed late last year and we had no idea where to go for anything other than the health department. It would nice if we had information to

know where to go, what to expect you what available to you. We don't have any idea. Plus the services we do have I'm not sure who doing what. I don't know what Nashville CARES doing I don't know what Columbia cares is doing I don't know what the health department does. I just know if we have a problem, we have to find somebody within those groups that supposed to help. But it's like which one, I had no idea

R3. We need more doctors in our area that specialize in HIV/AIDS.

R4. Nothing that I know of, it's been covered.

### **Transcription: Cookeville, Upper Cumberland Human Resource Agency**

E. Brown: So we are a research team from Tennessee State University we are working with the United Way. And the community HIV/AIDS partnership or CHAP. And we want to ask you a series of questions and we also are going to ask you some demographic questions in the way of survey for the purposes of taking the feedback that you provided to us. And hopefully effect change as it relates to the services that you feel you need.... gaps that might exist or to let CHAT and United Way know what it is that is OK and that you like of the services you are receiving that you're satisfied with. In addition we are working with the Ryan White Part B. Grant. And so we're getting information and feedback from the different regions of Clarksville, today Cookeville, and then yesterday we were in Colombia Tennessee.

So... we will let you take about ten minutes and fill out the surveys that Kelsey going to pass out even though I told your name... and these are persons I need to tell you about... I am Dr. Elizabeth Brown. I am one of the research team members. And again we're from the Department of Public Health, Health Administration, and Health Sciences at Tennessee State University if I did not say that.

Johnson: Owen Johnson also a faculty at Tennessee State University

Burrell: Wanda Burrell faculty at Tennessee State University

Briggs: Hi Revlon Briggs faculty

C. Brown: Good Morning. Charles Brown faculty member also within the department.

K. Burton: I'm Kelsey Burton I'm a graduate assistant for the project.

E. Brown: And let me say there's two other graduate assistants but we sent them out for lunch and that is Lauren Buford and then her twin Chelsea Burton

Johnson: Okay umm.

E. Brown: Let them introduce themselves, First name only.

Ashley: I'm Ashley, I am Peggy's caregiver.

Peggy: I'm Peggy

Tom: I'm Tom, I am from Coolville

Michael: And my name's Michael I am from Cookeville

Brown: Cookeville as well?

Peggy: Yea, I'm sorry

E. Brown: That's okay. Just want to make sure

Johnson: Alright so just to add what Dr. Brown said we're... I mean you know... to break it down very simple we're trying to identify some of the issues with the services, some of the concerns, some of the things that you do not get, some of things that you want, some of the problems the complication, the things you want solved. We want to umm... gather as much of those information. Take it back to United Way take it back to the Ryan White and see if we can get some of those issues addressed. So we're doing in Columbia, Clarksville, and Cookeville... there's a hopefully we get enough information that we can you know. Knock on doors and ask questions and get some of these issues addressed. So that's kind of what we're doing here. So we want you to be open and frank. You know... just say it as it is...do not hold back anything, because the more... the more you give us the more clarity the more germane them. Then the better we can advocate and make a case for change. So that's what we're doing.

Michael: That's a first what is actually homosexual/straight. (Laughter)

E. Brown: It has heterosexual on their too.

Michael: (Laughter) OH it does I was looking...

Peggy: What is the date for today?

Multiple People: the 7th

(Dead space)

E.Brown: Take off the Informed Consent forms.

(E.Brown and Johnson dialogue among themselves, participants are filling out survey)

Michael: How was the turn out in Colombia? How many of them? Where they pretty good.

Johnson: We had about....

E.Brown: eight

Michael: Really?... (Sigh) It's a struggle here. Bad... Even for our meetings. I mean it's a struggle. Like... I mean there's a Hiv/Aids population...there's quite a few but no one will... we cannot do it...Peggy is the only women we can get to come. We cannot get no women at all to come. I mean even the men.... It is ...usually at our support groups meetings we maybe have five... you think they be more open because you learn a lot of stuff. A lot you know you'd be surprised that much you learn....

Kelsey: Why do you think they do not come?

Michael: Fear is a worry. That's the reason like even in Cookeville right now... there are so many people having unsafe sex. Because they won't tell their partners...I mean it a shocker but it is true... because the town is so small and so if you...make one person mad or anything that's it... they're going to tell everybody. And I mean I don't think it's

something be ashamed of...you know. I'm open about it... (various conversations are happening)

Michael: But yeah...it's still bad...it's really bad it's has gotten really bad. I mean I go to the bar around here... and people talk about it...like really...you know. And I wish it would change, I just really really do. Because I was talking to Deb, and I said Deb you really be surprised the people you be signing up if people really went and get tested.

(Noise that is not clear of people talking)

E.Brown: Okay so we have some ground rules that we want to make sure we adhere to and we put some...we printed these before we end up meeting one more ground rule as it relates to us meeting here today. And I'm going to read them. (voices) So. I will read the ground rules. Only one person speaks at a time. Try not to interrupt anyone who is speaking. When asked you keep your responses for the purposes of the entire group. To about two minutes. And then we'll have sort of an open comment or dialogue... potentially. If you have questions that you want to ask of the research team time is available at the end of our session. As we want to make sure we get all of the feedback. So respect each other's ideas. You can agree or disagree about what others say. We just don't want anyone to make personal attacks. There is no wrong answers only honest answers we want your feedback. Openly and honestly. Every opinion is important. We want to hear a wide range of opinions. What is said in this room, stays in this room we're not asking for any identifying information. So therefore what you say is held in strict confidence and we've all signed confidentiality waivers. Would anyone like to add any other ground rules? Right now. OK In the last one this is the one we added after the fact and realize please Silence your cell phones. OK. Now we're already introduce ourselves... I will read a real bit more information. My role is to make sure we get through a few questions which I have here. That you each get a chance to talk about. Members of the Department of Public Health, Health Administration, and Health Sciences' research team will be helping take you...(cough) on various (cough) and other assignments that we are working on. This session will be and is audio recorded. Not video recorded... audio recorded. So is there anyone that has an issue with us audio recording. (pause) And then at the end of your session. You will receive a ten dollar gift card. Upon conclusion. And Dr. Briggs has a sheet were we ask you just to initial. For the purposes of receiving your ten dollar Kroger gift card. Confidentiality all information we collect here today is confidential we will not identify any of the participants in our notes. We will not use your name address or any other identifying information in reports or other materials related to the study. Make sure that you've read this time the consent form which we've provided for you. And then it is a time if you would like to opt out of participating or if you just like to be quiet and listen. You have that option because this is a voluntary. Experience. Also we provided you with some legal paper that you're free to write. If you have an opinion or comment that you want to make sure that we capture, then you can just provide it to us at the end of the session.

So if it's ok, we've already introduced ourselves. We would like our view to express your opinions about the discussion topics we're interested in multiple points of view about them. Again there are no right or wrong answers. We ask that you please refrain from holding side conversations, so that we are all able to hear what everyone has to say. Are there any questions. OK Any concerns. So we shall begin.

E. Brown: What agencies or types of services are you currently obtaining services from? What agencies or types of services or medical care are you currently obtaining services from? And I'll give you examples. Are service providers community based organizations providing social services? Neighborhood clinics hospitals etc. (pause) Name two or three or one.

Michael: I use the clinic here. The Department of Health here in Cookeville.

Tom: Neighborhood clinic here.

Peggy: I go to Nashville, I have my AIDS doctor there, my psychologist there at the CCC. I go there.

E.Brown: Okay Vanderbilt Comprehensive Care Clinic.

Peggy: Yes ma'am.

E.Brown: Any other services? Dental? Pharmacy?

Michael: We all use the Dental in Nashville.

Peggy: I don't

Michael: you don't use it? How you get then you don't.

Peggy: I don't know how and I don't get dental. I don't have them so I don't know how to do it.

Michael: Remind me and I'll tell you how to get you. We use. United Way or the Ryan White Dental Nashville Cares

E.Brown: Nashville Cares. Okay, any other services insurance and private.

Michael: I got private I got Medicaid.

E.Brown: OK.

Tom: I've got Medicare or receive services from here.

Michael: Yeah I don't have Medicare. I have just actually qualified for the extra services for that drug plan through. Ryan White Pharmacy, I use Nashville Pharmacy. I think it's through Nashville Cares. Works very well.

E.Brown: Okay Nashville Cares. Private insurance?

Peggy: No I am on Disability

E.Brown: Okay. Disability

Peggy: And then I have TennCare also.

E.Brown: Okay I also have S.S.I and TennCare.

Peggy: Yes ma'am.

E. Brown: Any other service?

Peggy: Well, I get, well like every year they have you sign up can for electrical help (voices)

E. Brown: She gets utilities

Peggy: Yes ma'am we do that one time each year and then from there I take it and get a card for gas to go to Nashville and then I get a Walmart gift card for food.

E. Brown: And what about food bags?

Peggy: We don't get any of those. No

E. Brown: No food bags here in the Cookeville region, so it's a Walmart gift card that's allocated.

Peggy: One time a month

E. Brown: from upper Cumberland

Peggy: From Deborah.

Michael: It's through United Way

E. Brown: Okay United Way ... Ryan White Gift card

Michael: Yeah Gift Card

Tom: Yeah but there are churches. That have food at the food pantry so.

E. Brown: At the food pantry?

Tom: Yeah

Peggy: But we don't got one

E. Brown: In Cookeville?

Peggy: Never mind

Michael: We don't have an HIV/AIDS food pantry or nothing like that here.

Multiple People: Yeah not one like that here in Cookeville.

E. Brown: OK.

Peggy: I'm not talk right.

Multiple People: No you're talking fine

Ashly: She just had a stroke so it...

E. Brown: That's fine you keep talking and we will take our time. We have plenty of time.

Johnson: What about transportation?

E. Brown That's coming...

Johnson: services

E. Brown: That okay though: Transportation.

Michael: There's only two different ones we have way they give us the twenty dollar gift card any time we have a dentist appointment or a doctor's appointment in Nashville that we can use and then if we goes over our twenty dollars, then of course we have to pay for it ourselves. Or you can schedule on the U-Cart through Deborah here which she actually pays for out of the Ryan White foundation or you know the united way money. And they will take you to your dentist appointment or doctor appointment in Nashville.

E. Brown: And the U-Cart is a part of upper Cumberland

Michael: Yes.

E. Brown: Upper Cumberland has a van.

Michael: Uhh. It's a van anybody can use it. That it's... They just have people with no vehicles to get to their doctors appointment or anywhere as long as you schedule and you pay not too late. You know. I think that's only two right?

Peggy: I am not able to use it.

E.Brown: So you're not able to use it... You use private?

Peggy: I have caregivers. So I can go somewhere (voices) so if they are not there I don't go

E.Brown: Private transportation...Oh go ahead

C.Brown: So when they are talking about the utilities is that a part of the Ryan White

Michael: No the utilities is not a part of the Ryan... its part of the Upper Cumberland. It's anybody required that can get it who qualifies for it. Its low income and you can sign up once a year it's called the LiHeap (hard to hear) and its heat...it's what it's supposed to be for. And usually sign up in October. And they give you roughly any were from three hundred to four fifty on your electric bill. But any low income families can qualify for it and it is through Cookeville County

E.Brown: So it's part of the utilities.

Michael: Yeah...Uhhh it's a part of U.C.H.

Peggy: I said it wrong.

Michael: No you said it right:

Peggy: And then also we can if we have a lot of medical bills. Then we can sign-up for their help. I don't know exactly but Deborah ...you can take your medical bills and then she will not but someone will.

E.Brown: Right. She just sends the Bills in

Peggy: No she pays the real and. I was going on a page in the villages. And then I'd say...tech. I wanted to build a site....

Michael: I will help you out. I think it's a part of that. Ryan White foundation... you can do it two times a year. Like if you need help and with your rent or utility bill separate. You can go through Deb which is....And she... and all you do is have proof of it and the reason why you need help and U.C.H. R. will write you a check. But it comes out of the funding through Ryan White and United Way yes.

E. Brown: So any other services?

Michael: I think that's it

E. Brown: Okay we can move on.

E.Brown: So, What are the most important HIV related services or care. You're using now or have used in last year. And I give you some examples. What are the most important HIV related services or care you are using now or have used in the last year-twelve months. Medical care? Prenatal services? Case Management? Transportation? Mental health? Substance abuse counseling? Support group? Etc. If there are others I didn't name. What are the most or are the most... you can you give how many important HIV of the related services or care you are using now or in the past twelve months here.

Michael: I think as far as me... medical and dental are the most important the gas cards really helps out a lot.

Tom: Uh medical, gas cards...uhhh

Peggy: I have more than that. Mine is medical and mental, I have to see a psychologist in Nashville. But I'll just see a therapist here. Because I only get to see her like every three months because she wants to make sure I get counseling.

E. Brown: Okay so you see the therapist here...in Cookeville

Peggy: Yeah...but that's private. Because they don't have one here and. So I go to Nashville that. So those are my two. You know

E.Brown: for mental health?

Peggy: Ummh. Yeah and the gas card helps tremendously and then the Walmart card for me...it helps a lot. I had...

E.Brown: Take your time

Peggy: I have to use a lot of help in the past year. My doctors up there work well with my doctors here. Because I go in and out the hospital a lot now. So, (hard to understand)

Question 3. E.Brown: OK. Have you ever not accessed care for a period of twelve months or more? And if yes. I have some other questions to ask. Is there anyone who has not accessed care in twelve months?

Michael: Recently or in the past?

E. Brown: Just in the past twelve months.

Michael: No.

Peggy: I don't understand...

Michael: You've gone to the doctor in the past months. And the past year.

Peggy: Yeah.

E.Brown: You've made all of your appointments. OK so based upon your hesitation on second part. Was there a time when you did not receive care or have access to care?

Michael: Yes yes. When I was in transit and transitions to moving from Florida to here. I went without care for over a year. Because it was of the...in Florida it was so hard to get into see the doctor because there was so many patients and it was quite a long waiting list and once I move here it was getting... or founding out how to do the services. Yeah. E.Brown: So you didn't know where to get information

Michael: Where to get information.

E.Brown: about where to go when you move to Tennessee

Michael: moved to Tennessee yes.

E.Brown: So the next category. Thank you... Satisfaction with services and quality of services. Question 4: What services are you most satisfied with in the current system of care and if so why. What services are you most satisfied with in the current system of care and why. That could be medical care, case management, transportation, mental health, substance abuse counseling support for.

Michael: Mine would have to be dental. Because they not so expensive...and I mean ... really even though they allot you a certain amount of money really helps out a lot. And I'm very happy with my medical care. We're going to Cookeville right now... who does know what we're going through a little. A little something here our nurse practitioners really sick she has cancer. So you know they are cancelling appointments but we

understand it's not a big deal at all but I'm really happy with the medical care I've always gotten really good medical care here

E.Brown: In Cookeville

Michael: In Cookeville

E. Brown: At the Health Department

Michael: Yeah. Even though we only see a nurse practitioner. I think I've seen the doctor one time and that's to say hello. You know. But I've never had a problem because I do realize that our nurse practitioners have to present in front of the doctors. So.

Tom: Mines of medical and mental because I see a psychologist too. And uhh the dental. And like they say while ago gas cards do help out and the Wal-Mart cards too.

Peggy: Umm...My medical care at Nashville is very, very good.

E.Brown: So you are satisfied with the care you receive at the C.C.C...

Peggy: Absolutely... And the gas card help as well and the food card that is the most important one. Because I could run out of food and everybody thinks that twenty dollars isn't much. But if you know how to shop then it is quite a bit of money and quite a bit of things you can get.

Johnson: Okay, so you go to the health department here...

Michael: Here in Cookeville

Johnson: So you don't have to leave to go see a doctor?

Michael: Well, No because I also have my primary care doctor here in Cookeville

Johnson: And you do not have a problem with your primary care.

Michael: No she's actually wonderful ...she works with...I'm not big on needles... weird... but I just don't like him at all and she's really good like she doesn't even draw blood or nothing I do all my blood at the health department. They transferred over to her. So I mean they work really really well together. I'm the first of the first HIV patients she's ever took on. And she's learned... she's learning a lot now and she's got actually I think she's got about five, so.

Johnson: So, where do you go for your medical the health department?

Tom: Yeah the regional health office.

Johnson: So you don't have to leave Cookeville to get any medical....

Tom: Nah nah

Johnson: You go to Nashville to get your medical, how often do you go.

Peggy: I go about every three to four months.

Johnson: Every three to four months. Okay

Peggy: Yeah and then, because I converted to AIDS. Last

Ashley: It's been a little longer than that (really low)

Michael: About two years ago, what'n it?

Peggy: Yeah, when I converted to full blown AIDS

Ashley: She had a lot of underlying health issues.

E.Brown: Comorbid

Michael: Yeah

Peggy: Yeah, we got.

Michael: Yeah. HIV for a lot of us is really not as much a problem as our other health issues. Yeah. I think our other health issues is hurting us more right now.

E.Brown: Could you elaborate

Michael: Like for instance I've had kidney failure twice. I've had a bacterial infection on my lungs. I'm diabetic. I'm high blood pressure. Me personally I would live with HIV AIDS any day over diabetic. Diabetes is the worst, to me one of the worst illness there are, because you just don't know how your body's going to feel you don't how your body is going to react. And it's just really really hard. And I've never been sick a day in my life I have had HIV and it did developed to AIDS, But I've never been sick till I got walking ammonia for overtime (speaking but not clear). I was diagnosed with diabetes and high blood pressure I developed a bacterial infection on my lungs and that's when I start have the kidney failure. You know. So to me that's more of a struggle right now than HIV/AIDS. You know. I'm maintain it good. And I'm doing really good at it... you know. And I know for Peggy. She's another one she's got other. That's really hard on her right now

Tom: I'm a diabetic and high blood pressure. (speaking but not clear)

Michael: Some of the medicine from like the diabetes. He's dealing with now that I just dealt with and it's rough on your body when you how severe diarrhea for two to three years and When I say severe diarrhea you go fifteen times a day it gets to person and you know it really and I've just come off one of the medicines from diabetes that did that to me. And that's what was doing it. I'm good. He's going through this right now where he just come off of it you know

Tom: (Says something low)

Michael: It's supposed to be a side effect but for a lot of people it is not a side effect ...you live with... I mean it's it's bad you know... you have to worry about... anytime I went to town I'd have to worry about it... anytime I want to do anything. I would have to take anti-diarrhea pills or something... you worry about if there is a bathroom nearby or something.

Johnson: So these comorbidities... Are there are results of the medication you are on or are these health issues you had before the AIDS and HIV.

Michael: The... it's the medicines

Johnson: Is it the medicine that you're on for the HIV?

Michael: Is not the HIV it's the other like for the diabetes. It's the medicines for that. As far as my...the medicines I started for HIV...I'm on my second regimen. My first regimen worked wonderful...uhh my T. cells were like twelve hundred... at that time I thought I knew everything I thought well I can come off of it I'm doing good. So I did come off the medicines for a couple years. And then that's when it start going down now my second round of medicines which I have not come off of I've never skipped the doses.

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