Ryan White Part A HIV Health Services Planning Council

Middlesex-Somerset-Hunterdon Transitional Grant Area

Needs Assessment

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Institute for Families
School of Social Work
Rutgers, The State University of New Jersey

Principal Investigator
Donna Van Alst, PhD

Project Director
Theresa Fox, MSW

Project Coordinator
Pamela Simone

Research Assistants
Joseph Gallo, MPH
Han Le, BASW
Roxanna Ast, MSc

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Introduction

Since 1996, the Middlesex-Somerset-Hunterdon tri-county area in New Jersey has been a recipient of Part A funds under the Ryan White HIV/AIDS Treatment Extension Act of 2009 (P.L. 106-345) (previously known at the Ryan White Comprehensive AIDS Resources Emergency (CARE) Act). The Ryan White Part A program provides emergency funds for local areas that are severely and disproportionally impacted by the HIV/AIDS epidemic. The Middlesex-Somerset-Hunterdon HIV Health Services Planning Council plays an instrumental role in ensuring the local availability of HIV/AIDS services in the Middlesex-Somerset-Hunterdon Transitional Grant Area (TGA). An integral part of the planning process involves conducting a needs assessment on an annual basis. As mandated by the Ryan White legislation, Planning Councils are required to assess (1) the needs of people living with and at-risk for HIV/AIDS within the geographic region, (2) the ability of the community to meet their needs, and (3) barriers to care.

The Middlesex County Office of Human Services, which is charged with administrating the Part A program serving Middlesex, Somerset and Hunterdon counties, contracted with the Institute for Families (IFF), a research center at the Rutgers University School of Social Work, to conduct a comprehensive needs assessment between December 2015 and September 2016.

The goals of the 2016 needs assessment were to identify and assess:

- The medical and social service needs of people living with or at-risk for HIV/AIDS in the TGA;
- The degree to which those needs have been met by the current system of care;
- Community resources that exist to meet needs; and,
- Barriers to medical care and social services.

The following report details the findings from the needs assessment that focused on two key populations. First, the needs of people living with HIV who are currently engaged in local HIV services were examined to determine the extent to which currently-funded services are meeting their needs. Additionally, the needs of individuals at risk of contracting HIV were examined to assess issues facing at-risk and newly-diagnosed populations.

The report is organized in the following manner. The report begins with a brief literature review on the needs of people living with HIV. Second, epidemiological data for New Jersey and the

Middlesex-Somerset-Hunterdon Transitional Grant Area are explored. The next sections present detailed findings from the studies that focused on the needs of people living with HIV and the needs of those at risk for the disease, along with a description of study methods. The final section of the report summarizes the key findings from both surveys.

Literature Review

People living with HIV/AIDS (PLWHA) have a wide array of needs that are related to entering and remaining in care and treatment. A number of studies have assessed needs among PLWHA to understand which needs are the most important and which are not being met. A nationwide study conducted in 2013 indicated that housing, substance abuse services, and mental health services were identified as the three greatest needs for PLWHA (Lennon et al., 2013). The results from that study also showed that dental care, employment assistance, and mental health services were the top needs not being met (Lennon et al., 2013).

Dental Care

The gap in dental care services was supported by another study that indicated that a majority (52.4%) of nearly 2,500 individuals with HIV surveyed had not seen a dentist in more than two years (Fox, Tobias, Bachman, Rajabium, & Verdecias., 2012). Out of the 2,500 PLWHA surveyed, 48.2% reported an unmet oral health-care need since testing positive for HIV, and 63.2% rated the health of their teeth and gums as "fair" or "poor" (Fox et al., 2012). Relatedly, another study focusing on the role of case management found that PLWHA had higher levels of oral health needs compared to the general population, but having case managers to coordinate care for clients' oral health needs helped more PLWHA become connected to oral health care and receive needed services (Lemay, Kretsedemas, & Graves, 2010).

Housing

The literature also identified housing as a fundamental unmet need for PLHWA. There is a direct relationship between health, housing, and other social factors that influence the health and well-being of PLWHA (Chambers et al., 2014). Chambers et al. (2014) found that housing supports the physical, mental, emotional, and social well-being of PLWHA. Individuals who are homeless or living in marginal conditions have an elevated burden of infection with HIV (Chambers et al., 2014). Studies indicate that being homeless or marginally-housed is common among PLWHA and is associated with poorer levels of access to medication and lower levels of medication adherence (Milloy, Marshall, Montaner, & Wood, 2012). Homelessness and

marginal housing are also associated with depression and substance abuse in PLWHA (Milloy et al., 2012).

Substance Abuse and Mental Health

Substance abuse and mental health services are two affiliated areas of high need for PLWHA. One study found that challenges such as financial concerns and limited transportation were significant barriers for PLWHA attempting to access mental health and substance abuse treatment. Positive client-provider relationships, accessible services, and case manager availability were influential in PLWHA accessing specialized services (Orellana et al., 2015). Martin and Wang (2013) found that Alcohol and Drug Abuse Programs (ADAPs) were partially responsible for the gap in substance abuse treatment. ADAPs could provide access to medication-assisted therapies for substance abuse treatment for a significant number of PLWHA, but these medications have not been widely covered in treatment program formularies.

Another large study in an urban clinic looked at the needs of PLWHA who had dropped out of care and were later re-engaged (Pecoraro et al., 2013). Dropping out was associated with substance abuse, unstable housing/homelessness, mental health problems, incarceration, and problems with HIV medications (Pecoraro et al., 2013).

Food and Transportation

Food and transportation were also high priority needs for PLWHA reflected in the literature. One study showed a link between food insecurity and poor medication access and adherence (Kalichman et al., 2014). This study also found a link between the need for food and the need for transportation. This study attests that PLHWA who had poor medication adherence also struggled with food insecurity and suggests that addressing basic survival needs by providing access to food and transportation services would meet a major need for PLWHA (Kalichman et al., 2014). Another study specifically identified transportation as one of the highest needs for PLWHA living in rural areas (Pellowski, 2013). Further, lack of transportation was connected to poor medication adherence and poor medical outcomes (Pellowski, 2013).

Epidemiological Profile

According to the Center for Disease Control and Prevention (CDC, 2001), the first cases of acquired immunodeficiency syndrome (AIDS) were reported in the United States in June 1981. The number of cases and deaths among persons with AIDS increased rapidly during the 1980s. AIDS incidence peaked in 1992 at 202,520 cases (CDC, 2001). The first drugs to treat the

human immunodeficiency virus (HIV) were introduced in the early 1990s to reduce the occurrence of deadly opportunistic infections (U.S. Food & Drug Administration, 2016). Additional medical advancements and new pharmaceutical treatment options have slowed the progression of symptoms associated with HIV, allowing PLWHA to live longer and healthier lives (Omobosola, 2003). Today, an estimated 1.2 million people are living with HIV in the United States (CDC, 2016). Between 2000 and 2009, more and more drug combinations were tested to reduce pill burden, and work was begun to improve the HIV screening process (U.S. Food & Drug Administration, 2016). In more recent years, testing has improved to shorten the window between testing and diagnosis, and medications have entered generic status, lowering the costs of treatment (U.S. Food & Drug Administration, 2016).

Initially, attention was drawn to HIV/AIDS through its seemingly singular impact on young gay men. However, HIV risk impacts all sectors of the population regardless of race, sexual orientation, age, or gender. Some groups, however, have been severely and disproportionately impacted. The following section examines the impact of the HIV epidemic in the Middlesex-Somerset-Hunterdon TGA.

Middlesex-Somerset-Hunterdon Transitional Grant Area

The Middlesex-Somerset-Hunterdon TGA includes three central New Jersey counties and occupies a total of 1,053 square miles. The TGA is centrally located between New York and Philadelphia, two major port cities on the Eastern seaboard. The area serves as a major transportation corridor and, for this reason, has experienced significant increases in population and economic activity over the last decade. The TGA is densely populated and divided into 72 municipalities that range in classification from rural to urban.

According to the 2010-2014 American Community Survey, an estimated 1,279,496 individuals reside within the tri-county area, accounting for 14.4% of New Jersey's population (United States Census Bureau, 2010). Middlesex County has the largest portion of the TGA's population with 824,046 residents, followed by Somerset County (328,704), and Hunterdon County (126,746) (United States Census Bureau, 2010).

The largest racial/ethnic group in the TGA is White (56%), followed by Hispanic (17%), Asian (16%), Black/African American (8%), and other races or ethnicities (2%). Both Caucasians and Asians are over-represented in the TGA when compared to the demographics of the State of New Jersey. Of the three counties in the TGA, Middlesex County has the largest proportion of

residents who identify as Asian (24%), Hispanic (19.9%), or Black/African American (11.2%). Hunterdon County has the largest proportion of individuals identifying as White (92%) (United States Census Bureau, 2010).

Overall, the TGA has a lower rate of poverty when compared to state and national poverty rates. Within the TGA, 8.2% of Middlesex County residents, 4.7% of Hunterdon's residents, and 4.1% of Somerset's live below the poverty line, compared to the poverty rates of 11% in New Jersey and 14.5% in the nation (United States Census Bureau, 2014).

Key Points:

- The TGA accounts for 14.5% of the New Jersey population and is densely populated.
- The largest racial/ethnic group in the TGA is White (56%), followed by Hispanic (17%), Asian (16%), and Black/African American (8%), and those of other race/ethnicities (2%).
- Middlesex County has the largest proportion of racial/ethnic minorities in the TGA (38%).
- A smaller proportion in the TGA lives below the poverty line compared to New Jersey and the United States.

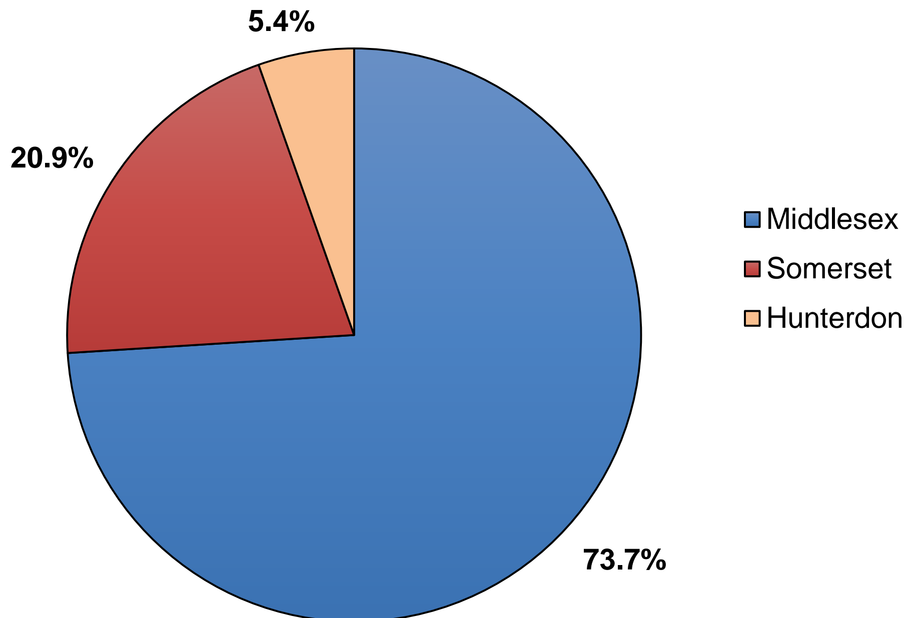
The HIV/AIDS Epidemic

New Jersey ranks sixth in the nation in the number of adults and adolescents diagnosed with HIV (CDC, 2015). The Middlesex-Somerset-Hunterdon TGA accounts for 7.6% of all New Jersey cases. The number of HIV/AIDS diagnoses in the TGA increased throughout the 1980s and early 1990s. However, the number of new HIV/AIDS cases has declined steadily since 1994.

Demographics

In 2015, there were 37,435 people living with HIV/AIDS in New Jersey, 2,920 of whom resided in the Middlesex-Somerset-Hunterdon TGA (State of New Jersey Department of Health, 2015). As shown in Figure 1 below, the majority of PLWHA living in the TGA in 2015 were concentrated in Middlesex County (State of New Jersey Department of Health, 2015).

Figure 1. Persons Living with HIV by County in 2015 (n=2920)



Risk Factors

Across the United States, men who have sex with men (MSM) are the most common patient group. However, New Jersey differs from the majority of the nation in that the most common mode of transmission is heterosexual contact (CDC, 2015). The Middlesex-Somerset-Hunterdon TGA also has a high proportion of clients who contracted HIV through heterosexual contact.

Women are typically infected with HIV from either intravenous drug use or from having sexual intercourse with men who are living with HIV. Women of a certain age are no longer at risk for pregnancy and are less likely to protect themselves with condoms during intercourse, which puts them at risk for HIV (Andany, Kennedy, Aden, & Loutfy, 2016).

Age

In terms of age, the demographic distribution of HIV/AIDS in the TGA mirrors that of the state (Figure 2). In New Jersey and in the TGA, the epidemic is concentrated among adults. Approximately 18% of PLWHA in the TGA are ages 25-44, 36% are ages 45-54, and 33% are over age 50. However, adults in these age groups constitute a much smaller portion of the general population, indicating that the epidemic is highly prevalent in these age categories.

See Table 1. for comparison. The aging of the population living with HIV may be attributed to improved medical care and treatment which contribute to prolonged life expectancy and an increase of reported cases in older adults (NJDHSS, 2003). With increased longevity and a better quality of life due to better treatments, the number of older adults living with HIV is expected to increase in the future as well (CDC, 2016).

Race/Ethnicity

The HIV/AIDS epidemic has severely and disproportionately impacted racial and ethnic minorities, particularly Black/African Americans and Hispanics in New Jersey. While Black/African Americans represent 8% of the total population in the TGA, this group accounts for 36% of all residents living in the TGA with HIV/AIDS. According to the CDC, a lack of awareness of HIV status among positive Black/African American individuals can lead to a higher rate of infection in this group (CDC, 2016). Late diagnosis of HIV infection is common among Black/African American individuals, which results in missed opportunities to obtain early medical care and prevent transmission to others (CDC, 2016). Black/African American people experience a higher poverty rate than other racial/ethnic groups (CDC, 2016). The socioeconomic issues related to this phenomenon directly and indirectly affect the health of those who are living with HIV or are at-risk for contracting HIV due to a lack of high-quality health care, safe and affordable housing, or HIV prevention (CDC, 2016).

While a disproportionate impact in the Black/African American community is observable in the TGA, this phenomenon exists in the Hispanic population as well. Hispanic people represent 16% of the general population, and this group accounts for 29% of PLWHA in the TGA. White people comprise 55% of the general population, but only 31% of PLWHA. People of other or unknown races or ethnicities are collectively underrepresented among PLWHA in the TGA. It is unclear if this is true across all racial/ethnic groups as this figure is provided in aggregate in the epidemiological profile.

Table 1. Demographics of PLWHA in the TGA by Race/Ethnicity, Gender and Age

Demographic Group / Exposure Category	General Population of TGA 12/31/2014		PLWHA in TGA as of 12/31/2014	
Race/Ethnicity	***Number***	***% of Total***	***Number***	***% of Total***
White, not Hispanic	709,623	55%	893	31%
Black, not Hispanic	106,184	8%	1,049	36%
Hispanic	207,189	16%	852	29%
Other/Unknown	271,936	21%	95	4%

Table 1. Demographics of PLWHA in the TGA by Race/Ethnicity, Gender and Age				
Demographic Group / Exposure Category	**General Population of TGA 12/31/2014**		**PLWHA in TGA as of 12/31/2014**	
Total	**1,294,932**	**100%**	**2,889**	**100%**
Gender	***Number***	***% of Total***	***Number***	***% of Total***
Male	636,001	49%	1,887	65%
Female	658,931	51%	1002	35%
Total	**1,294,932**	**100%**	**2889**	**100%**
Age	***Number***	***% of Total***	***Number***	***% of Total***
<14	235,812	19%	7	<1%
13-24	170,276	13%	55	2%
25-44	340,405	26%	780	27%
45-64	369,856	29%	1967	68%
65+	178,583	14%	80	3%
Total	**1,294,932**	**100%**	**2889**	**100%**

Gender

In New Jersey as well as the TGA, the majority of PLWHA are male (Table 1). The rates of women living with HIV in New Jersey are the fifth highest in the country; 35% of those who are infected are women. The incidence rate for women is on the rise, particularly among Black/African American women (New Jersey Department of Health, 2014).

Key Points:

- New Jersey ranks 6th in the nation for the number of adults and adolescents diagnosed with HIV (CDC, 2016).
- The majority of PLWHA living in the TGA reside in Middlesex County.
- The largest patient group contracted HIV through heterosexual contact.
- The majority of PLWHA in the TGA are adults age 45 and older.
- African American and Hispanic individuals are disproportionately impacted by the HIV/AIDS epidemic.
- The majority of PLWHA in the TGA are male. However, the rate of infection among women is on the rise.

Study I: Client Survey

Method

The Rutgers School of Social Work, Institute for Families, Office of Research and Evaluation conducted the 2016 needs assessment for the Middlesex-Somerset-Hunterdon HIV Health Services Planning Council. The Planning Council is funded by the Middlesex County Office of Human Services through a federal grant from the United States Department of Health and Human Services Health Resources and Services Administration HIV/AIDS Bureau. The goal of the Planning Council is to prioritize local care and treatment services for HIV positive individuals residing in Middlesex, Somerset, and Hunterdon counties. The needs assessment provides data that will be used to guide to the Planning Council in undertaking this task.

To assess the needs of individuals living with HIV/AIDS in the transitional grant area survey data was collected. This section provides a brief description of how this component of the needs assessment was conducted.

Sample

Subjects were invited to participate at community agency sites that provide Ryan White-funded services for individuals with HIV/AIDS in the tri-county area. Working in collaboration with agency staff, the research team conducted interviews in private spaces at these sites with PLWHA who came for their regular appointments.

Research Design

The needs assessment study employed a cross-sectional, non-experimental research design. Non-experimental designs are appropriate to examine the point-in-type condition of a particular population, such as the needs of people living with HIV. They do not, however, allow for the identification of causal relationships. Hence, while this study describes the needs of various populations living with HIV/AIDS, causal relationships between having HIV and any specific needs cannot be assumed.

Measures

The survey instrument was developed for this study by the research team, in collaboration with the Middlesex-Somerset-Hunterdon HIV Health Services Planning Council and with input from consumers. The survey began with a brief assent script describing the study and ensuring

participants knew that their responses would be kept confidential and their participation was voluntary.

The first part of the survey focused on client needs and receipt of services. Respondents first answered an open-ended question about their most important service need for their HIV/AIDS-related health. The second question required respondents to indicate on a Likert-type scale (ranging from “Not at All” to “A Great Deal”) the extent to which they have a need for 29 different services allowable through the Ryan White Part A program. In addition, respondents indicated whether they are currently receiving each service. The final question in this section allowed respondents to indicate why they were not receiving a service if they needed it.

The next section of the survey collected demographic information about respondents including age, ethnicity, race, year of diagnosis, gender, and insurance status. Additional questions in this section explored insurance status, as well as changes in insurance related to the Affordable Care Act.

Data Collection

The survey was administered in-person at local Ryan White service provider locations throughout the community. Researchers spent three to four days a week at sites throughout Middlesex, Somerset, and Hunterdon counties until 268 surveys were completed with PLWHA. One staff member at each provider site was designated to recruit potential survey participants on clinic days where private space to conduct the survey could be provided. The staff member invited the potential participant to complete the needs assessment survey when they arrived for their service appointment.

Each site designated a secure and private space for the researcher to administer the needs assessment survey. Research assistants read an assent script to each participant and reminded them that they could skip any questions that made them feel uncomfortable or that they did not wish to answer. Upon confirming assent to participate, the researcher read through the survey to elicit responses from the participant. After completing the interview, participants received a $25 Target gift card for their participation.

Data Analysis

Data were analyzed using SPSS (Version 22). Frequencies were the main statistical technique used in the analysis.

Qualitative data were coded and explored to identify common themes that emerged from the data.

Limitations

This study has several limitations. First, the sample was not randomly selected. Rather, individuals who were engaged in care and had medical appointments comprised a large part of the sample, likely resulting in overrepresentation of people who have access to medical care. The research team also did not have access to PLWHA who were not receiving services through the Ryan White program. Second, needs in the context of this survey are limited to those that have been previously identified as those services that are understood to have an impact on HIV care. Finally, there were some variations in representation by age.

Findings

Demographics of Participants

Gender

A total of 268 PLWHA residing in the Middlesex, Somerset, and Hunterdon tri-county area completed the survey. The race/ethnicity, gender, and age of respondents are detailed in Table 2 below.

Of the 268 participants, 52% were male, 47% were female and 1% were transgender. Given that 42% of those who received Ryan White services in the TGA are female, women slightly over-sampled in this study; resulting in men being slightly under-sampled. The sampling of transgender persons was reflective of the population served through Ryan White program in the TGA.

Table 2. Demographics of PLWHA Respondents Compared to All PLWHA in TGA

Demographic Group / Exposure Category	PLWHA in TGA Under Ryan White Care as of 12/31/2014		Participants in TGA that were Surveyed	
Race/Ethnicity	***Number***	***% of Total***	***Number***	***% of Total***
White, not Hispanic	270	21%	51	19%
Black, not Hispanic	533	41%	110	41%
Hispanic	439	34%	80	30%
Other/Unknown	44	4%	27	10%
Total	**1,286**	**100%**	**268**	**100%**
Gender	***Number***	***% of Total***	***Number***	***% of Total***
Male	736	57%	139	52%
Female	541	42%	126	47%
Transgender	9	1%	3	1%
Total	**1,286**	**100%**	**268**	**100%**
Age	***Number***	***% of Total***	***Number***	***% of Total***
<13	64	5%	1	<1%
13-24	85	7%	8	3%
25-34	177	14%	24	9%
35-44	225	17%	30	11%
45-54	382	30%	94	35%
>55	353	27%	111	41%
Total	**1,286**	**100%**	**268**	**100%**

Race/Ethnicity

The race/ethnicity of this study's participants is as follows: 41% were non-Hispanic Black, 30% were Hispanic, and 19% were White. The remaining 10% were of unknown or other race or ethnicity. The sample population was generally representative of the epidemic in the TGA among Black, non-Hispanic residents, but the population of both White and Hispanic PLWHA in the TGA was slightly underrepresented.

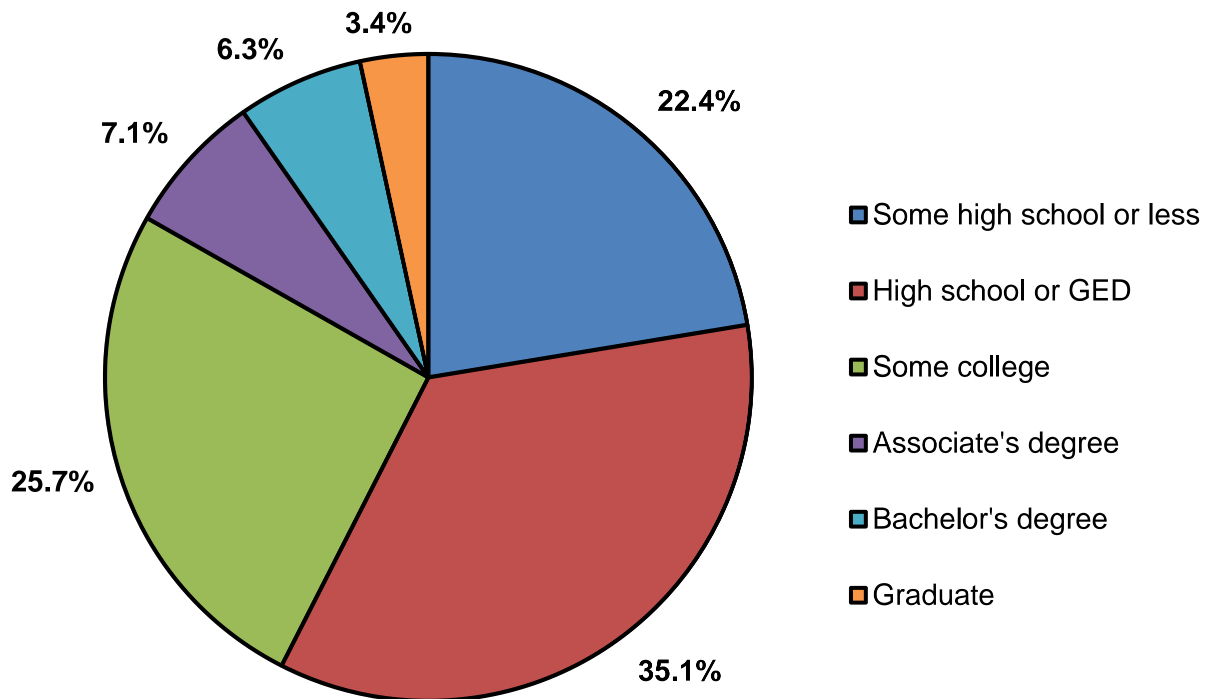
Age

Data were collected from participants of a variety of ages, from under 13 years to over 55 years. Less than 1% of those surveyed were less than 13 years old, 3% were between 13 and 24, 9% were between 25 and 34, 11% were between 35 and 44, 35% were between 44 and 54, and 41% were 55 years old or older. Accessing young people under the age of 24 is more difficult due to hesitation of providers, parents, and the youth themselves to participate in HIV-specific surveys. Some youth who are under the age of 18 may not even be aware of their status. Those who were between 35 and 54 years old were also slightly under-represented in the needs assessment's sample. A possible explanation for this under sampling is that the majority of interviews took place in a doctor's office after a medical appointment. It has been suggested that older adults are more likely to have health insurance and are thus more likely to keep their medical appointments (Vance, Mugavero, Willig, Raper, & Saag, 2011). As such, older adults might have been present at doctors' offices more frequently and might have been more likely to end up in the survey sample.

Level of Education

As shown in Figure 2, the majority of the participants surveyed had obtained at least a high school diploma or GED (77.6%). Less than a quarter had not earned a high school diploma or GED (22.4%). More than 7% of respondents reported that they had earned an Associate's degree, 6.3% a Bachelor's degree, and 3.4% a graduate degree.

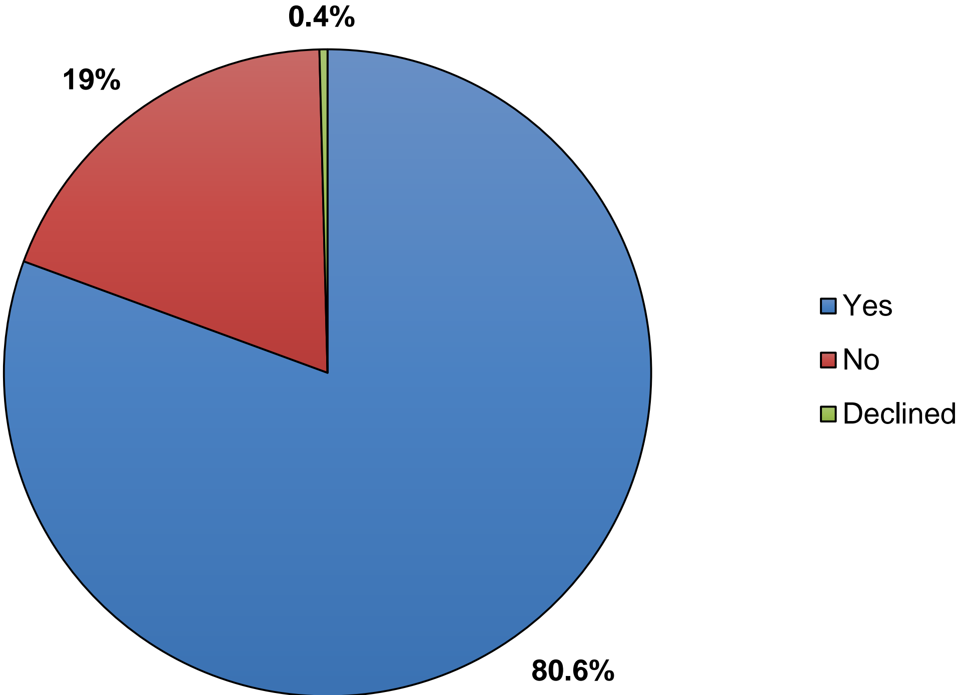
Figure 2. Education Level of PLWHA (n=267)



Place of Diagnosis

A majority of participants, or 80.6%, had been diagnosed with HIV in New Jersey, while 19% were diagnosed elsewhere. See Figure 3. Few respondents declined to answer this question.

Figure 3. Respondent PLWHA Diagnosed in New Jersey (n=268)

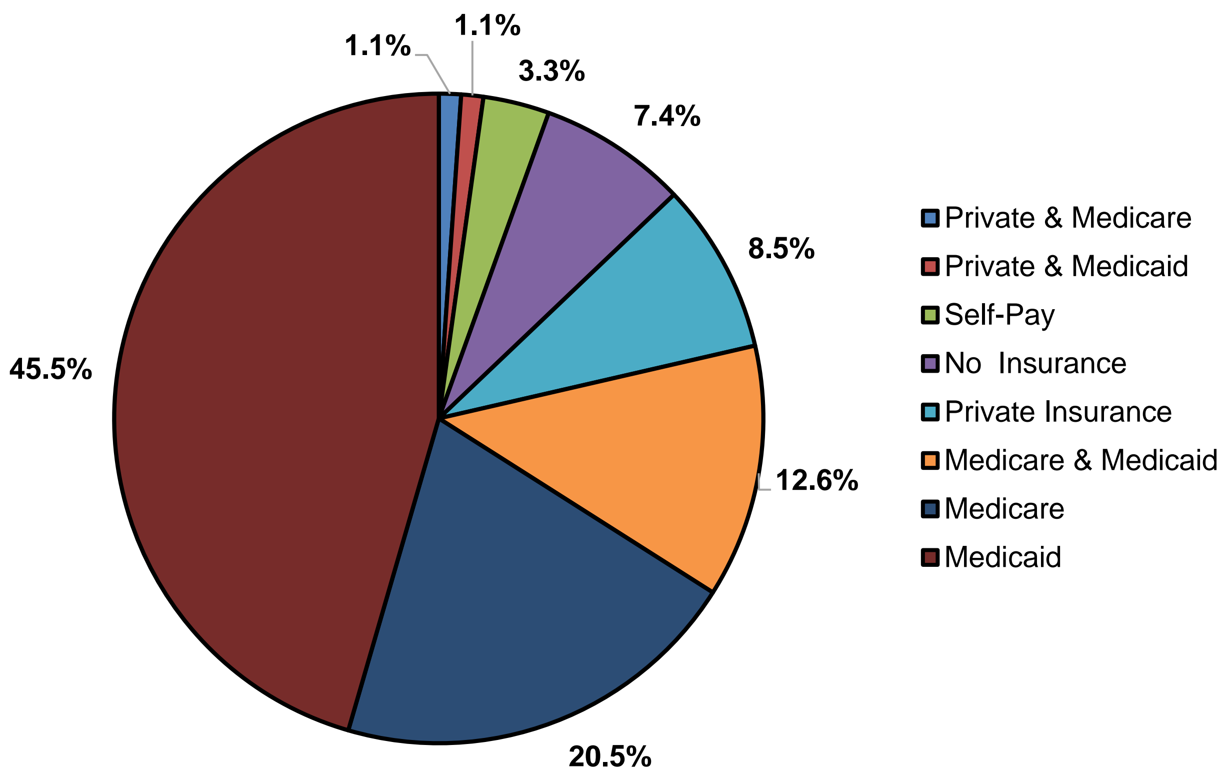


Health Insurance

Participants were asked about their insurance status and whether they had purchased insurance through the Affordable Care Act (ACA).

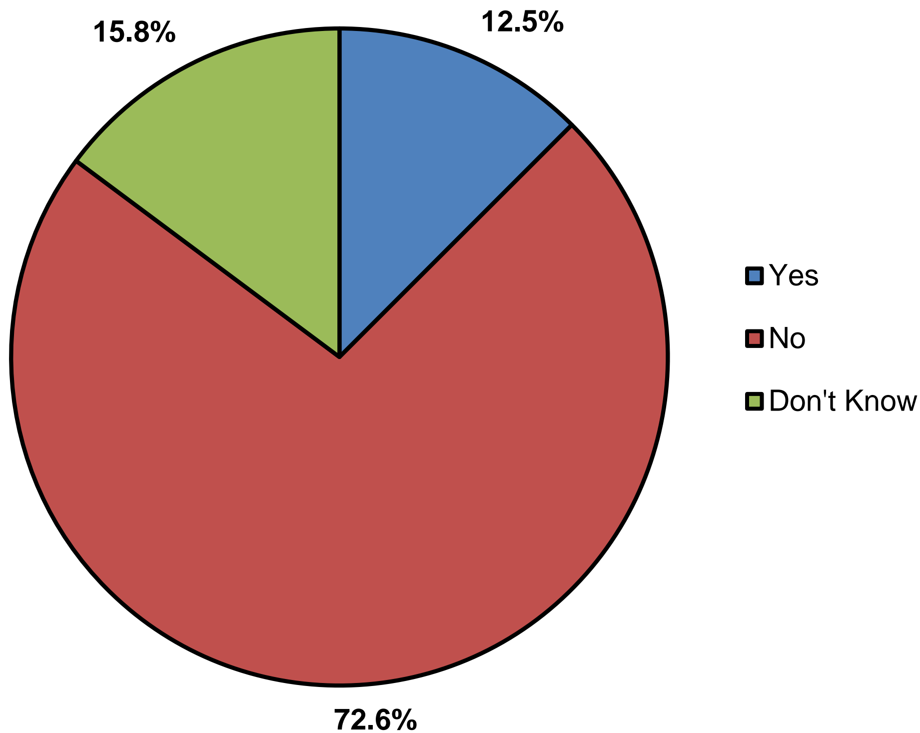
As indicated in Figure 4, Medicaid was the most common type of health insurance among survey respondents (45.5%). An additional 20.5% of respondents reported having Medicare. Slightly more than 7% of respondents reported being uninsured.

Figure 4. Types of Insurance Amongst PLWHA (n=268)



With the implementation of the Affordable Care Act (ACA), 12.5% of the participants surveyed transferred to Medicaid. Nearly 16% of respondents did not know if their insurance had changed since implementation of the Affordable Care Act. Participants indicated their medical case manager processed the paperwork. Out of the 268 participants, 72.6% did not transfer to Medicaid under the Affordable Care Act. Most participants did not purchase insurance through the ACA. Surveyed clients stated they could not afford even the most basic necessities if they were required to pay for insurance out of pocket. See Figure 5.

Figure 5. Survey Transfers to Medicaid under the Affordable Care Act (n=268)



As a result of the ambiguity of the survey data collected, supplemental CAREWare data was analyzed to assess the impacts of the ACA on Ryan White service users. Table 3 shows the extent to which all clients throughout the TGA changed their insurance status during the implementation of the ACA. This table was derived from service utilization data collected

through CAREWare for all Ryan White clients in the TGA. Between 2011 and 2015, the number of uninsured people decreased by 150. There are 134 additional people enrolled in Medicaid in 2015 compared to 2011, before the implementation of the ACA. Still, one in five people who receive Ryan White services in the TGA are without insurance.

Table 3. Insurance Status of PLWHA in the TGA, Pre- and Post-ACA

	Number	*Percent*	*Number*	*Percent*	*Change*
Medicaid	319	27%	473	40%	+13%
Medicare	182	15%	219	18%	+3%
Marketplace Exchange	N/A	0%	35	3%	+3%
Private	243	21%	172	14%	-7%
Without Insurance	415	35%	265	22%	-13%
Other	14	1%	4	1%	-
Unknown	8	1%	21	2%	+1%

Summary of CAREWare Health Insurance Sub-study

Nineteen percent of Ryan White service users experienced a change in insurance type. Figure 4 and Table 3 highlight the need for additional supportive services to help clients navigate the healthcare system, particularly as related to changes in insurance type.

Comorbid Risk Factors for PLWHA

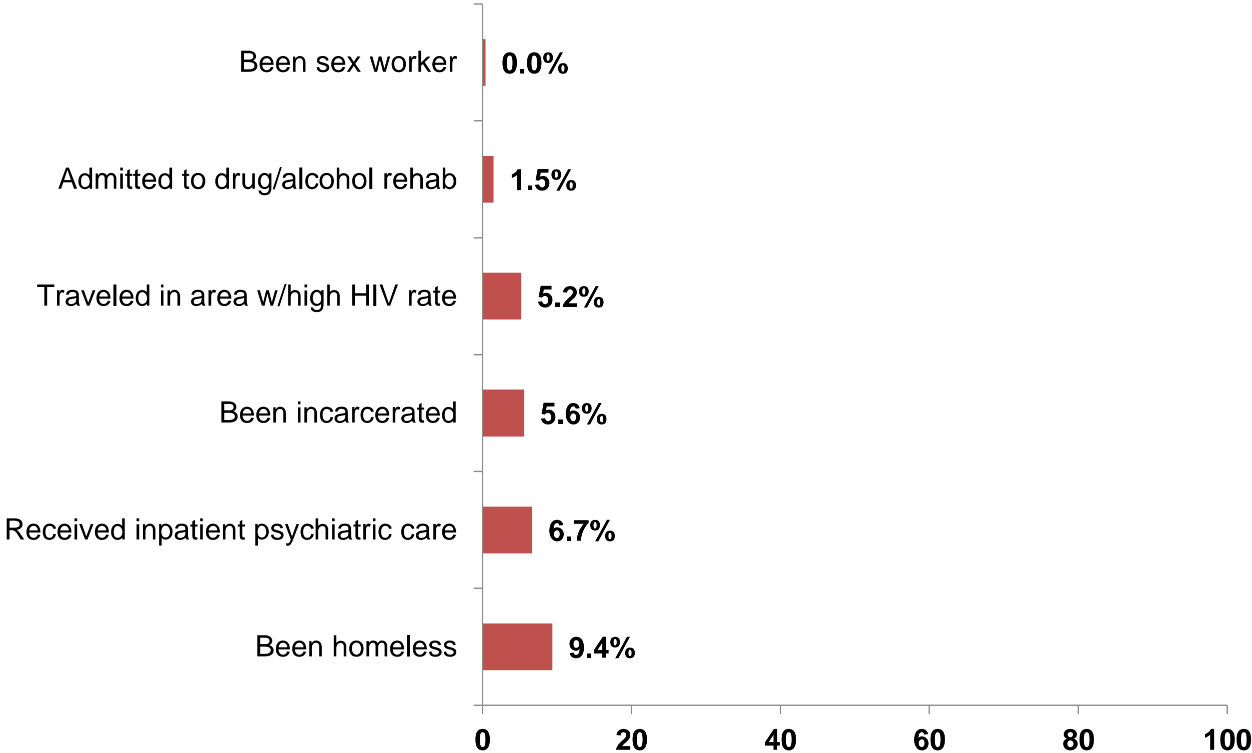
Respondents were asked to identify whether they experienced a number of risk factors that add to the cost and complexity of providing care (Figure 6). Out of the 268 participants, 9.4% had been homeless in the past 12 months. It is important for people living with HIV to have safe, decent and affordable housing (Shubert & Bernstine, 2007). With stable housing, people living with HIV are better able see their health care provider regularly, take their HI

V medications consistently and have comprehensive access to health care and supportive services (Aidala, Lee, Abramson, Messeri & Siegler, 2007). Individuals with HIV who are homeless or lack stable housing are more likely to delay HIV treatment, have poorer access to regular care, and are less likely adhere to taking medications (Aidala et al., 2007). People with HIV risk losing their housing due to increased medical costs, limited income, and/or a reduced ability to keep working due to health related issues. Securing stable housing is a key factor achieving successful HIV outcomes (USDHHS, 2016).

Of those surveyed, 5.6% shared that they had been incarcerated in the past 12 months. Clients that have been incarcerated may have additional needs. For example, clients might be facing homelessness, poverty, and other chronic health problems (Wilson, 2013).

In addition, 6.7% respondents had received inpatient psychiatric care in the past 12 months. Persons with mental illness are at increased risk for contracting and transmitting HIV (Blank, Himelhoch, Walkup, & Eisenberg, 2013). People receiving mental health care are up to four times more likely to be infected with HIV (Blank et al., 2013). This increased risk is thought to be contributed to high rates of substance abuse, risky sexual behavior, sexual victimization, and prostitution (Blank et al., 2013).

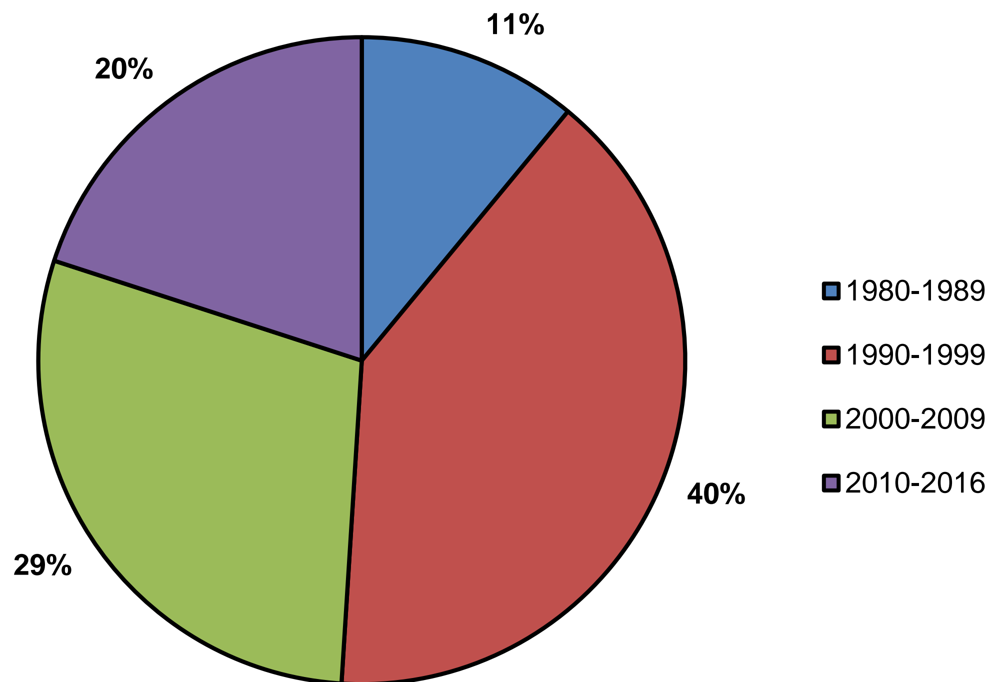
Figure 6. PLWHA Exposure to Risk Factors in the Last 12 Months (n=268)



Year of Diagnosis

Nearly half of PLWHA in the TGA were diagnosed in the last 15 years, 40% were diagnosed between 1990 and 1999, and the remaining 11% were diagnosed between 1980 and 1989. Advancements in medications and higher levels of client engagement in systems of care have contributed to PLWHA living longer with HIV/AIDS. See Figure 7.

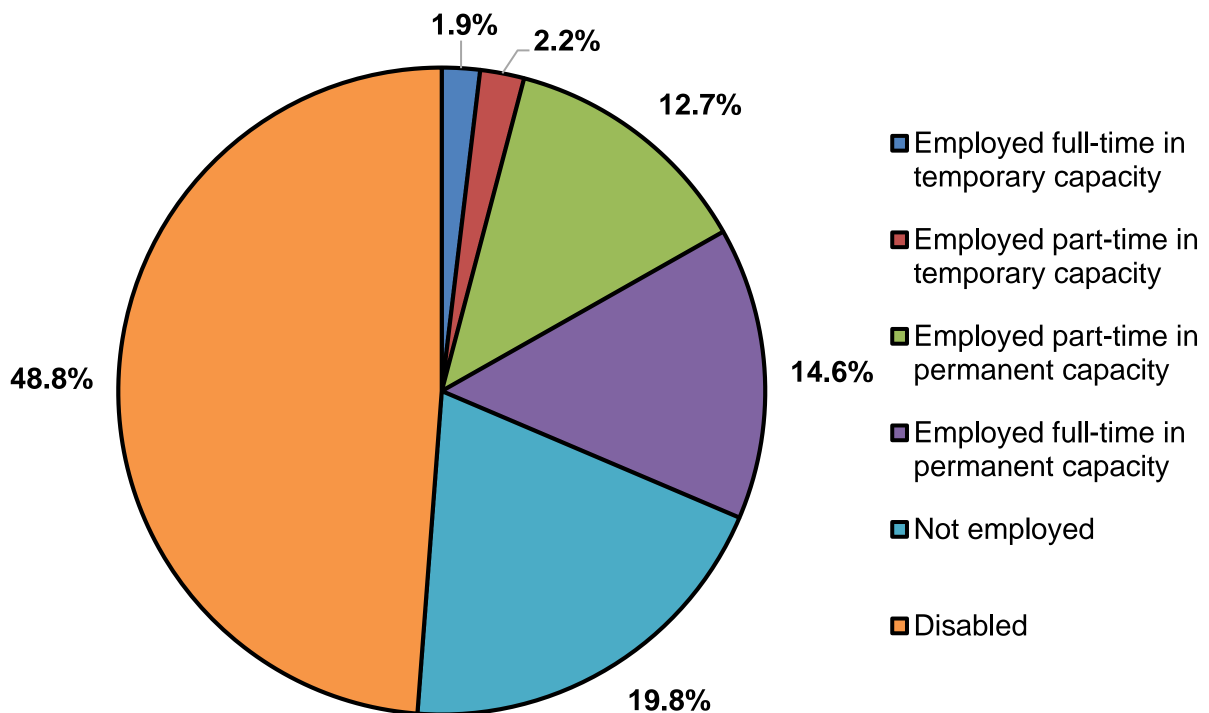
Figure 7. Year of Diagnosis of PLWHA (n=268)



Employment Status

Almost half of the participants surveyed are receiving SSI/SSD benefits. As can be seen in Figure 8, 19.8% of the participants are not employed. Of the 268 participants surveyed, 14.6% are employed full-time in a permanent capacity, and 1.9% of participants are employed full-time in a temporary capacity. Since private health insurance is usually linked to work, it is consistent that 8.5% of participants have private insurance, 1.1% have private insurance and Medicare, and 1.1% have private insurance and Medicaid.

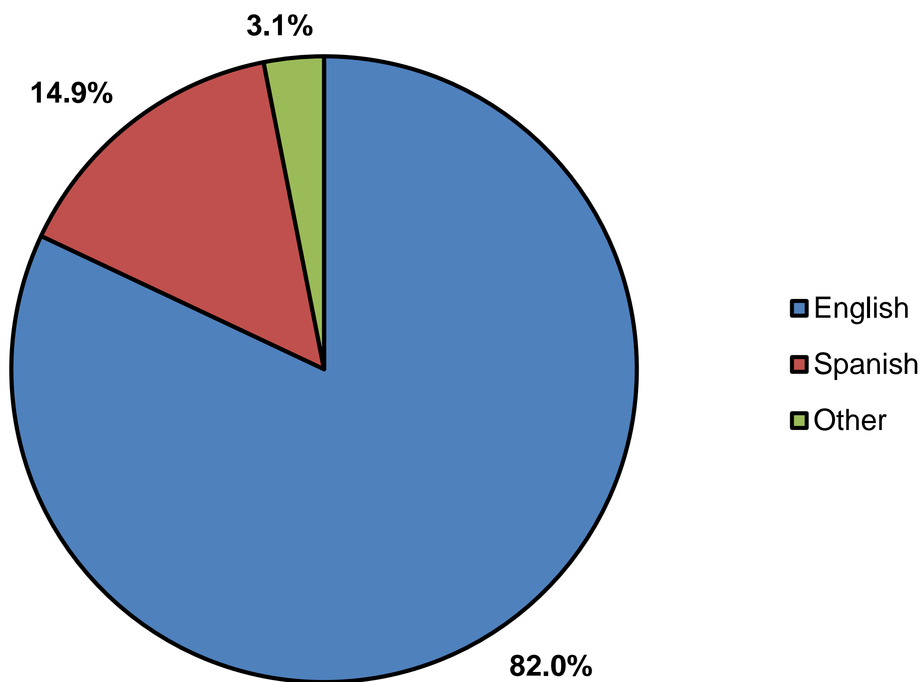
Figure 8. Employment Status of PLWHA (n=268)



Primary Language

English was the primary language of the majority of PLWHA surveyed. Although 14.9% indicated Spanish is their primary language and 3.1% spoke another language, 94.4% of the participants surveyed do not need linguistic services. As such, it seems that most of those surveyed can communicate in English. See Figure 9.

Figure 9. Primary Language of PLWHA (n=268)

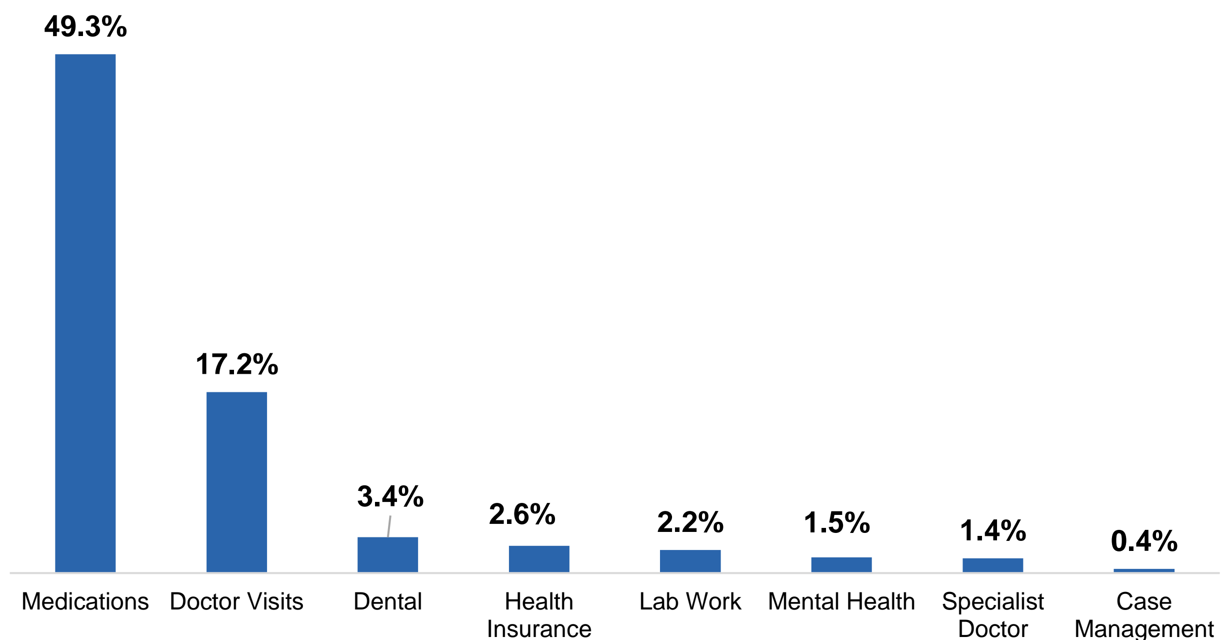


Most Important Service Needs

Participants were asked to identify their single most important service need in relation to their HIV/AIDS status. As Figures 10 and 11 illustrate, the most important core service need was medications, while the most important support service need was housing assistance (broadly defined as housing services including finding housing, rental assistance, and other services that promote housing stability).

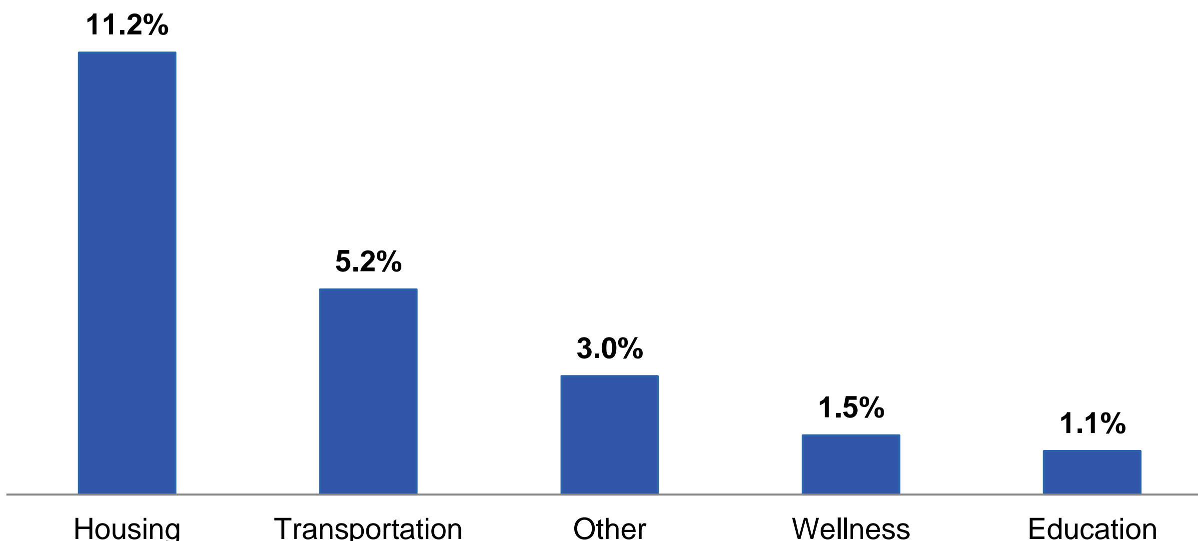
Clients need a wide range of core services. Medications were the most important service need for 49.3% of participants, while another 17.2% felt doctor visits were their most important need. Oral Health, Insurance, lab work mental health and specialist care were identified by 3.4%-to 1.4% the participants surveyed. Case management was the core service that very few people stated they need the most.

Figure 10. Most Important Core Service Needs for PLWHA (n=265)



Some participants reported their most important service need was a support service. According to the data, 11.2% reported housing as their most important service need. This is the third ranking service need overall, right after medications and doctor visits. Transportation was ranked as the second most important support service need, with 5.2% of respondents indicating so. Other participants felt wellness or education was their most important service need.

Figure 11. Most Important Support Service Needs for PLWHA (n=265)



A proportion of these findings may be explained by where the surveys were administered, as many interviews were conducted in the context of a doctor's office after a medical visit. As such, clients may have been focused more on healthcare related issues at that given time. Participants' feedback regarding transportation services indicated that these services are very unreliable, are habitually late, or do not show up at all.

Needs and Receipt of Services

Survey participants were asked to rate their need for services – regardless of whether or not they were currently receiving that service – on a four-point Likert scale in which 1 represents the response "Not at all" and 4 represents "A Great Deal." The frequency with which participants selected each response for each question is detailed in Table 4.

Participants needed key core services that pertain to their physical health a great deal. Of the participants surveyed, 90.6% reported needing HIV medical care/doctor visits a great deal, and 83.9% reported needing local HIV/AIDS pharmaceutical assistance a great deal. This data

suggests participants understand the importance of taking their medications and seeing the doctor. Of the 268 participants, 64.4% felt they needed dental care/oral health a great deal. While this service may not appear to be amongst the highest service needs, data presented in Figure 10 indicate the importance of this service for some clients. Although the majority of participants need case management to some extent, only 0.4% (see Figure 10.) felt it was the most important service need..

The majority of those interviewed did not need hospice or respite care. Hospice services are generally utilized by very ill patients. The majority of the surveys were administered at a doctor's office to clients actively engaged in care. Patients that need specialized services may be too sick to go to the doctor's office. This could explain why those needing specialized services were not well represented in the sample.

The vast majority of participants surveyed did not have service needs related to children. Almost all participants reported they did not need child care services, or pediatric developmental assessment and early intervention services. Childcare and developmental assessment services are related to children with HIV and covered by Ryan White Part D. Over 75% of the participants were over the age of 44. Services related to children become less critical to these individuals because they do not have children or their children have grown.

Table 4. How Much PLWHA Need Services

	Not at All	A Little	Some	A Great Deal
HIV medical care/doctor visits	1.1%	2.3%	6.0%	90.6%
Local HIV/AIDS	9.0%	2.6%	4.5%	83.9%
Dental care/oral health	16.1%	10.1%	9.4%	64.4%
Housing assistance services	44.9%	1.9%	3.0%	50.2%
Medical case management	24.8%	16.5%	15.8%	42.9%
Food services	45.7%	4.5%	10.9%	38.9%
Health insurance premium	61.8%	0.4%	5.7%	32.1%
Early intervention services	62.9%	6.1%	6.5%	24.5%
Emergency financial assistance	62.5%	2.7%	9.9%	24.9%
Non-medical case management	60.8%	4.5%	10.9%	23.8%
Mental health services	63.0%	6.8%	8.4%	21.8%
Psychosocial support services	65.0%	4.6%	10.6%	19.8%
Referral for health care/	67.7%	4.9%	9.9%	17.5%
Medical nutrition therapy	73.0%	4.2%	9.5%	13.3%
Health education and risk reduction	79.8%	3.1%	4.2%	12.9%
Legal services	84.4%	1.5%	4.2%	9.9%
Outreach services	86.8%	1.1%	4.9%	7.2%

Table 4. How Much PLWHA Need Services	Not at All	A Little	Some	A Great Deal
Rehabilitation services	87.1%	1.5%	4.9%	6.5%
Substance abuse treatment/	90.5%	1.1%	3.0%	5.4%
Home health care	89.8%	2.3%	3.4%	4.5%
Treatment adherence counseling	92.8%	2.2%	0.8%	4.2%
Home and community-based	93.9%	1.1%	0.8%	4.2%
Permanency planning	93.6%	1.9%	1.1%	3.4%
Linguistic services	94.4%	1.2%	1.0%	3.4%
Respite care	97.7%	0.0%	0.8%	1.5%
Pediatric developmental assessment	97.4%	1.1%	0.0%	1.5%
Child care services	98.1%	0.4%	0.0%	1.5%
Substance abuse services - residential	98.5%	0.4%	0.0%	1.1%
Hospice services	98.4%	0.00%	0.8%	0.8%

Most participants expressed needing medical case management at least a little. Case management plays an essential role in linking clients to services. Medical case management is implemented or supervised by a nurse and it includes coordination of medical benefits and specialty services. Medical case management is an essential service need for the majority of the participants even if they only feel that they need it ‘a little’, due the difficulty of navigating the health care system. Access to some of the other Ryan White services requires a case manager’s referral. Services such as food and transportation cannot be obtained without a referral from a case manager.

Health insurance premium and cost sharing assistance is a service need that 62.8%; 32% stated that it’s something they would need a great deal. This service involves financial assistance to cover the health insurance premium and/or co-pays for doctor visits, which can be so high that they constitute a barrier to treatment.

Over 50% of participants said they needed food services, and of those who needed this service, most said they needed it a great deal. Over 50% of participants reported needing housing assistance services a great deal. More than a third of participants indicated needing emergency financial assistance at least a little.

Less than half of the participants expressed a need for non-medical case management or referrals for health care or supportive services. Some of the participants said their nurse or

case manager refers them to anything they need. Other participants understood how to navigate their own non-medical needs. Nonmedical case management services support individuals in the TGA by promoting housing stability.

Of the participants surveyed, 35% expressed a need for psychosocial support. This service category is a very personal decision. Some clients feel it is important to surround themselves with individuals that understand their situation. Other individuals may be uncomfortable in a group setting. Psychosocial support is intended to promote stability in care.

Health education and treatment adherence counseling are services most participants did not need. Many of the interviews were conducted in a doctor's office after a medical appointment, and it is possible that the surveyed population already understands the importance of regular doctors' visits and treatment adherence. Due to various reasons, including frequent doctor visits and education, most participants likely already had an understanding of HIV transmission and how to reduce the risk of HIV transmission.

A limited number of respondents indicated that they needed legal services. Of the participants surveyed, 84.5% stated they did not need these services at all. Participants that needed legal services wanted assistance with writing wills and testaments and appointing a power of attorney. Some of the respondents had not looked into services yet or did not know such services existed.

Of those surveyed, 86.8% did not need outreach services at all. Participants were aware of their serostatus, and many of them have been living with HIV for a number of years. Given how they were recruited, these clients are currently enrolled and actively engaged in HIV care.

A small percentage of participants stated they need linguistic services.

Study II: At-Risk Assessment Study

Rationale

The information collected from this assessment will be used by the Planning Council to guide the annual prioritization of services and allocation of grant funds. This data is used to approximate the cost and complexity of those who are newly diagnosed and/or new to a system of care.

Measures

The purpose of this study is to measure the care needs of individuals at-risk of HIV who are living in the Middlesex, Somerset, and Hunterdon tri-county area. This information will provide a detailed description of the care needs of this population and how accessible these services are for the at-risk population.

Procedures

To collect data for the at-risk assessment study, locations were selected because a number of individuals who frequent these providers also receive HIV counseling and testing as part of the cadre of services offered. The researcher visited four different locations across the tri-county area: Elijah's Promise, Street Smart, Eric B. Chandler Health Center, and the 2015 Community Health Fair, the last of which was sponsored by Making It Possible to End Homelessness.

The surveys were administrated in-person in a private and confidential space. The researcher invited each potential participant to complete the at-risk assessment survey when they came in for their service appointment or when they came to the health fair. Each site designated a secure and private space for the researcher to administer the at-risk assessment survey. The researcher read an assent script to each participant and reminded them that they could skip any questions that made them feel uncomfortable or that they did not wish to answer. At the end of the survey, participants received a $25 gift card. Only the researchers on this project had access to the tracking sheet, and all project materials are kept in a locked cabinet. The data gathered from these interviews were coded and analyzed in SPSS.

Limitations

There were limitations to the study. The sampling pool was both small and not randomly selected, which hinders the validity and reliability of the at-risk research study. Future needs assessments shall consider having a larger sampling pool with a better representation of

diverse populations. A large number of the participants in this study were individuals interested in learning about their HIV status and are actively conscious about health related issues.

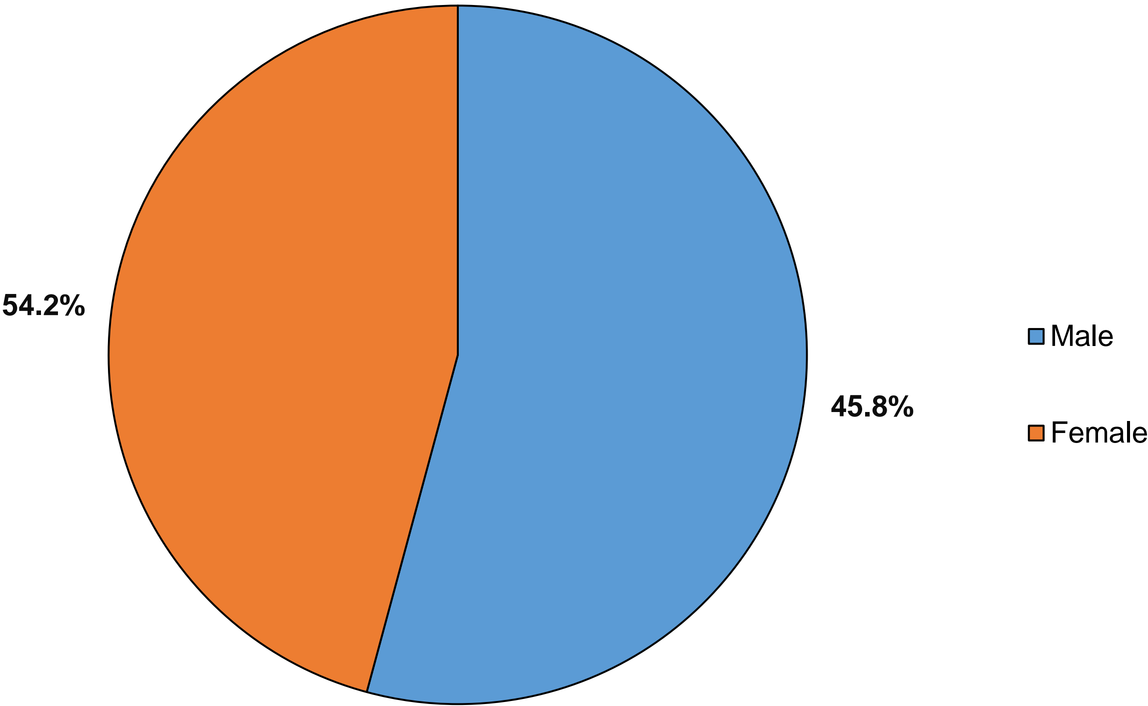
Demographics

A total number of 59 at-risk individuals residing within the Middlesex, Somerset, and Hunterdon tri-county area completed the assessment survey.

Gender

Of the 59 participants, 54.2% were male, and 45.8% were female. See Figure 12.

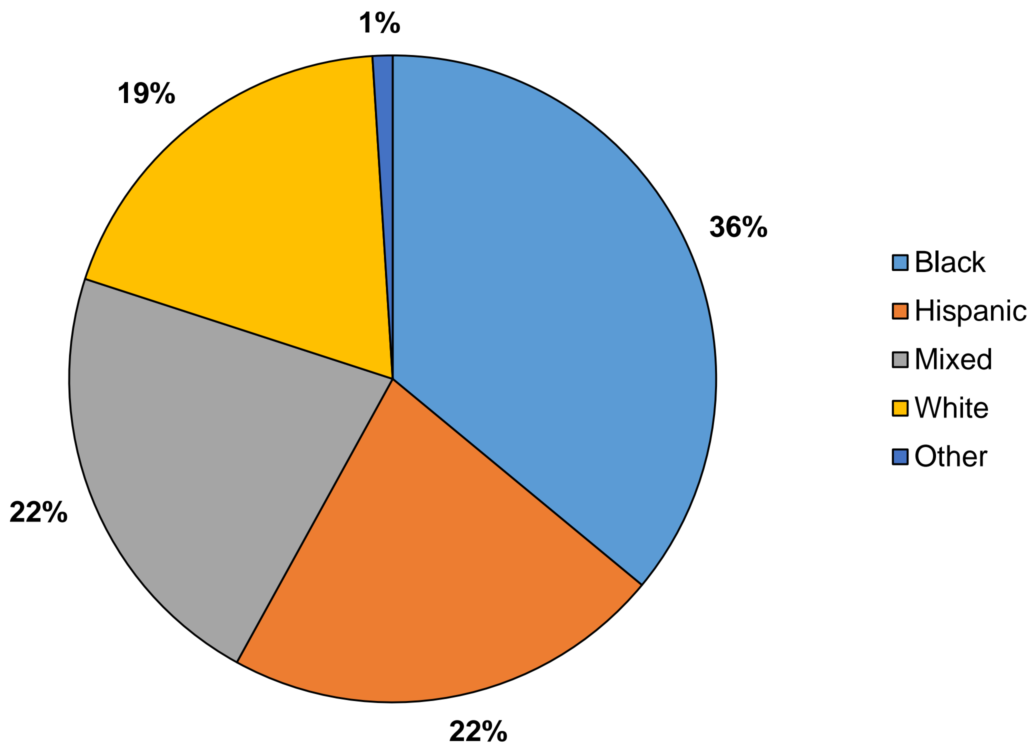
Figure 12 Gender of Individuals At-risk for HIV/AIDS (n=59)



Race and Ethnicity

Of the total number of participants, 22% identified as Hispanic. The racial demographic of the at-risk population is 36% Black/African American, 22% mixed race, 19% White, and 1% Other. See Figure 13.

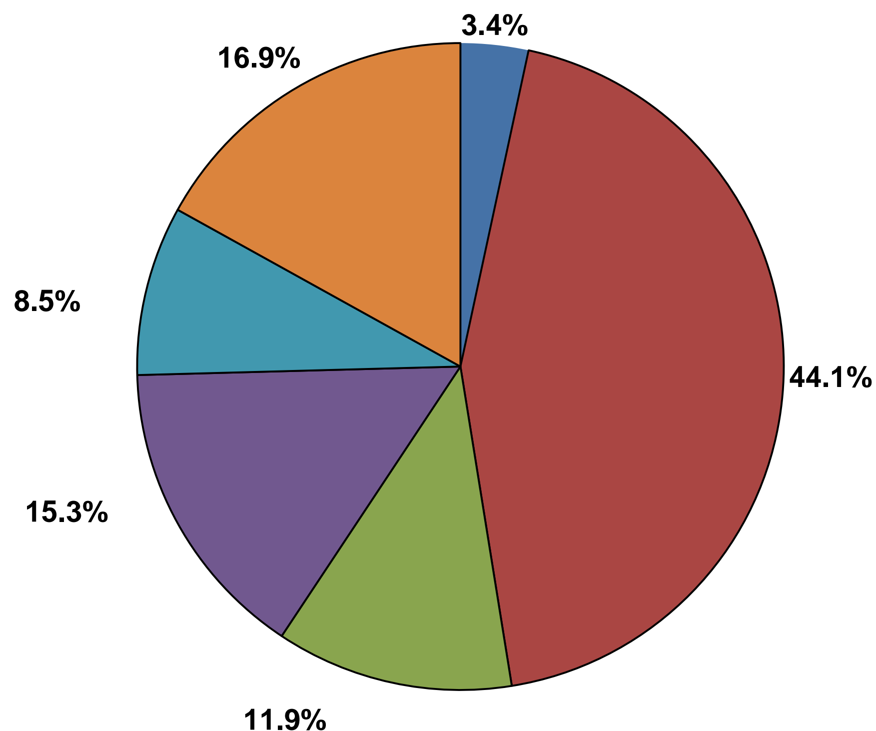
Figure 13. Race/Ethnicity for Individuals At-risk for HIV/AIDS (n=59)



Age

Participants' ages ranged anywhere from under 18 to 65, but as illustrated in Figure 14, the majority of the at-risk population surveyed was under 24.Of the 59 participants, 3.4% were under 18, 44.1% were 18-24, 11.9% were 25-33, 15.3% were 34-44, 8.5% were 45-54, and 16.9% were 55-65.

Figure 14. Age of Individuals At-risk for HIV/AIDS (n=59)



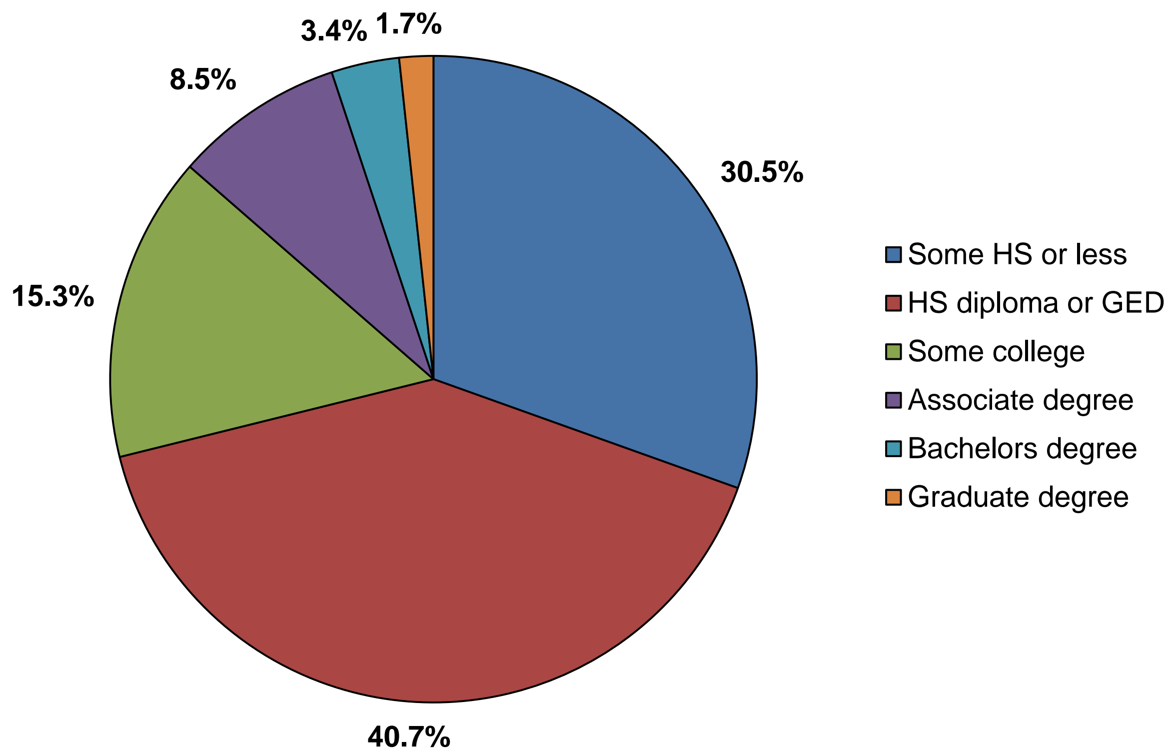
Demographics of Individuals At-risk for HIV/AIDS:

- Of the 59 participants, 32 were male, and 27 were female;
- The racial/ethnicity breakdown of the participants is 36% Black/African-American, 22% Hispanic, 22% mixed, 19% White, and 1% other;
- A large proportion of participants was between 18 and 24 years old.

Level of Education and Employment

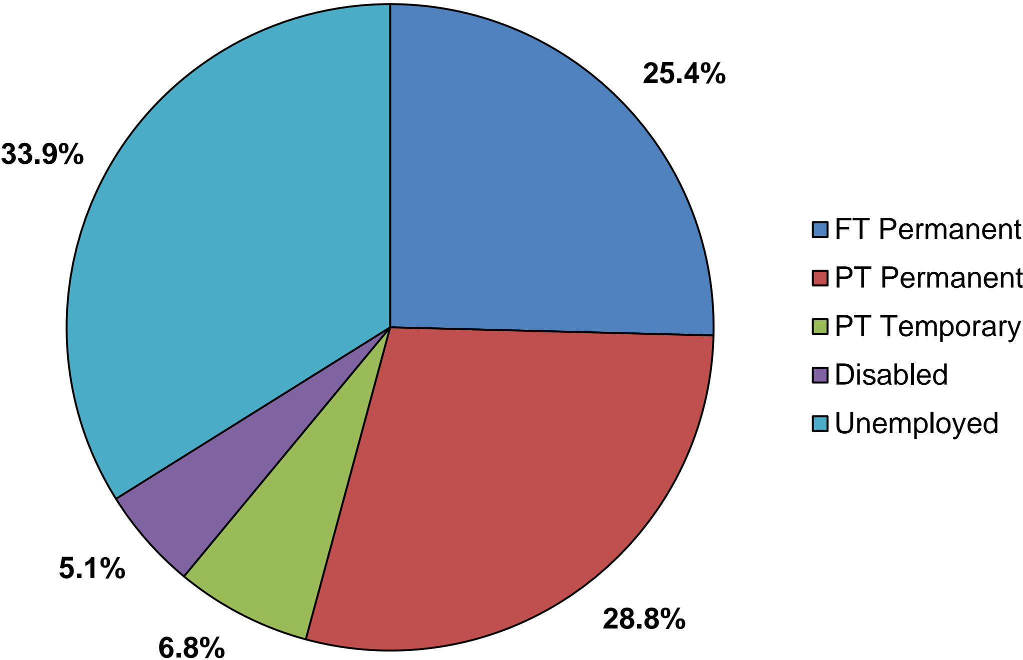
Figure 15 shows the level of education for the at-risk sample. Forty-four percent of the sample was between the ages of 18-24; 40.7% have acquired at least a HS diploma or GED. Interestingly, another 30.5% have less than a high school education. Thus, the majority (71%) of participants have a high school diploma or less.

Figure 15. Level of Education of Individuals At-risk for HIV/AIDS (n=59)



Despite overall low levels of educational attainment, more than a quarter of at-risk participants have attained permanent full-time employment. A majority of participants are either unemployed or have part-time employment (33.9% and 28.8%). See Figure 16.

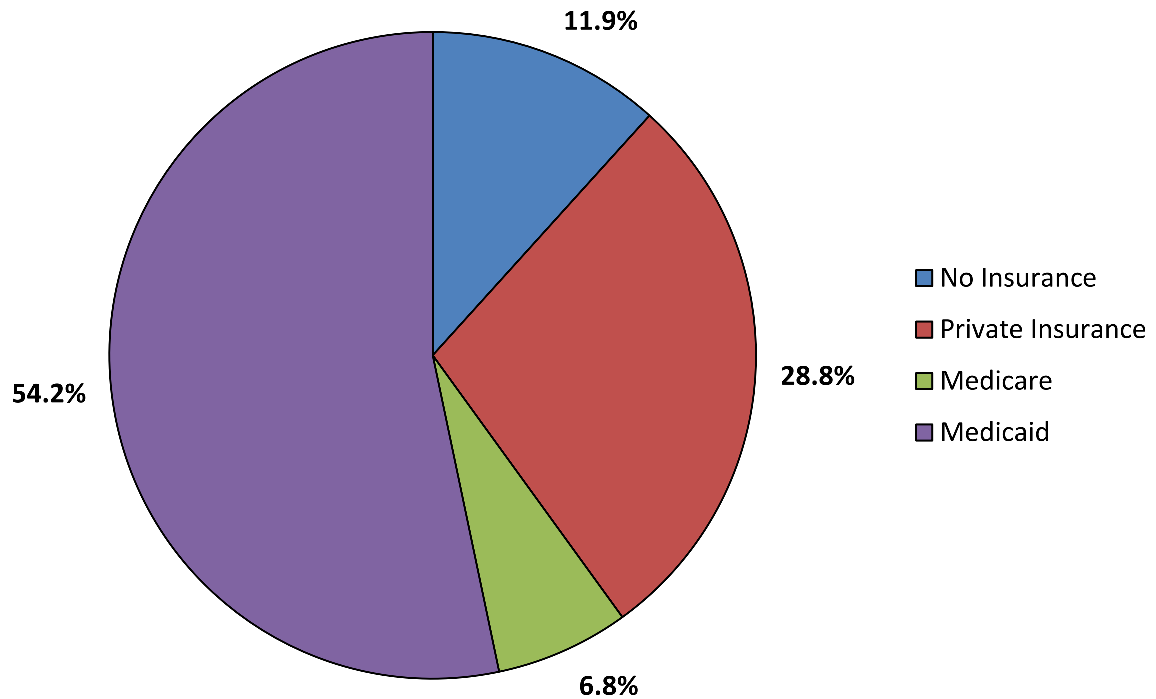
Figure 16. Employment Status of Individuals At-risk for HIV/AIDS (n=59)



Health Insurance

As seen in Figure 17, the majority of participants (54.2%) have Medicaid, followed by private insurance (28.8%), no insurance (11.9%), and a small portion of the subjects (6.8%) use Medicare as their primary type of insurance.

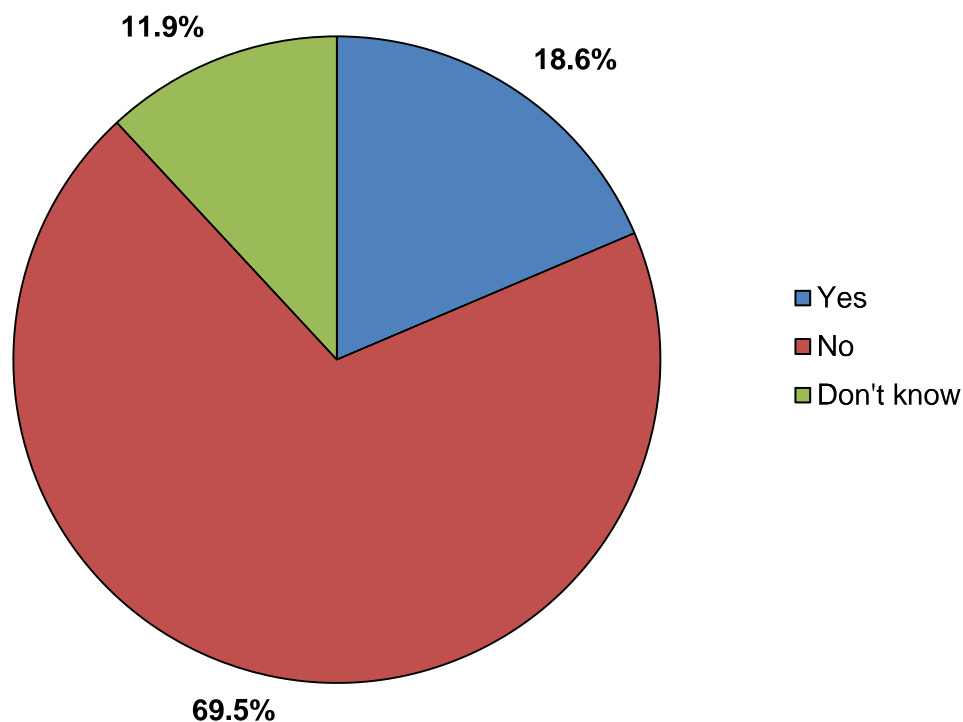
Figure 17. Types of Insurance amongst Individuals At-risk for HIV/AIDS (n=59)



Next, participants were asked if they had transferred to Medicaid under the Affordable Care Act (ACA) and whether they purchased their insurance through the ACA marketplace.

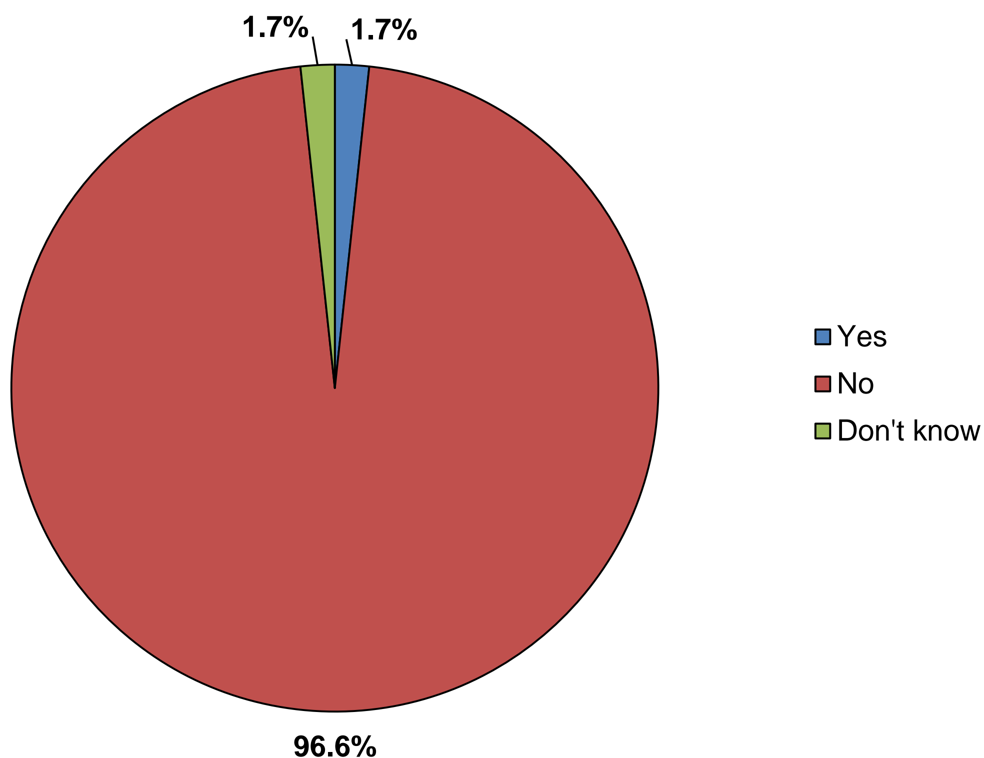
As Figure 18 shows, the majority of the participants did not transfer to Medicaid under the Affordable Care Act. However, almost 12% didn't know and another 19% did change insurance related to the ACA implementation.

Figure 18. Individuals At-risk for HIV/AIDS Who Transferred to Medicaid Under ACA (n=59)



In addition, as Figure 19 illustrates that 96% the participants did not purchase their insurance from the Affordable Care Act Marketplace at all. Only a small percentage of participants (1.7%) used the Affordable Care Act marketplace to purchase insurance.

Figure 19. Individuals At-risk for HIV/AIDS Purchasing Insurance Under ACA (n=59)

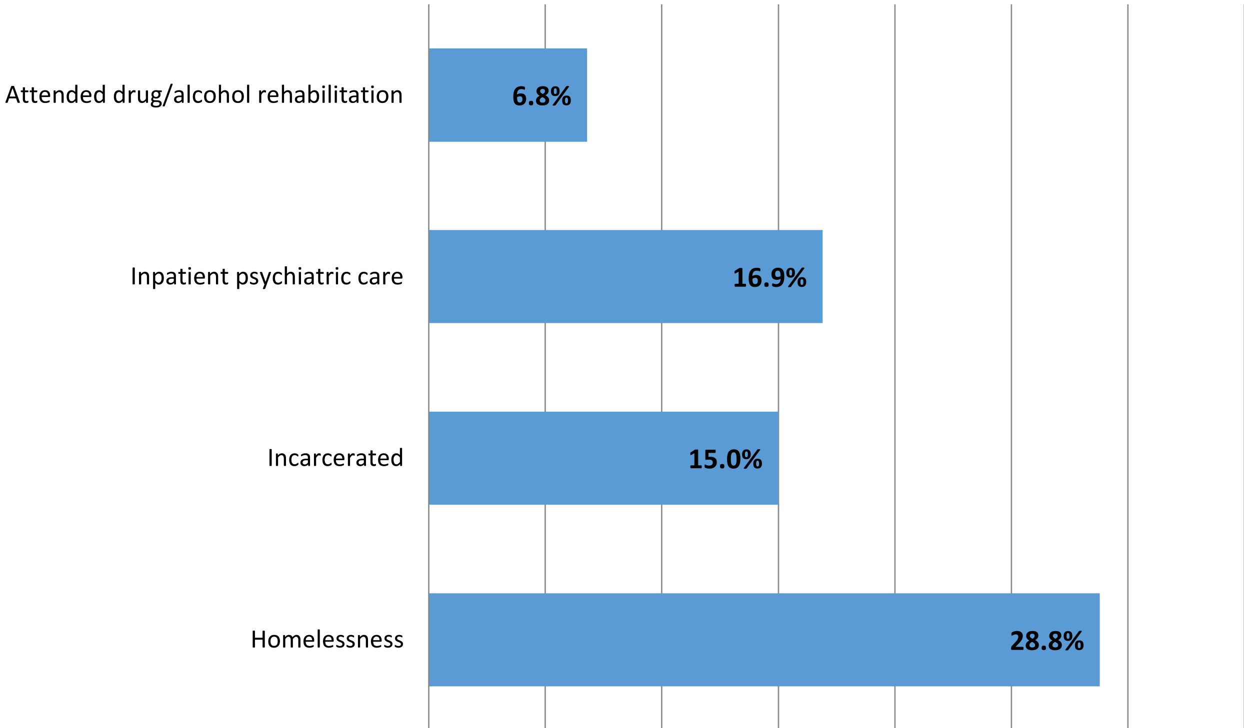


Comorbid Risk Factors for PLWHA

Participants were also asked to answer questions about whether they had been incarcerated, homeless, admitted into inpatient psychiatric care, or attended drug/alcohol rehabilitation services during the past 12 months. As presented in Figure 20, over a quarter of participants (28.8%) had experienced homelessness in the past 12 months. This information is extremely

important, as not having a permanent residency or living in unstable conditions can put the participants at a higher risk of becoming infected with HIV (Milloy, Marshall, Montane, & Wood, 2012). Additionally, 16.9% of participants reported having been admitted to inpatient psychiatric care, and 15.0% of the participants said they had been incarcerated.

Figure 20. Exposure to Risk Factors in Past 12 Months amongst At-Risk Individuals (n=59)



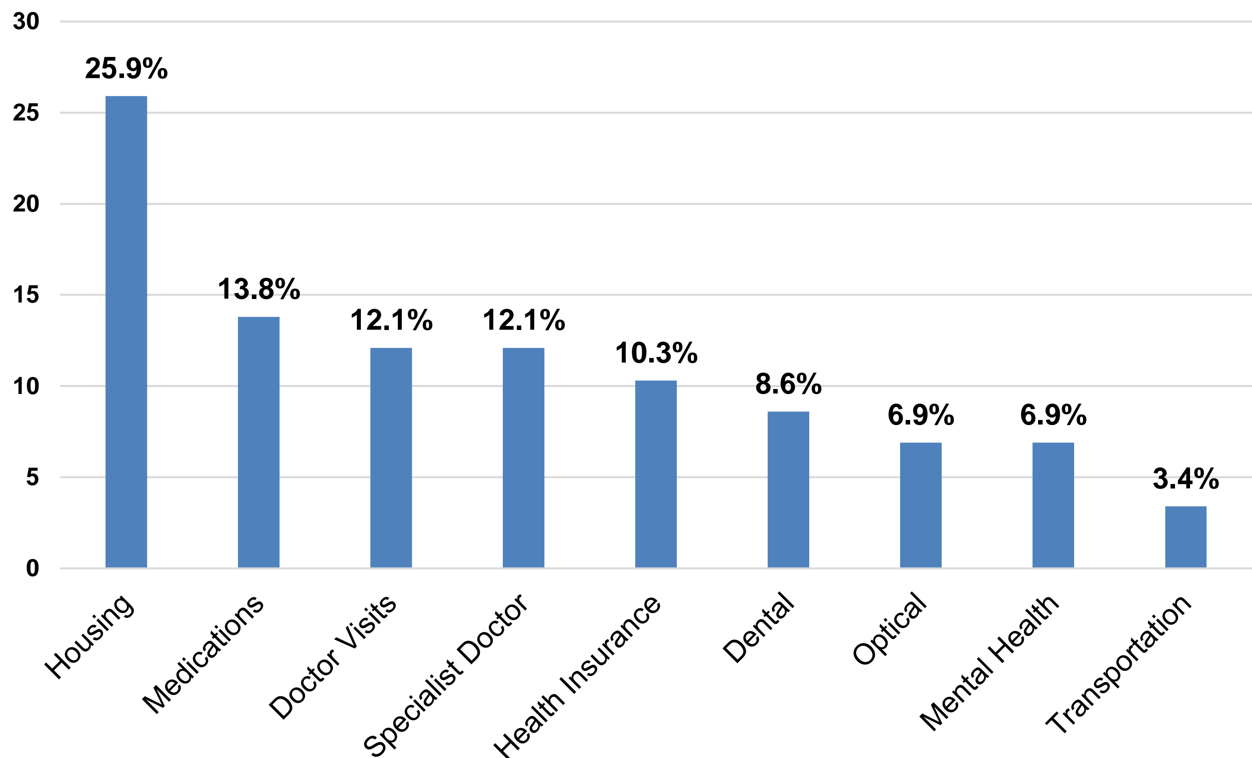
Most common risk factors:

- Homelessness is the most common risk factor the at-risk populations face, followed by inpatient psychiatric care and incarceration.
- In the past 12 months, 28.8% of the at-risk population interviewed had been homeless.
- In the past 12 months, 15% of the at-risk population interviewed had been incarcerated.

Most Important Service Needs

Participants were asked to identify their single most important service need related to their health. Figure 20 illustrates the most important service needs among those at risk for HIV who were surveyed.

Figure 20. Most Important Service Need for Individuals At-risk for HIV/AIDS (n=59)



Housing was the most important service need for 25.9% of those surveyed. Over a quarter of participants had been homeless over the past twelve months. This service gap can be related to the limited resources available for housing and the difficulty of finding safe, affordable housing (Aidala et al. 2007). Some of the at-risk population that experienced homelessness had recently been incarcerated or released from a mental health facility.

Mental health was the most important service need for 6.9% of the at-risk population. Some of the participants indicated they had problems with substance abuse and other behavioral health issues. A number of participants stated they cannot access behavioral health care due to lack of insurance and high cost of such services.

Based on the responses, 13.8% said medications were their most important service need, and another 12.1% said doctor visits and specialists doctors were most important. Optical insurance was the most important service need for 6.9% of the at-risk population.

Health insurance was the most important service need for 10.3% of the population. Of those surveyed, 11.9% indicated they had no health insurance. Many of the participants do not see a doctor or take prescribed medications because they have no insurance. This can lead to other serious health issues if illnesses are left untreated.

Transportation was the most important service need for 3.4% of the at-risk population. Respondents had difficulty getting to doctors' appointments due to a lack of public and personal transportation.

Needs and Receipt of Services

Survey participants were asked to rate their need for services – regardless of whether or not they were currently receiving that service – on a four-point Likert scale in which 1 represents the response "Not at all" and 4 represents "A Great Deal." The frequency with which participants selected each response for each question is detailed in Table 5. Services such as medication, pharmaceutical assistance, dental care, and food services are among the top service needs within the at-risk population.

Participants surveyed needed services pertaining to their physical health. Of the 59 participants surveyed, 18.6% said they did not need medical care or doctor visits at all. Responses to whether participants needed pharmaceutical assistance were divided: 39% said they needed this service a great deal, and 44.1% said they did not need this service at all. The majority of the participants surveyed were between the ages of 18-24, and medications may not be a significant part of their daily lives. Alternatively, those who need medications realize they need assistance a great deal, while those who do not need medications see no need for pharmaceutical assistance. Dental care and oral health is a service the majority of the at-risk group expressed needing at least a little bit.

Health insurance premiums and cost sharing assistance is a service that some of the participants needed. Over half of the participants (53%) are on Medicaid. Medicaid is a government-sponsored program that does not collect premiums or co-payments. This may explain why most said they did not need health insurance premiums and cost sharing assistance at all.

The majority of participants did not need a medical case manager. Most of the participants (83.1%) said they do not need medical case management at all. This can be attributed to the fact that many of the participants are not engaged in a system of care due to a chronic illness, unlike PLWHA.

Table 5. Need for and Receipt of Services amongst Individuals At-risk for HIV (n=59)

	Not at All	A Little	Some	A Great Deal
Medical care/doctor visits	18.6%	25.5%	16.9%	39.0%
Local pharmaceutical assistance	44.1%	8.4%	8.5%	39.0%
Dental care/oral health	30.5%	13.6%	18.6%	37.3%
Early intervention services	88.1%	3.4%	1.7%	6.8%
Health insurance premium and cost sharing assistance	79.7%	1.7%	3.3%	15.3%
Home health care	94.9%	0.0%	0.0%	5.1%
Home and community-based health services	94.9%	0.0%	0.0%	5.1%
Hospice services	96.6%	0.0%	0.0%	3.4%
Mental health services	72.9%	5.6%	5.6%	15.9%
Medical nutrition therapy	79.7%	3.4%	3.3%	13.6%
Medical case management (coordination of medical care)	83.1%	5.1%	5.1%	6.7%
Substance abuse treatment/addiction services	88.1%	0.0%	1.7%	10.2%
Non-medical case management (coordination of non-medical care)	71.2%	6.7%	8.5%	13.6%
Child care services	96.6%	1.7%	0.0%	1.7%
Pediatric developmental assessment & early intervention services	100.0%	0.0%	0.0%	0.0%
Emergency Financial Assistance	79.7%	1.7%	5.1%	13.5%
Food Services	52.5%	6.8%	8.5%	32.2%
Health Education and Risk Reduction	93.2%	1.7%	0.0%	5.1%
Housing assistance services	44.1%	1.7%	6.7%	47.5%
Legal services	86.4%	1.7%	1.7%	10.2%
Linguistic services	98.3%	0.0%	0.0%	1.7%
Outreach services	98.3%	0.0%	0.0%	1.7%
Permanency planning	94.9%	0.0%	1.7%	3.4%
Psychosocial support services	79.6%	5.1%	5.1%	10.2%
Referral for health care/supportive services	78.0%	5.1%	1.6%	15.3%
Rehabilitation services	89.8%	1.7%	1.7%	6.8%
Respite care	100.0%	0.0%	0.0%	0.0%

Table 5. Need for and Receipt of Services amongst Individuals At-risk for HIV (n=59)				
	Not at All	A Little	Some	A Great Deal
Substance abuse services-residential	96.6%	0.0%	1.7%	1.7%
Treatment adherence counseling	98.3%	0.0%	0.0%	1.7%

Participants did have some need for mental health services. Of the 59 surveyed, 27.1% said they needed mental health services. Approximately a quarter of the participants surveyed indicated they needed psychosocial support services.

Housing assistance is a service 47.5% of the at-risk population needed a great deal. Food services are needed a great deal by 32.2% of the at-risk population. Of those surveyed, 13.5% needed emergency financial assistance a great deal, indicating that some at-risk individuals have difficulties sustaining their basic needs of living.

Less than 80% of the participants needed non-medical case management or referrals for health care and supportive services. Some participants have an understanding of how to navigate their own non-medical needs. This population may not be experiencing chronic illnesses at this time, and therefore does not have an immediate need for this service.

Legal services are a category 86.4% of the participants did not need at all. It is likely that a majority of participants had basic needs that are currently unfulfilled, and their focus was on such needs rather than legal needs.

The least needed services for the at-risk population are respite care, pediatric developmental assessment, and early intervention services, with all respondents indicating no need for these services at all. More than 90% of participants said they did not need the following services at all: treatment adherence counseling, residential substance abuse services, permanency planning, outreach services, linguistic services, health education and risk reduction, child care services, home health care, home and community-based health services, and hospice services.

Unmet Needs and Service Gaps

Whether or not participants reported needing a particular service, the interviewer asked if they were receiving each service. Table 6 includes only those who said they needed a service. The last two columns detail whether or not clients who needed each service were receiving it.

A majority of the participants indicated they need medical visits and local pharmaceutical assistance. A large portion of the participants that need this service are receiving it. Of the participants surveyed, 85.4% of those who need medical visits are receiving them, and 84.8% of those who need local pharmaceutical assistance are receiving it. Medical case management is an unmet need for 40% of the ten individuals who needed this service.

Table 6. Unmet Needs and Services Gaps of Individuals At-risk for HIV/AIDS (n=59)

	Number of subjects in need	Percentage of subjects in need	Percentage of subjects who need and receive services	Percentage of subjects who need and do not receive services
Medical care/doctor visits	48	81.3%	85.4%	14.6%
Pharmaceutical assistance	33	55.9%	84.8%	15.2%
Dental care/oral health	41	69.4%	61.0%	39.0%
Early intervention services	7	11.9%	71.4%	28.6%
Health insurance premium and cost sharing assistance	12	20.3%	50.0%	50.0%
Home health care	3	0.5%	66.7%	33.3%
Home and community-based health services	3	0.5%	33.3%	66.7%
Hospice services	0	0.0%	0.0%	0.0%
Mental health services	15	25.4%	53.3%	46.7%
Medical nutrition therapy	11	18.6%	18.2%	81.8%
Medical case management (coordination of medical care)	10	16.9%	60.0%	40.0%
Substance abuse treatment/ addiction services	7	11.9%	71.4%	28.6%
Non-medical case management (coordination of non-medical care)	17	28.8%	82.4%	17.6%
Child care services	2	0.3%	50.0%	50.0%
Pediatric developmental assessment & early intervention services	0	0.0%	0.0%	0.0%
Emergency financial assistance	12	20.3%	58.3%	41.7%
Food Services	28	47.5%	82.1%	17.9%
Health education and risk reduction	4	0.7%	50.0%	50.0%
Housing assistance services	33	55.9%	45.5%	54.5%
Legal services	8	13.6%	37.5%	62.5%
Linguistic services	1	0.2%	100.0%	0.0%
Outreach services	1	0.2%	100.0%	0.0%
Permanency planning	1	0.2%	100.0%	0.0%

Table 6. Unmet Needs and Services Gaps of Individuals At-risk for HIV/AIDS (n=59)				
	Number of subjects in need	Percentage of subjects in need	Percentage of subjects who need and receive services	Percentage of subjects who need and do not receive services
Psychosocial support services	12	20.3%	58.3%	41.7%
Referral for health care/supportive services	13	22.0%	61.5%	38.5%
Rehabilitation services	6	10.2%	33.3%	66.7%
Respite care	0	0.0%	0.0%	0.0%
Substance abuse services-residential	2	0.3%	100.0%	0.0%
Treatment adherence counseling	1	0.2%	100.0%	0.0%

Out of the 69.4% who said they needed dental care or oral health care, 39% said they were not receiving this service. Some participants indicated they have no dental or insurance, and individuals that do have insurance often cannot find a dentist that accepts their policy. Other participants were in transition between insurance policies.

One in five needed assistance with health insurance premium and cost sharing assistance. Although more than half of participants were enrolled in Medicaid, which prohibits charging clients, 28.8% had private insurance, and 6.8% were enrolled in Medicare. Those who have private insurance or Medicare have out of pocket expenses, and individuals might need assistance because of the high cost of medical care. Half of those who needed health insurance premium and cost sharing assistance were not receiving this service. Participants were not receiving it because they either did not know how to access such services, and or they were unaware that such services existed.

Mental health services and medical nutrition therapy were unmet needs for some of the participants. Nearly half of those who needed mental health services were not receiving them, and more than 80% of those who needed medical nutrition therapy were not receiving the service. These needs go unmet because of the difficulty of finding a provider that accepts their insurance. Another issue is that insurance does not always cover these services, or may have a limited coverage allotted each year.

There are some service categories participants did not need at all, including hospice services, respite care, and pediatric development and early intervention services. Few people said they

needed home health care, home and community-based health services, child care services, health education and risk reduction, linguistic services, outreach services, permanency planning, residential substance abuse services, or treatment adherence counseling.

More than a quarter of participants indicated they needed non-medical case management, and more than a fifth needed referrals for health care and supportive services. Over 80% of participants that needed non-medical case management were receiving these services. However, only 61.5% of those needing referrals for health care and supportive services were receiving referrals. The majority of the participants surveyed were unaware of where to access such services.

Several participants said they needed legal services, but 62.5% were not receiving this service. Many of the participants that needed the service did not know it existed. Participants indicated they did not know where or how to apply for legal services. Some of the participants had recently been released from incarceration or discharged from a mental health facility. These participants indicated they were focused on their immediate needs of their current situation.

Psychosocial support is a service gap for at-risk individuals. Of those who said they needed psychosocial support, 41.7% were not receiving this service. Some respondents did not know where to go for services or had not looked into it yet. Individuals expressed the need to socialize and have a support system.

Nearly half of participants needed food services and over 80% of those who needed the service were receiving it. Only 17.9% of those who needed the service were not receiving it.

Two in five of those who needed emergency financial assistance were not receiving the service. Respondents indicated they were unaware such services existed and did not know where to apply for services. If individuals are aware of and know where to apply for services, the gap might be substantially smaller.

According to the survey, 28.8% of participants have been homeless over the past year. More than half of all participants needed housing assistance, with most needing this service a great deal, and 54.5% of them were not receiving these services. Reasons why clients were not getting housing assistance services vary from the long waiting lists for Section 8 housing, a lack of affordable housing, and the fact that Section 8 is no longer accepting applications, which has left clients with little information on where to apply for assistance. In addition, participants

expressed a need for assistance when looking for housing due to the complexity of navigating the system.

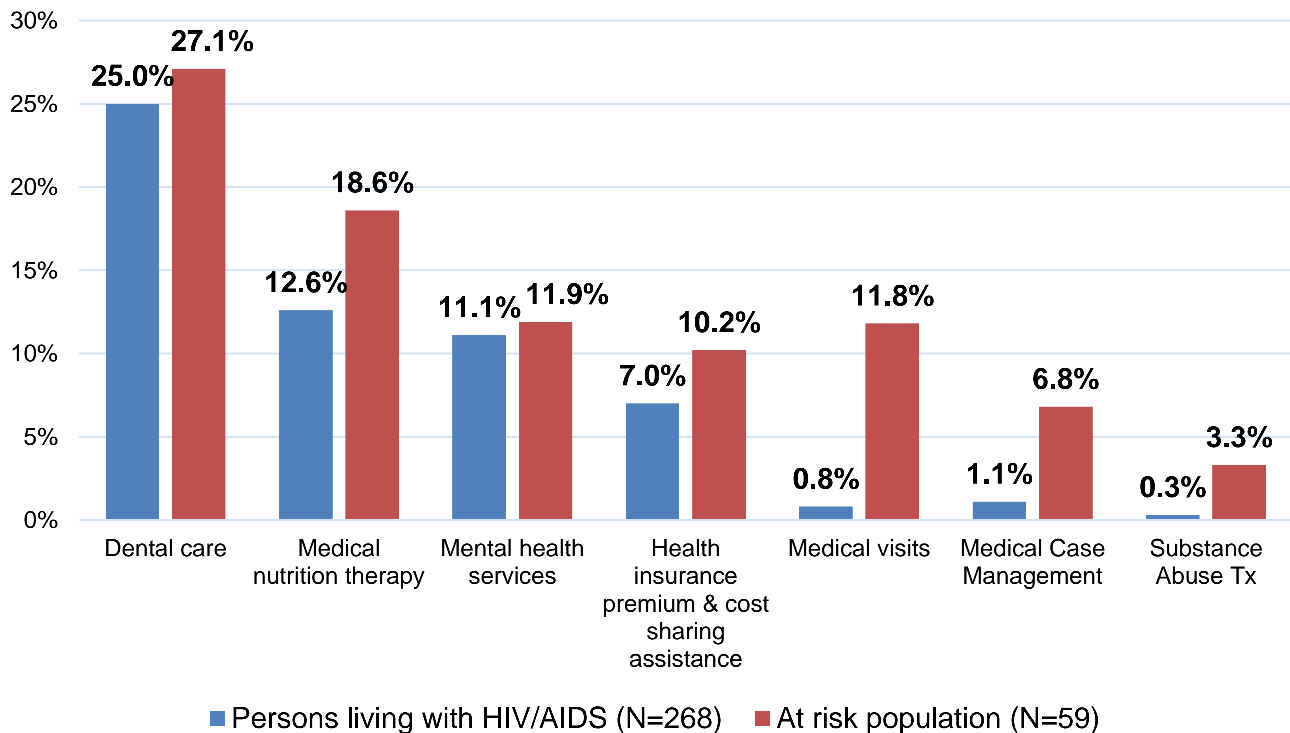
Key Points:

- Unmet need for at-risk individuals were greatest for medical nutrition therapy, community based health service, insurance premium and mental health services.
- Service gaps were described by a greater number of those at-risk.
- The largest service gaps include legal services, housing and health education/risk management.

Comparison of Needs of PLWHA and those At-risk

Data collected for unmet need and service gaps were compared for PLWHA and individuals who are at-risk. Both groups indicated having similar rates of unmet dental care needs. Both populations had a similar proportion of unmet need for mental health services, with 11.1%

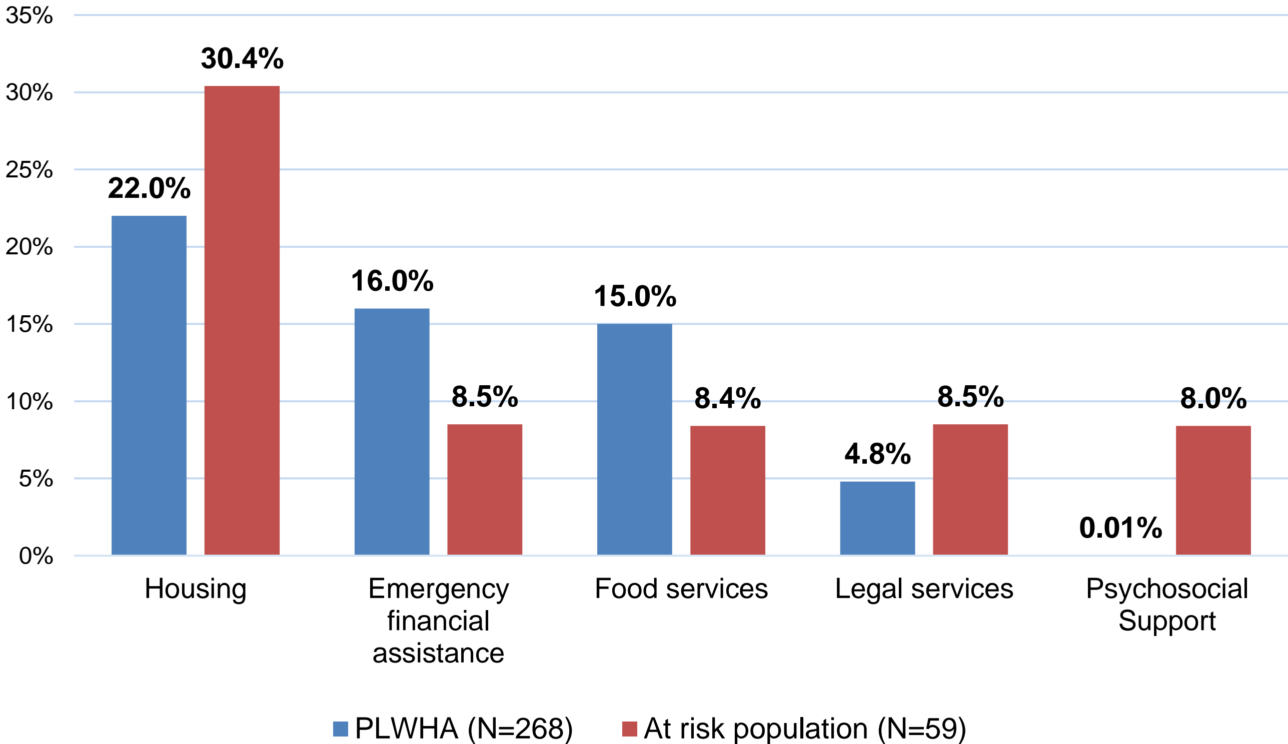
Figure 22. Unmet Needs for PLWHA and Individuals At-risk for HIV/AIDS



of PLWHA and 11.9% at-risk individuals with an unmet need in this area. Health insurance premium and cost sharing assistance has similar findings: 7.0% of PLWHA and 10.2% of at-risk individuals are not receiving assistance with costs associated with healthcare. Among PLWHA, 12.6% experienced an unmet need, while 18.6% of at-risk individuals had an unmet need for medical nutrition therapy.

Both populations cited some of the same reasons for not receiving various services, such as issues related to insurance. In most cases, a person's insurance did not cover a needed service, which has a major impact on whether a need goes unmet. Other reasons include long approval waiting lists from insurance companies or difficulty finding a provider that accepts a particular insurance policy. Another obstacle is when participants are in transition between policies and cannot access services. The unmet need is higher for the at-risk population than for PLWHA who are receiving Ryan White services. Figure 23 compares the gaps in supportive services for PLWHA and at-risk individuals. There are various reasons why such gaps exist. For instance, participants may be unaware that

Figure 23. Service Gaps for PLWHA and Individuals At-risk for HIV/AIDS



services exist, or they might not know where and whom to contact for services. Other participants shared that they were aware that such services existed, but they had not looked into them for various reasons.

There is a disparity between PLWHA and at-risk individuals for psychosocial support services. PLWHA have a service gap of 0.01%, while at-risk individuals have 8.0% gap. There is a gap in legal services for both PLWHA and at-risk population, as 4.8% of PLWHA and 8.5% of at-risk individuals are not receiving legal services.

Emergency financial assistance and food services are areas in which both populations are not receiving services. Based on the data collected, PLWHA have a larger service gap in these categories than persons at-risk for contracting HIV/AIDS. The findings indicate that 15.0% of PLWHA and 8.4% of at-risk individuals are not receiving needed food services. Similarly, 16.0% of PLWHA and 8.5% of at-risk individuals are not receiving needed emergency financial assistance.

Both PLWHA and the at-risk population are in need of housing services, and both groups are experiencing service gaps. Among PLWHA, 22.0% are not receiving this needed service, compared to 30.4% of at-risk individuals not receiving this service. There are distinct reasons for this service gap, including a lack of affordable housing availability on the waiting list for Section 8 as well as Section 8 housing not accepting new applications. Other participants indicated they did not know where to apply for services.

Conclusions

Interviews for both PLWHA and at-risk individuals were not randomly selected. Both groups interviewed were either engaged in a system of care or were accessing some type of service. The needs of the disengaged are not represented in this study.

The overall needs of people are similar to both groups. PLWHA and at-risk individuals have a significant need to see their doctor and take care of their oral health. Individuals surveyed in both groups have a need for mental health services and psychosocial support to some extent. Medical case management is a service for which both populations expressed need; however; this need was greater for those who are at-risk.

At-risk individuals have a greater need for basic survival. Some of these needs include shelter and food. Many individuals at-risk for HIV are homeless, have been recently incarcerated or have mental health issues. This can directly impact the manner in which these individuals

prioritize and access services. This data represents an approximation of the needs of individuals who are new to care. Planning for services must include access to basic needs to aid in promoting stability and ultimately, retention in care.

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Appendix A: Needs Assessment

Survey

DATE: ___________

INTERVIEWER: ____________ LOCATION: _______________

2016 Needs Assessment Survey
Thank you for your interest in participating in this survey. It will take about 10 to15 minutes to complete. By responding to this questionnaire, you will help the Middlesex, Somerset, and Hunterdon HIV Health Services Planning Council plan for effective HIV/AIDS care and treatment services targeting our community. We would appreciate it if you answered every question, but you may skip any question you do not want to answer. Your responses will be confidential. There are no questions that can identify you with the answers you provide. If you have questions at any time about the research or the procedures, you may contact the Natalie Aloyets Artel at 55 Commercial Avenue 3rd floor New Brunswick, NJ 08901 or at 848-932-0530 or by email at: naartel@ssw.rutgers.edu.

If you have any questions about your rights as a research subject, you may contact the IRB Administrator at Rutgers University at: Rutgers University, the State University of New Jersey, Institutional Review Board for the Protection of Human Subjects, Office of Research and Sponsored Programs, 3 Rutgers Plaza, New Brunswick, NJ 08901-8559 Tel: 848-932-0150,

Email: humansubjects@orsp.rutgers.edu

After the interview is complete, I will give you a grocery store gift certificate worth $25.

I would like to stress the following:

- Your responses will be kept confidential.
- Your participation is completely voluntary; therefore you do not have to participate. If you decide not to participate, it will not affect the services you currently receive or may seek in the future.
- Your participation is not required by any service provider.
- You may decide to skip any questions that you don't want to answer.
- You may decide not to finish and to withdraw from participation at any time without any penalty. If you decide to withdraw, it will not affect the services you currently receive or may seek in the future.

Do you agree to participate in the needs assessment study? May we begin?

Section 1. Needs and Receipt of Services

The first part of our survey focuses on your needs and the services that you are receiving.

1. In your opinion, what is your most important service need for your HIV/AIDS-related health?

____

2. **I am now going to go through a list of services. For each service, I would like you to tell me three things: First, regardless of whether or not you are receiving this service, indicate how much you need it. Second, tell me if you are receiving the service. Third, if you need the service and are not receiving it, please tell us why.**

Ryan White Service Category	**Regardless of whether or not you are receiving this service, how much do you need this service now?**				**Are you receiving this service?**		**If you need the service and are not receiving it, why? (only ask when service is needed but not received)**
	Not at all (0)	**A little (1)**	**Some (2)**	**A great deal (3)**	**Yes (1)**	**No (0)**	
HIV medical care/doctor visits							
Local HIV/AIDS pharmaceutical assistance							
Dental care/oral health							
Early intervention services							
Health insurance premium & cost sharing assistance							
Home health care							

Ryan White Service Category	Regardless of whether or not you are receiving this service, how much do you need this service now?				Are you receiving this service?		If you need the service and are not receiving it, why? (only ask when service is needed but not received)
	Not at all (0)	A little (1)	Some (2)	A great deal (3)	Yes (1)	No (0)	
Home and community-based health services							
Hospice services							
Mental health services							
Medical nutrition therapy							
Medical case management (coordination for medical care)							
Substance abuse treatment/addiction services							
Non-medical case management (coordination for non-medical care)							

Ryan White Service Category	Regardless of whether or not you are receiving this service, how much do you need this service now?				Are you receiving this service?		If you need the service and are not receiving it, why? (only ask when service is needed but not received)
	Not at all (0)	A little (1)	Some (2)	A great deal (3)	Yes (1)	No (0)	
Child care services							
Pediatric developmental assessment and early intervention services							
Emergency financial assistance							
Food services							
Health education and risk reduction							
Housing assistance services							
Legal services							

Ryan White Service Category	Regardless of whether or not you are receiving this service, how much do you need this service now?				Are you receiving this service?		If you need the service and are not receiving it, why? (only ask when service is needed but not received)
	Not at all (0)	A little (1)	Some (2)	A great deal (3)	Yes (1)	No (0)	
Linguistic services							
Outreach services							
Permanency planning							
Psychosocial support services							
Referral for health care/supportive services							
Rehabilitation services							
Respite care							
Substance abuse services - residential							

Ryan White Service Category	Regardless of whether or not you are receiving this service, how much do you need this service now?				Are you receiving this service?		If you need the service and are not receiving it, why? (only ask when service is needed but not received)
	Not at all (0)	A little (1)	Some (2)	A great deal (3)	Yes (1)	No (0)	
Treatment adherence counseling							

Section 2. Demographic Information

We are interested in knowing some demographic information about the people who participate in this survey. Collecting this information helps us to understand how service needs differ for the different clients that the Ryan White program serves. The following questions ask about your initial diagnosis, your insurance status, your employment status and other demographic information. Please keep in mind that you may skip answering a question if you prefer to do so.

1. What year were you born? ____________________	2. What is your ethnicity? ❑ Hispanic ❑ Non-Hispanic ❑ Unknown	3. What is your race? (Check all that apply) ❑ Black or African American ❑ White ❑ Asian ❑ Native Hawaiian/Other Pacific Islander ❑ American Indian/Alaskan Native ❑ Other ❑ Declined
4. What is your zip code? ____________________	5. In what year were you diagnosed with HIV? ____________________	6. Were you diagnosed in NJ? ❑ Yes ❑ No ❑ Don't know ❑ Declined
7. What is your gender? (Check one) ❑ Male ❑ Female ❑ Transgender (male to female) ❑ Transgender (female to male)		8. Is English your primary language? ❑ Yes ❑ No, please specify primary language:

	____________________
9. What is your method of insurance? ❑ None ❑ Private insurance (includes HMOs) ❑ Medicare ❑ Medicaid ❑ Self-pay ❑ Other, please specify: ____________________	10. Did you transfer to Medicaid under the Affordable Care Act? ❑ Yes ❑ No ❑ Don't know ❑ Declined
11. Did you purchase insurance through the Affordable Care Act marketplace? ❑ Yes ❑ No ❑ Don't know ❑ Declined	12. What is your employment status? (Select one) ❑ Employed full-time, in a permanent capacity (more than 35 hours) ❑ Employed part-time, in a permanent capacity (less than 35 hours) ❑ Employed full-time, in a temporary capacity ❑ Employed part-time, in a temporary capacity ❑ Disabled ❑ Not employed

13. What is the highest level of education that you completed? ❑ Some high school or less ❑ High school diploma or GED ❑ Some college	14. In the past twelve months have you: (Check all that apply) ❑ Been incarcerated ❑ Been homeless ❑ Traveled to an area with a high rate of HIV

❑ Associate's degree ❑ Bachelor's degree ❑ Graduate	❑ Been a sex worker – traded sex for resources ❑ Received inpatient psychiatric care ❑ Been admitted for drug or alcohol rehabilitation

Section 3. Accessing Health Care

15. What challenges/concerns did you have in the past 12 months taking care of yourself?

- ❑ Help with activities of daily living? e.g. light housekeeping
- ❑ Obtaining care in home
- ❑ Personal hygiene (self-care) bath, dress, etc.
- ❑ Shopping and cooking

Other ____

____

16. In the past year have there been any changes in the way HIV/AIDS care is administered?

1	2	3	4	5	6	7
Not at all	A little	Neutral	Some	A great deal	Don't know	Not applicable

17. Rate your satisfaction with your HIV/AIDS services

1	2	3	4	5	6	7	8	9	10
Very dissatisfied									Very satisfied

18. To what extent have you had difficulty obtaining HIV/AIDS care and treatment that you need?

    Please describe. ____

19. Where do you receive information about your health? (Check all that apply.)
    - ❑ Clinic visit
    - ❑ Service organization
    - ❑ Support group
    - ❑ Online (internet, Facebook, etc.)
    - ❑ Case manager
    - ❑ Other, please specify: _______________

20. What impact has the Affordable Care Act (Medicaid or marketplace insurance plan) had on your health care services?

    Please describe. ____

21. On average how long does it take you to get from your home to your doctor's office?
    - ❑ Less than 15 minutes
    - ❑ 16 minutes to 30 minutes
    - ❑ 31 to 45 minutes
    - ❑ More than 45 minute

22. Are the services you receive at your doctor's office culturally competent?

    - ❑ Yes
    - ❑ No
    - ❑ Don't know
    - ❑ Declined

23. Have you experienced stigma at your treatment provider(s)?
- ❑ Yes
- ❑ No
- ❑ Don’t know
- ❑ Declined

Please describe. ____

Appendix B: High Risk Individuals Survey

DATE: ___________

INTERVIEWER: ____________ LOCATION:_______________

2016 Needs Assessment Survey

Thank you for your interest in participating in this survey. It will take about 10 to15 minutes to complete. By responding to this questionnaire, you will help a local health program plan for effective care and treatment services targeting our community. We would appreciate it if you answered every question, but you may skip any question you do not want to answer. Your responses will be confidential. There are no questions that can identify you with the answers you provide. If you have questions at any time about the research or the procedures, you may contact the Natalie Aloyets Artel at 55 Commercial Avenue 3rd floor New Brunswick, NJ 08901 or at 848-932-0530 or by email at: naartel@ssw.rutgers.edu.

If you have any questions about your rights as a research subject, you may contact the IRB Administrator at Rutgers University at: Institutional Review Board, Rutgers University, the State University of New Jersey, Liberty Plaza / Suite 3200 335 George Street, 3rd Floor

New Brunswick, NJ 08901 or at 732.235.9806 or by email: humansubjects@orsp.rutgers.edu

After the interview is complete, I will give you a grocery store gift certificate worth $25.

I would like to stress the following:

- Your responses will be kept confidential.
- Your participation is completely voluntary; therefore you do not have to participate. If you decide not to participate, it will not affect the services you currently receive or may seek in the future.
- Your participation is not required by any service provider.
- You may decide to skip any questions that you don't want to answer.
- You may decide not to finish and to withdraw from participation at any time without any penalty. If you decide to withdraw, it will not affect the services you currently receive or may seek in the future.

Do you agree to participate in the needs assessment study? May we begin?

Section 1. Needs and Receipt of Services

The first part of our survey focuses on your needs and the services that you are receiving.

1. In your opinion, what is your most important health related service need?

____

2. **I am now going to go through a list of services. For each service, I would like you to tell me three things: First, regardless of whether or not you are receiving this service, indicate how much you need it. Second, tell me if you are receiving the service. Third, if you need the service and are not receiving it, please tell us why.**

Health Service Category	**Regardless of whether or not you are receiving this service, how much do you need this service now?**				**Are you receiving this service?**		**If you need the service and are not receiving it, why? (only ask when service is needed but not received)**
	Not at all (0)	**A little (1)**	**Some (2)**	**A great deal (3)**	**Yes (1)**	**No (0)**	
Medical care/doctor visits							
Local pharmaceutical assistance							
Dental care/oral health							
Early intervention services							
Health insurance premium & cost sharing assistance							
Home health care							

Health Service Category	Regardless of whether or not you are receiving this service, how much do you need this service now?				Are you receiving this service?		If you need the service and are not receiving it, why? (only ask when service is needed but not received)
	Not at all (0)	A little (1)	Some (2)	A great deal (3)	Yes (1)	No (0)	
Home and community-based health services							
Hospice services							
Mental health services							
Medical nutrition therapy							
Medical case management (coordination for medical care)							
Substance abuse treatment/addiction services							
Non-medical case management (coordination for non-medical care)							

Health Service Category	Regardless of whether or not you are receiving this service, how much do you need this service now?				Are you receiving this service?		If you need the service and are not receiving it, why? (only ask when service is needed but not received)
	Not at all (0)	A little (1)	Some (2)	A great deal (3)	Yes (1)	No (0)	
Child care services							
Pediatric developmental assessment and early intervention services							
Emergency financial assistance							
Food services							
Health education and risk reduction							
Housing assistance services							
Legal services							

Health Service Category	Regardless of whether or not you are receiving this service, how much do you need this service now?				Are you receiving this service?		If you need the service and are not receiving it, why? (only ask when service is needed but not received)
	Not at all (0)	A little (1)	Some (2)	A great deal (3)	Yes (1)	No (0)	
Linguistic services							
Outreach services							
Permanency planning							
Psychosocial support services							
Referral for health care/supportive services							
Rehabilitation services							
Respite care							
Substance abuse services - residential							

Health Service Category	Regardless of whether or not you are receiving this service, how much do you need this service now?				Are you receiving this service?		If you need the service and are not receiving it, why? (only ask when service is needed but not received)
	Not at all (0)	A little (1)	Some (2)	A great deal (3)	Yes (1)	No (0)	
Treatment adherence counseling							

Section 2. Demographic Information

We are interested in knowing some demographic information about the people who participate in this survey. Collecting this information helps us to understand how service needs differ for the different clients. The following questions ask about your initial diagnosis, your insurance status, your employment status and other demographic information. Please keep in mind that you may skip answering a question if you prefer to do so.

1. What year were you born? ____________________	2. What is your ethnicity? ❑ Hispanic ❑ Non-Hispanic ❑ Unknown	3. What is your race? (Check all that apply) ❑ Black or African American ❑ White ❑ Asian ❑ Native Hawaiian/Other Pacific Islander ❑ American Indian/Alaskan Native ❑ Other ❑ Declined
4. What is your zip code? ____________________	5. What is your gender? (Check one) ❑ Male ❑ Female ❑ Transgender (male to female) ❑ Transgender (female to male)	6. Is English your primary language? ❑ Yes ❑ No, please specify primary language: ____________________________________

7. What is your method of insurance?

- ❑ None
- ❑ Private insurance (includes HMOs)
- ❑ Medicare
- ❑ Medicaid
- ❑ Self-pay
- ❑ Other, please specify: ______________________

8. Did you transfer to Medicaid under the Affordable Care Act?

- ❑ Yes
- ❑ No
- ❑ Don't know
- ❑ Declined

9 .Did you purchase insurance through the Affordable Care Act marketplace?

- ❑ Yes
- ❑ No
- ❑ Don't know
- ❑ Declined

10. What is your employment status? (Select one)

- ❑ Employed full-time, in a permanent capacity (more than 35 hours)
- ❑ Employed part-time, in a permanent capacity (less than 35 hours)
- ❑ Employed full-time, in a temporary capacity
- ❑ Employed part-time, in a temporary capacity
- ❑ Disabled
- ❑ Not employed

11. What is the highest level of education that you completed?

- ❑ Some high school or less
- ❑ High school diploma or GED
- ❑ Some college
- ❑ Associate's degree
- ❑ Bachelor's degree
- ❑ Graduate

12.. In the past twelve months have you: (Check all that apply)

- ❑ Been incarcerated
- ❑ Been homeless
- ❑ Traveled to an area with a high rate of HIV
- ❑ Been a sex worker – traded sex for resources
- ❑ Received inpatient psychiatric care
- ❑ Been admitted for drug or alcohol rehabilitation

Section 3. Accessing Health Care

13. What challenges/concerns did you have in the past 12 months taking care of yourself?

- ❑ Help with activities of daily living? e.g. light housekeeping
- ❑ Obtaining care in home
- ❑ Personal hygiene (self-care) bath, dress, etc.
- ❑ Shopping and cooking

Other ____

____

14. In the past year have there been any changes in the way your health care is administered?

1	2	3	4	5	6	7
Not at All	A little	Neutral	Some	A great deal	Don't know	Not applicable

15. Rate your satisfaction with your health care services

1	2	3	4	5	6	7	8	9	10

Very dissatisfied									Very satisfied

16. To what extent have you had difficulty obtaining the health care and treatment that you need?

Please describe. ____

17. Where do you receive information about your health? (Check all that apply.)

- ❑ Clinic visit
- ❑ Service organization
- ❑ Support group
- ❑ Online (internet, Facebook, etc.)
- ❑ Case manager
- ❒ Other, please specify:___________________

18. What impact has the Affordable Care Act (Medicaid or marketplace insurance plan) had on your health care services?

Please describe. ____

19. On average how long does it take you to get from your home to your doctor's office?

- ❑ Less than 15 minutes
- ❑ 16 minutes to 30 minutes
- ❑ 31 to 45 minutes
- ❑ More than 45 minute

20. Are the services you receive at your doctor's office culturally competent?

- ❑ Yes
- ❑ No
- ❑ Don't know
- ❑ Declined

19. Have you experienced stigma at your treatment provider(s)?
- ❑ Yes
- ❑ No
- ❑ Don't know
- ❑ Declined

Please describe. ____