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RYAN WHITE PART A
NASHVILLE TRANSITIONAL
GRANT AREA
NEEDS ASSESSMENT
SUPPLEMENTAL VOLUME I



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SERVICE NEEDS AND GAPS

BACKGROUND

In 2011, a service gaps survey was created by the MPHD Research Analyst and the Needs Assessment Committee to determine what medical and support services were needed by PLWHA in the Nashville TGA who were in care. The survey was aimed at ascertaining what services a person knew about, what services a person needed, what services a person was receiving, whether or not those services were meeting the client's needs, and any barriers the person had experienced in accessing services.

METHODOLOGY

Survey Development: An appropriate sample size was determined to be at least 344 PLWHA living in the TGA, in order to maintain a margin of error of +/-5 percentage points with a 95% confidence level for a population of 3,319 (the number of PLWHA who received HIV services at a Ryan White Part A funded provider in 2010).

The survey was created by the MPHD Research Analyst. Some questions were adapted from other surveys/interview guides, including the Las Vegas TGA's Consumer Survey of PLWHA.

Confidentiality Measures: All peers and volunteers helping to execute the survey signed a confidentiality agreement. Each participant who completed a survey at a provider site was informed by a peer or staff member that the survey was voluntary and confidential. Participants receiving a survey with home-delivered food bags received a document explaining that the survey was voluntary, anonymous, and that their individual answers would remain confidential. All respondents were instructed to omit their name and any other identifiable information from the survey. No survey questions required identifiable information to be disclosed.

Survey Administration: The survey was administered by peers at provider sites in an attempt to strengthen the integrity of the survey by (a) ensuring more accurate responses from the respondents, and (b) increasing the response rate within the HIV-positive population due to having a good rapport amongst the individuals. The peers were trained by the Research Analyst on the following:

- The importance of informing participants of the voluntary nature of the survey, as well as the survey's anonymity and therefore inherent confidentiality of personal information.
- How to administer the survey without bias.
- The importance of accurate and honest data collection.

After the peers were trained they conducted surveys at their provider sites through convenience sampling. Provider sites being used included the First Response Center, the Meharry Wellness Center, Nashville Cares and Vanderbilt's Comprehensive Care Clinic. Nashville Cares also delivered surveys to clients receiving home-delivered food bags.

Data Entry and Data Cleaning: A corresponding survey was created using SurveyMonkey in order to allow for more accurate data entry. This survey was used only by Ryan White Part A staff for data entry purposes. Directions for data cleaning and entry were established and reviewed to ensure employees entered survey data in a consistent manner. The surveys were numbered and manually entered into SurveyMonkey following the coding guidelines.

Data entry was completed by the Research Analyst, as well as other members of the Ryan White Part A Program, as surveys were received until all surveys were entered. The data were checked by the Research Analyst after data entry was completed to ensure data accuracy and to correct improper coding.

It is important to note that each question except one allowed for only one response, and therefore the number of responses for each question is indicative of the number of respondents answering the question. However, respondents could mark more than one HIV provider whom she or he had received services from within the last year.

Limitations: Participant responses were based on the perceptions of the participant and therefore are only representative of his/her perceptions. Also, the perceptions of individuals not participating in the survey are not known, nor is there any way to determine what characteristics may vary between individuals participating in the survey from those who did not. Surveys were only conducted at Ryan White Part A funded providers. Consequently PLWHA who did not receive services from these providers or did not receive services from these providers during the surveying time period did not have the opportunity to disclose their perceptions of HIV care and support services.

Analysis: Frequency counts were conducted on all demographic information, including

- HIV status
- Gender
- Zip code
- Race and ethnicity
- Age

Average and range were calculated for age as well. Percentages were also calculated for HIV status, gender, race and ethnicity.

Frequency counts and percentages were performed for (a) the length of time since the client last saw a medical provider, (b) the number of clients receiving services from each HIV provider within the last year, (c) yes or no questions about experiences within the past year, and (d) barriers to accessing services.

Survey participants ranked their top five services (of the 24 services that Ryan White Part A funds) according to importance. Responses were weighted as indicated by the order of importance assigned by the participant; frequency for how often the service was included in the top five services was also noted. Frequency counts and percentages were conducted for whether or not a client knew about a service, was receiving a service, and was satisfied with the service if he received it.

Cross tabulations were performed on several data elements.

Analyses were only conducted on valid, non-missing responses; if a respondent did not answer a question or did not give a valid response, the response was not included in the analysis for that question.

KEY FINDINGS

A total of 427 surveys were submitted by PLWHA. Of these, 19 surveys were not included in the study due to incompleteness and another 20 surveys were omitted because the persons did not actually live within the Nashville TGA. Therefore, a total of 388 valid surveys were submitted.

It is important to note that some respondents may not have answered every question and therefore the n-value for each question is different. As a result, comparing frequencies across questions is not an accurate measure of difference; comparing percentages allows for a more accurate assessment.

DEMOGRAPHIC INFORMATION

The majority (74%, 287) of individuals participating in this survey were living with HIV, 18.3% (71) were living with AIDS, and 7.7% (30) were not sure if they had HIV or had progressed to AIDS. Ages ranged from 18 to 81, with the average age of respondents being 43.7. The majority (63.6%) of respondents were between the ages of 35 and 54. The proportion of ages of survey respondents was similar to that of the general HIV disease population in the Nashville TGA.

Males accounted for 71.7% (274) of respondents, with females accounting for 26.7% (102), and transgender persons accounting for 1.6% (6). The majority (54.9%) of respondents were Black, 37% were White, and 8.2% of participants identified as Other. Twenty-seven (27) of those who identified as the Other race did not specify another race; two people identified as Native American, one as Asian, and one as multiple races. By race and gender, 37.5% of respondents were Black males, 28.4% were White males, 16.1% were Black females, 8.3% were White females, 0.8% were Black transgender, and 0.8% were White transgender.

Figure 1: Respondents by Age Group

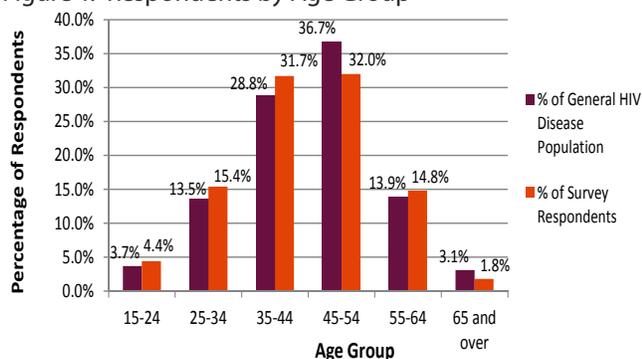
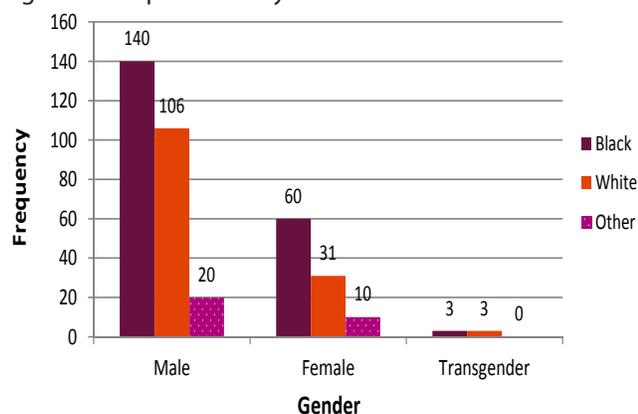


Figure 2: Respondents by Gender and Race



The majority (57%) of respondents with HIV were Black, 35% were White, and 7.5% identified as Other. Of those individuals who had been diagnosed with AIDS, 48% were Black, 42% were White, and 10% were Other. Individuals not knowing whether their current diagnosis was HIV or AIDS were 48% Black, 41% White, and 10% Other. The racial/ethnic breakdown of respondents was similar between those with AIDS and those not knowing if they had HIV or AIDS. However, the number of respondents with HIV had a significantly higher frequency of Blacks and fewer Whites.

Eight respondents (4.6%, 8) identified as Hispanic, while 165 respondents (95.4%) identified as non-Hispanic. However, of the 388 survey respondents, only 173 persons (44.6%) responded to this question; 215 persons skipped this question. Therefore, it is likely that this measure did not accurately capture the true number of Hispanic and non-Hispanic individuals completing the survey. Consequently, Hispanic ethnicity data were not used in survey analysis.

The majority of respondents resided in Davidson County (298), accounting for 89.8% of responses. Thirty-four (34) individuals lived outside of Davidson County, but were still located within the TGA; these individuals accounted for 10.2% of responses. Fifty-six (56) participants did not provide their zip code. The most common zip codes were 37209 (39), 37208 (31), 37203 (29), and 37207 (28). The most common non-Davidson County zip code was 37086 (4), located in Rutherford County.

Because only 10% of respondents lived in non-Davidson counties, and 19% of PLWHA in the Nashville TGA lived in non-Davidson counties, the demographic make-up of the survey respondents was not representative of PLWHA in the Nashville TGA. As a result, conclusions may not be as representative for individuals living outside of Davidson County as they are for those living within Davidson County.

HISTORY OF SERVICES

Most (97%, 363 of 376 responses) respondents had seen a medical provider for HIV medical care

Figure 3: Respondents by Diagnosis and Race

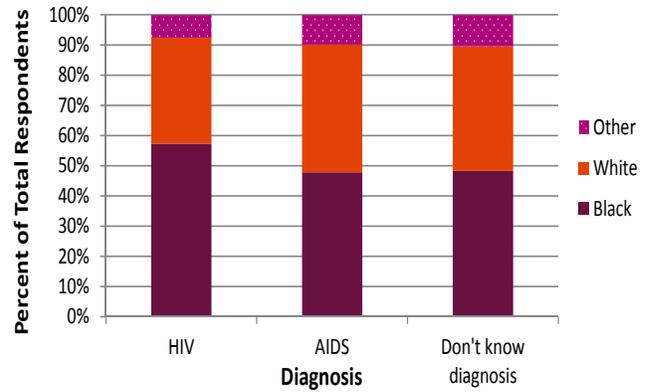
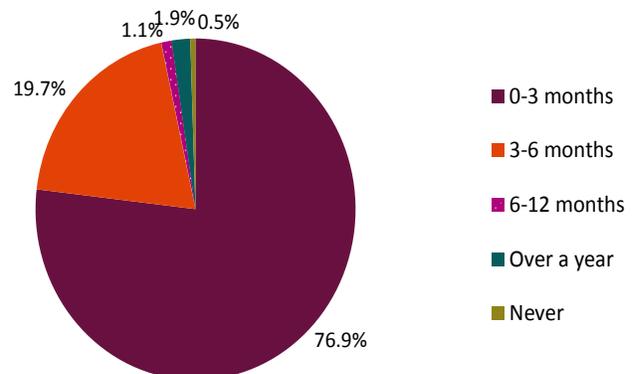
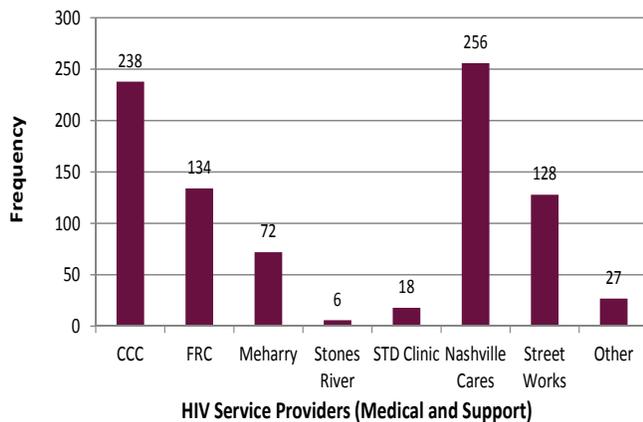


Figure 4: Respondents by Time since Last Saw an HIV Medical Provider



within the last six months. Seventy-seven percent (77%, 289) of respondents had seen a medical provider for HIV care within the last three months and 20% (74) had seen one in the last three to six months. Four respondents reported not having seen an HIV medical professional for 6 to 12 months and 7 respondents had not seen an HIV medical provider in over a year. Two individuals (0.5%) had never seen an HIV medical provider for HIV medical care.

Figure 5: Providers Respondents have Received Services from within the Last Year



Participants received HIV services from multiple providers within the last year. The most frequented HIV support service provider was Nashville Cares, having served 66.8% (256) of respondents within the last year. Street Works served 33.4% (128) of respondents and the MPH STD Clinic served 4.7% (18) of respondents.

The HIV medical provider serving the most respondents was Vanderbilt’s Comprehensive Care Clinic, with 62.1% (238). The other HIV medical providers providing services to respondents included the First Response Center (35%, 134), the Meharry Wellness Center (18.8%, 72), and Stones River (1.6%, 6). Of those persons selecting Other, eight individuals noted that they received HIV services from the VA within the last year and three persons indicated they received HIV services through the jail system.

It is important to note that respondents could select multiple HIV providers that they had seen within the last year. Therefore, the total number of responses did not equal the number of respondents answering the question, but rather the actual number of providers utilized. Also, the percentages do not total to 100% because each provider was analyzed separately.

EXPERIENCES WITHIN THE LAST YEAR

Nutrition: Nearly one-quarter (24.4%, 94) of respondents did not have enough food to eat for three or more days in a row. Twenty-four percent (23.6%, 91) of respondents were told by their doctor to take a nutritional supplement to support their health; of those individuals, 43% (39) did not have enough food to eat for three or more days in a row.

Housing: Being homeless within the last year was reported by 19.8% (76) of respondents, meaning they were either living in a shelter or on the street for some period of time.

Other Health Problems: Fifteen percent (14.9%, 57) of respondents had another health problem and did not know where to go.

Jail/Prison: Incarceration (jail or prison) during the last year was reported by 14.1% (54) of respondents.

HIV Medical Service Utilization: Most (94.3%, 365) respondents saw their HIV doctor at least two times within the last year; 22 individuals did not see their HIV doctor at least two times in the past year. Almost half (47.8%, 184) of respondents saw a dentist at least once within the last year; 201 respondents did not see a dentist in the past year. Most (88.8%, 341) respondents got all of the medications they needed in the last year; 43 persons were not able to get all of the medications they needed.

Need for Assistance from Others: A need for help in dealing with sadness, stress, or other emotional issues was reported by 43% (165) of respondents. A need for help dealing with alcohol or drug use during the last year was reported by 18.8% (72) of respondents. Nearly half (48.3%, 187) of respondents needed to talk with someone else who was HIV-positive. Almost one-quarter (23.4%, 89) of respondents needed to talk with a member of the clergy or a pastor within the last year.

Need for Assistance in Understanding How to Manage Their HIV Disease: Over one-third (35.5%, 135) of respondents needed help finding and getting the services they needed within the last year. A need for help understanding doctor's directions and/or their medications was reported by 18.7% (72) of respondents. Twelve percent (11.7%, 45) of respondents had unanswered questions about their HIV disease and how to stay healthy. Having unanswered questions about what they should eat to stay healthy was reported by 19.6% (75) of respondents.

Figure 6: Respondents' Utilization of HIV Medical Services within the Last Year

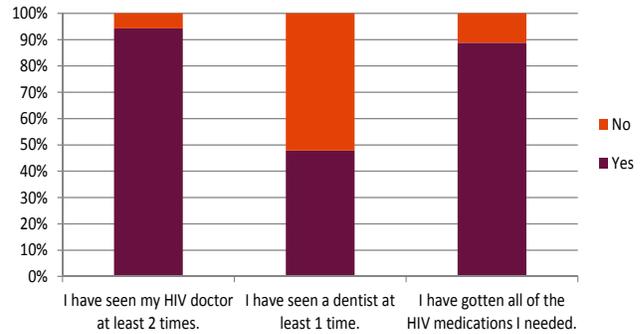


Figure 7: Respondents' Need for Assistance from Others within the Last Year

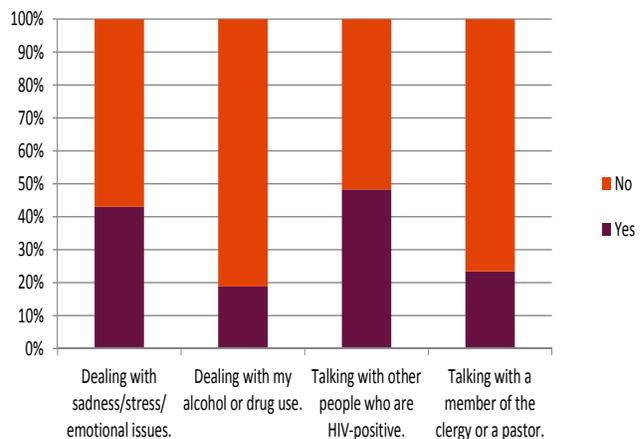


Figure 8: Respondents' Need for Help in Understanding How to Manage Their HIV Disease in the Last Year

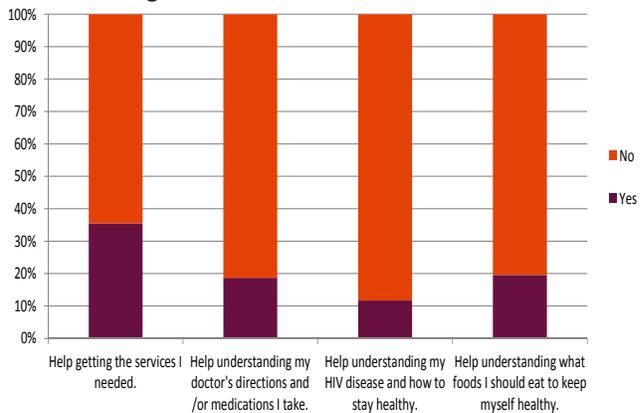
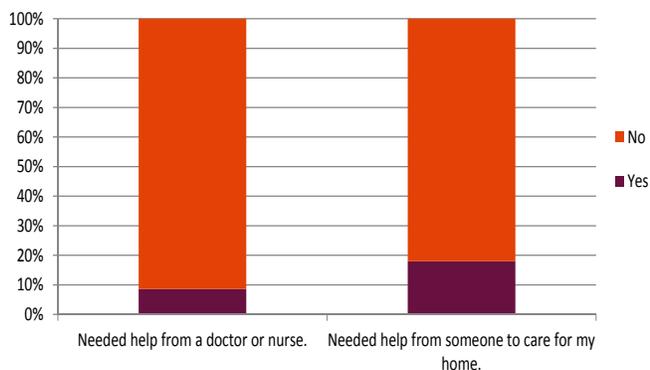


Figure 9: Respondents' Homebound for One Month or More in Need of HIV Services



Homebound Persons: Nine percent (8.6%, 33) of respondents were homebound for a month or longer during the last year due to illness and needed help from a doctor or nurse. Eighteen percent (18%, 69) needed help from someone to help care for their home, providing services such as cooking and cleaning.

SERVICE PRIORITIES

Respondents were asked to rank the top five services they needed to maintain their health. The top five services selected, in order of priority, were

as follows: HIV medical care, HIV medications, dental care, housing, and food. Although fewer people included housing in their top five services than included food, housing received an overall higher ranking of importance than did food.

The Services by Frequency column indicates the number of people who included that service in their top five most important services, while the Services by Priority Level column indicates the services by order of importance. This column was calculated by multiplying the frequency in which the service was chosen with the average ranking of importance it was assigned.

Table 1: Respondents' Service Priorities

	Services by Frequency	Services by Priority Level
1	HIV medical care (290)	HIV medical care
2	HIV medication (254)	HIV medications
3	Dental care (200)	Dental care
4	Food (145)	Housing
5	Housing (138)	Food
6	Transportation for HIV care (107)	Transportation for HIV care
7	Help paying for insurance (71)	Help paying for insurance
8	Help paying utilities (57)	Support groups
9	Support group (54)	Help paying utilities
10	Counseling (50)	Counseling
11	Help finding services (35)	Help finding services
12	Nutritional supplements (29)	Drug/alcohol treatment
13	HIV education (27)	Nutritional supplements
14	Drug/alcohol treatment (26)	Talking with someone HIV-positive
15	Talking with someone HIV-positive (22)	HIV education
16	Counseling from a dietician (14)	Counseling from a dietician
17	Legal services for power of attorney (POA), do not resuscitate (DNR), accessing benefits (14)	Legal services for power of attorney (POA), do not resuscitate (DNR), and accessing benefits
18	HIV medical care at home (9)	HIV medical care at home
19	Child care services (6)	Pastoral/clergy support
20	Physical therapy (6)	Physical therapy
21	Pastoral/clergy support (6)	Child care services
22	Time off for my caregiver (2)	Time off for my caregiver
23	Language interpretation (1)	Language interpretation
24	Hospice care (1)	Hospice care

Personal Barriers: Not being ready to deal with their HIV disease diagnosis was reported by 21.6% (83) of respondents. Over one-third (34.4%, 131) of respondents were worried about other people finding out they had HIV disease.

Knowledge Barriers: Not knowing the location of the organization providing a service was reported by 13.3% (51) of respondents. Not knowing what services they needed in order to deal with their HIV disease was reported by 14.1% (54) of respondents. Not knowing where to go or who to ask for help was reported by 14.5% (56) of respondents.

Appointment Barriers: Having to wait too long to get an appointment with their HIV doctor was reported by 12.6% (48) of respondents. Thirteen percent (12.8%, 49) of people were not able to access services because the hours the provider is open did not work with their schedule. Nearly one-quarter (24.7%, 94) of respondents did not have transportation to get to their appointments.

Financial Barriers: Not being able to afford the services they needed was reported by 18.8% (72) of respondents. Lack of health insurance as a barrier to care was reported by 22.7% (87) of respondents. Fifteen percent (14.9%, 57) of respondents reported an inability to qualify for services because of their income. Twenty percent (19.6%, 75) of respondents had insurance, but the insurance did not cover the full costs of services needed.

Staff Barriers: Twelve percent (12.1%, 46) of respondents reported that no one was willing to answer questions or explain things to them. Impolite or unhelpful treatment by service staff was reported by 14.4% (55) of respondents. And fourteen percent (14.2%, 54) of respondents reported feeling that the provider did not really understand what they needed.

System Barriers: Ten percent (9.7%, 37) of respondents felt the system of HIV care was too confusing. Inability to get referrals for the services they needed was reported by 15.2% (58) of respondents. Nineteen percent (18.5%, 71) of respondents reported that the services that were supposedly available were not there when they

Figure 10: Barriers to HIV Care: Personal Barriers

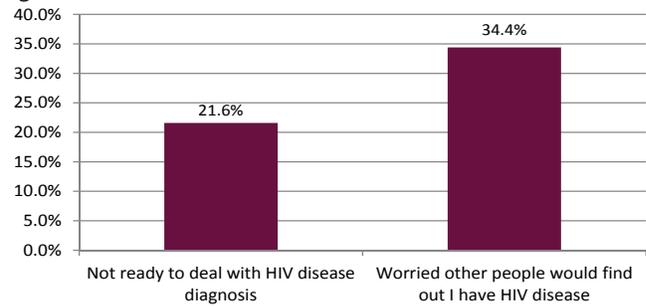


Figure 11: Barriers to HIV Care: Knowledge Barriers

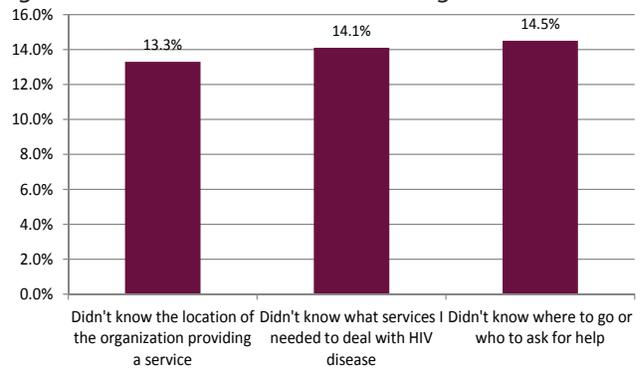


Figure 12: Barriers to HIV Care: Appointment Barriers

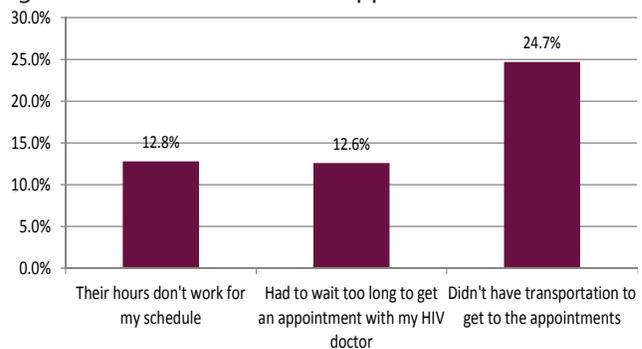


Figure 13: Barriers to HIV Care: Financial Barriers

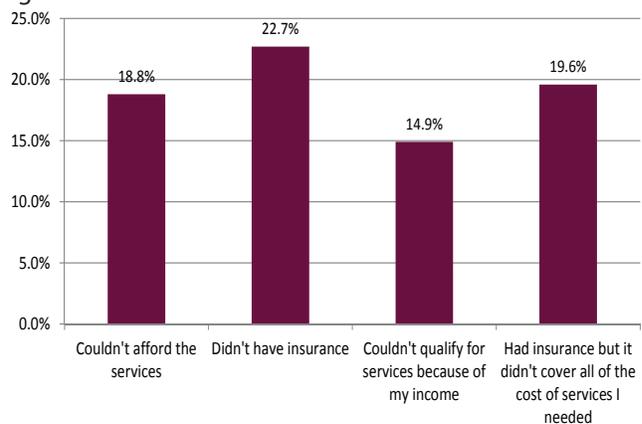


Figure 14: Barriers to HIV Care: Staff Barriers

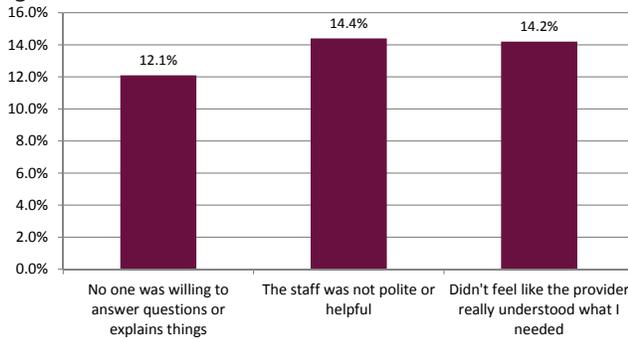


Figure 15: Barriers to HIV Care: System Barriers

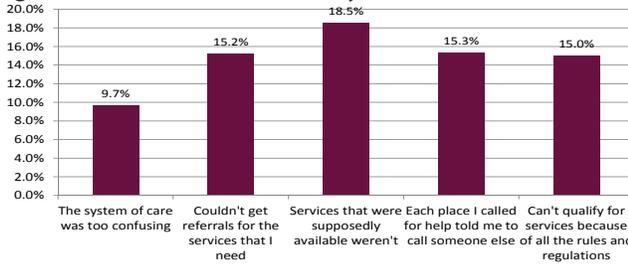


Figure 16: Respondents' Inability to Attend Appointments within the Last Year

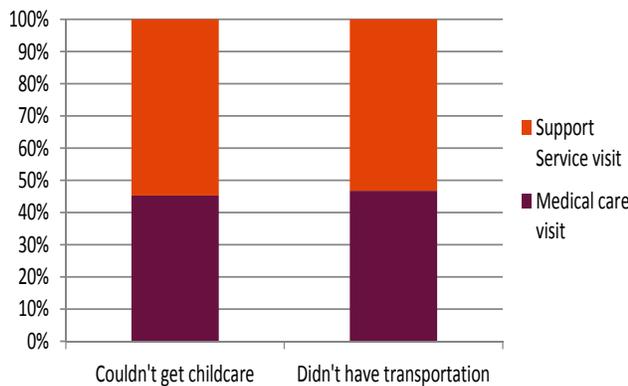
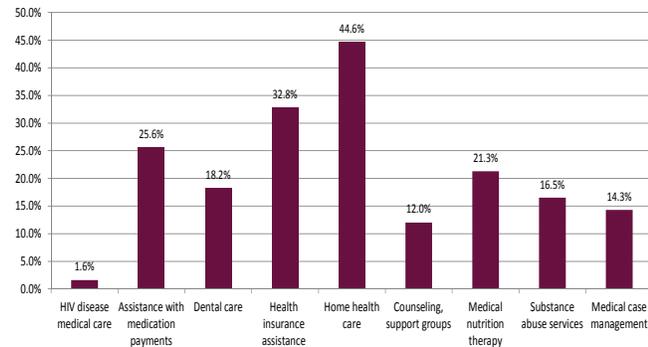


Figure 17: I Don't Know this Service Exists: HIV Disease Core Medical Services



tried to get them. Fifteen percent (15.3%, 58) of respondents reported that each place they called for help told them to call someone else. Not being able to qualify for services because of all of the rules and regulations was reported by 15% (57) of respondents.

Inability to Attend HIV Appointments: Ten percent (10.1%, 39) of respondents missed an appointment with their HIV doctor in the last year because they did not have child care and 12.2% (47) missed an appointment with an HIV support service provider because of not having child care. Nearly one-quarter (23.7%, 91) of respondents missed an appointment with their HIV doctor because they did not have a way to get there and 27% (103) missed an appointment with an HIV support service provider due to not having transportation.

KNOWLEDGE OF HIV DISEASE SERVICES

Overall, respondents were more aware of HIV disease core medical services than they were of support services. The average percentage of respondents not knowing that a core medical service exists was 20.8%, while on average 27% of respondents did not know a support service exists. The service known by the most respondents was HIV disease medical care (98.1%), with only six respondents not knowing about it. Other services known by most respondents included HIV education (87.9%), counseling and support groups (87.4%), medical case management (85.7%), and substance abuse services (82.9%). The service known by the fewest respondents was child care, with only 48.1% of respondents knowing it exists for HIV-positive persons. Other services with a low percentage of awareness included interpretation and language translation (49%), home health care (54.2%), and health insurance assistance (66.7%).

On the whole, persons were satisfied with the services they were receiving. Everyone receiving home health care reported that the service met their needs. On average, only 2.7% of respondents felt that a service did not meet their needs. According to respondents receiving each service, the services most commonly reported for not meeting the client's needs were dental care (7.8%,

13), interpretation and language translation (7.1%, 2), child care services (5.3%, 2), and health insurance assistance (4.8%, 6). It is important to remember that the number of respondents reporting they received these services is small in some cases. Therefore, the percentage of people not being satisfied with services may be deceptive.

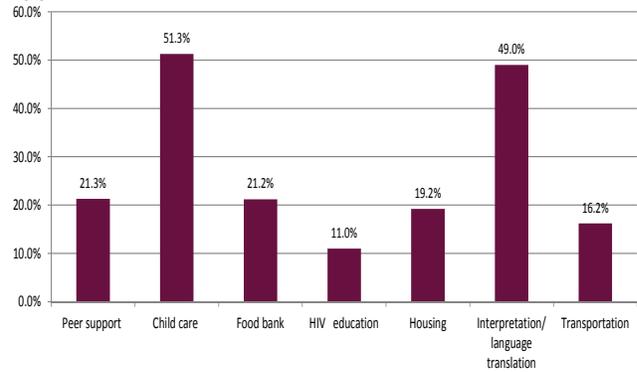
CONCLUSIONS

The most prominent gaps in HIV services as reported by survey respondents were dental care, housing, food, and transportation. These services were listed by the respondents as the third through sixth most important services. Even though HIV medical care and HIV medications were prioritized as the top two services, respondents were receiving these services, as is indicated by 94% of respondents reporting that they had seen an HIV doctor at least twice in the last year and 89% of respondents reporting that they were getting the HIV medications they needed. However, 52.2% of respondents were not being seen by a dentist at least once a year. Dental care was also the service most often stated as not meeting the needs of those persons receiving it.

A significant number (19.8%) of respondents were living on the street or in a shelter for some part of the last year. Those individuals staying with friends or family, staying in a half-way house or treatment facility, or staying in some other form of temporary housing are not accounted for in this question; therefore the number of individuals not having stable housing is likely to be even higher than the percentage reported here.

Almost one-quarter (24.4%) of respondents reported that they did not have enough food to eat for three or more days in a row at some point within the last year. This does not account for those persons not having enough food to eat for one or two days at a time. Although three days in a row without enough food was thought to indicate people who truly did not have enough food, for those persons needing to eat before taking their HIV medications, any length of time without food is a problem.

Figure 18: I Don't Know this Service Exists: HIV Disease Support Services



Almost one-quarter (23.7%) of respondents missed appointments with their HIV doctor because they did not have transportation and 27% of respondents missed appointments with HIV support service providers because of not having transportation. Lack of transportation has actually prevented 24.7% of respondents from receiving HIV care, however this does not mean that they have never been able to receive care as a result of transportation issues.

While there will always be some gaps in services, certain services are more essential to the survival of a person living with HIV disease. Food and housing are necessary for everyone to lead a healthy life; however when a person is dealing with HIV disease as well, these elements become even more important because they impact other facets of a person's HIV care. An individual may not be able to appropriately store HIV medications if he does not have housing or may not be able to take the medications if he does not have food to take with them. Or a person's immune system may be weakened due to insufficient nutrition or rest, leaving him vulnerable to opportunistic infections. In addition, while dental care and transportation may be beneficial for the average person's life, they are even more critical to PLWHA. HIV-positive individuals are at greater risk for oral health problems and without proper dental care they could become susceptible to other infections. Transportation is critical as well; without transportation a person may not be able to receive necessary HIV medical care, pick up HIV medications, or pick up food bags.

It is through the experiential contributions of PLWHA that a better understanding of the needs of persons living with HIV disease can be achieved.

KEY INFORMANT INTERVIEWS

BACKGROUND

In 2011, key informant interviews were conducted by the MPHD Research Analyst, examining the types and availability of HIV services in the Nashville TGA. The interviews were aimed at understanding the full system of HIV care, including those secondary services that are indirectly related to a person's HIV care, but directly impact one's overall health.

METHODOLOGY

Interview Development: In order to get a good understanding of the current system of HIV care in the Nashville TGA, interview questions were centered on the strengths and weaknesses of available services. Some questions were taken and modified from other surveys, including the Indiana Provider Survey (2009) and Central Florida's Provider Survey (2005).

Key Informant Identification: Key informants were initially identified by the type of service provided. A comprehensive list of HIV-related service categories was created and key informants were identified for each kind. Categories selected include:

- Federally-funded health center
- HIV medical provider
- HIV/AIDS service organization
- Mental health provider/substance abuse provider
- Rural provider
- Women and families provider
- Youth-oriented provider

Speaking with knowledgeable persons associated with the field of HIV was desirable for getting insightful and informed opinions and experiences.

Interview Administration: The interviews were conducted by the MPHD Research Analyst via telephone. The Research Analyst sent informants the interview questions in advance, however asked the informant each question as well. Seven interviews were conducted.

Data Entry and Data Cleaning: Responses were recorded by the Research Analyst using modified short-hand as the informants answered questions. Responses were then reviewed and cleaned immediately following each interview to ensure recording accuracy and completeness.

Analysis: Each question, except one, was open-ended allowing respondents to provide specific opinions and details. These responses were coded for themes and analyzed as such. Anecdotal information was also noted to provide qualitative meaning to informants' views on the current system of HIV care.

KEY FINDINGS

WHAT IS WORKING WELL WITH THE SYSTEM OF CARE IN KEEPING PERSONS FROM CONTRACTING HIV DISEASE?

Various aspects of the current system of care were listed as working well in keeping people from contracting HIV. Three informants stated that testing has done well to keep people from contracting HIV; conducting rapid testing and expanding testing services to allow more people access to testing has been key. A mental health/substance abuse key informant, who believes testing has been very important, noted that his organization goes out and looks for people to be tested. He added, "People with addiction disorders are certainly at higher risk of contracting HIV." Taking the added step of actively looking for people to be tested can reduce the number of persons contracting the disease. Increased HIV disease education and cultural relevance were other aspects of the system mentioned by informants.

Early intervention services (EIS) was mentioned by three informants as being a good way of preventing HIV. While EIS does not actually do prevention services, it helps to link people who are HIV-positive to care, lowering the community viral load, which in turn lowers the risk of contracting HIV for people who are not HIV-positive.

The rural key informant stated that her organization does not really provide any prevention services because they do not have the staff or resources for these services. Therefore, they are only able to provide treatment for those individuals who are already HIV-positive.

It is important to note that some individuals listed services that are not prevention services; they are not services directed at persons who are HIV-negative, but rather services for people who are already HIV-positive. Perhaps there is a disconnect between prevention and treatment and HIV-negatives and HIV-positives. A number of the informants seemed to skip over prevention for people who are HIV-negative and immediately focus on those who are HIV-positive. In order to reduce the number of people needing treatment, we must recognize the need for reaching people while they are still HIV-negative.

WHERE ARE THE MAJOR GAPS IN PROVIDING SERVICES TO KEEP PERSONS HIV-NEGATIVE?

Six of the seven informants stated that education is a major gap in preventing persons from contracting HIV. Two individuals noted that they believe people have become complacent with HIV and that they do not fully appreciate the severity of the disease because current treatment and medications have greatly improved the course of the disease. They believe people are not seeing the side of the disease that kills so callously and therefore they have adopted attitudes towards the disease that are simply not compatible with the reality of the disease. People need to be appropriately educated about the truths of the disease. And while one informant proposed that greater focus needs to be on educating high risk populations, another person questioned the need for educating other groups as well. She said, "Individuals with high-risk see messages all the time, but other groups don't necessarily."

Aside from educating people specifically on HIV disease, one informant discussed the importance of educating people on how to disclose their status to their partners in order to prevent spreading the disease to them. "The lack of these skills can inhibit people from doing these things and they can't

make informed decisions about risk.” Learning to talk about the disease is important on the individual level, but also on the community level. One informant noted that certain aspects of the disease are ignored or not discussed in our community because of religious and racial factors. She said, “If you create a space where people are comfortable to talk about it then they will, but if there’s too much stigma they won’t.”

Not surprisingly, funding was pointed out as a major gap by four informants. Without sufficient funding there are staff that cannot be hired and services that cannot be provided.

Prevention services directed at ethnic communities were also noted by two informants. There are language and cultural needs of these communities beyond the general prevention services. And while many ethnic communities are present in Nashville, the Hispanic and Kurdish communities were specifically mentioned.

Other services such as housing, food, and mental health were also pointed out. Without these services a person cannot even begin to think about HIV, whether they are HIV-positive or HIV-negative. A person’s basic life needs must first be met before he can begin worrying about HIV. Therefore, people need greater access to basic services in order to put them in a position to even be concerned about HIV disease.

WHAT IS WORKING WELL WITH THE SYSTEM OF CARE IN GETTING HIV MEDICAL TREATMENT AND OTHER HIV SUPPORT SERVICES FOR PERSONS WHO ARE HIV-POSITIVE?

Informants gave very different responses for what aspects of the system of care are working well for providing care to HIV-positive individuals. And while some services were mentioned by one informant as a service that is working, others mentioned it as a service that was not working very well. One informant noted the vast number of people working in the HIV field. “One of the things working well is the multitude of people doing work. I’m continually learning about all of the services places are providing, all of the places doing work, the grassroots organizations...” Another informant commented that collaborations between some organizations have been very beneficial. These collaborations can be helpful when considering the loss of care population. Connections between organizations can help to build connections with clients and keep them in care.

Other services brought up by informants included medical care, providing comprehensive care, EIS, case management, and medications. Although these services are working pretty well given the limits, they are not enough. Almost all of the informants believed that some services are helping, but felt the need to quantify them as still lacking.

EXCLUDING LACK OF FUNDING, WHAT ARE THE TOP 3 CHALLENGES YOU HAVE FACED WHEN PROVIDING HIV MEDICAL TREATMENT AND OTHER HIV SUPPORT SERVICES TO PEOPLE LIVING WITH HIV OR AIDS?

Some informants answered this question with the challenges that they are directly faced with when providing care to consumers, while others answered with challenges that they are only indirectly faced with, but are more so challenges for the consumer. The most common challenge given was transportation, stated by four informants. Without transportation consumers cannot get the services they need. Referring a consumer elsewhere may be a moot point if the consumer does not have any means of getting there. It is more difficult to get people in care and get them to stay in care if transportation is a problem. The rural informant stated her average client must travel 45 minutes to an hour to get to the clinic. Public transportation is not an option for consumers in much of the rural area. Accessibility to

services, such as timing, is also closely related. If a person is not available to get the service when the provider is open, then he may not be able to get that service.

Stigma was mentioned by two informants as creating challenges to giving HIV care. There is still a lot of judgment with the disease amongst the community and churches. If people are concerned about being stigmatized they may choose to not receive services. This can make it difficult for getting people in care, as well as keeping them in care. An individual's denial of the disease is also problematic. If a person just ignores their HIV disease diagnosis hoping it will go away, he risks his own health, as well as the health of others if he spreads the disease.

An informant located within Davidson County noted the limited resources that exist outside of Davidson County. This was also noted by the key informant from the rural clinic. She discussed the challenges with mental health services in the rural areas. There is only one mental health provider and so if a patient does not like that provider or does not "gel" with them, there is not anywhere else for them to go unless they drive all the way into Nashville.

Some of the challenges directly faced by providers include staffing issues and the unit system in which medical care is built on. Sometimes patients have multiple co-morbidities and the 15-minute increments for doctors to be able to bill by can make it very difficult to give sufficient care. The informant from the rural clinic noted that staffing is a major issue. She discussed the problem of not having sufficient staff members. "I'm a nurse; I'm not a social worker. But I'm put in situations that I have to provide social work services to people, so it's an injustice to people. It's not that I can't do the job, but I'm just not trained in the proper way."

Other challenges include insufficient housing; the strictness of guidelines/limitations of resources in employment and housing for individuals who have had problems in their past (such as substance abuse or jail); not enough peer services; insufficient education; changes that occur in relationships when a person is diagnosed with HIV disease; not having medical providers that have experience with HIV; people not being comfortable talking about HIV, talking about HIV and sexuality, condom negotiation and refusal skills; and waiting lists. It was also mentioned that the networking between organizations needs to be improved. In addition, having a more comprehensive sense of who is providing what services, as well as what services are actually available, is needed. There may be resources that are available to consumers that even some service providers are not aware of.

FOR THE SERVICES THAT RYAN WHITE FUNDS, ARE THERE SERVICES THAT ARE NOT AVAILABLE AT ALL OR NOT ENOUGH OF? IF YES, WHAT SPECIFIC SERVICES?

The most commonly reported service that is insufficient was medical case management. Informants discussed the heavy case loads of medical case managers. "Most case managers' case loads are so large they have difficulty finding adequate time taking care of all of those [cases] and [the] case manager at times can be overloaded and can't do what is needed." Another informant proposed that the case load could be alleviated to a degree if medical case managers had peers working with them.

Adequate housing was once again discussed, along with food and transportation. Insufficient dental care and mental health services, including mental health providers who are experienced with mental health as it pertains to HIV, were also mentioned. Some other services that were brought up include outpatient/ambulatory care, services for women and children, substance abuse, treatment on demand, and respite type services. Employment needs were also mentioned, including assistance directed

towards returning to work, moving out of unemployment or underemployment, and disclosing status to an employer, etc.

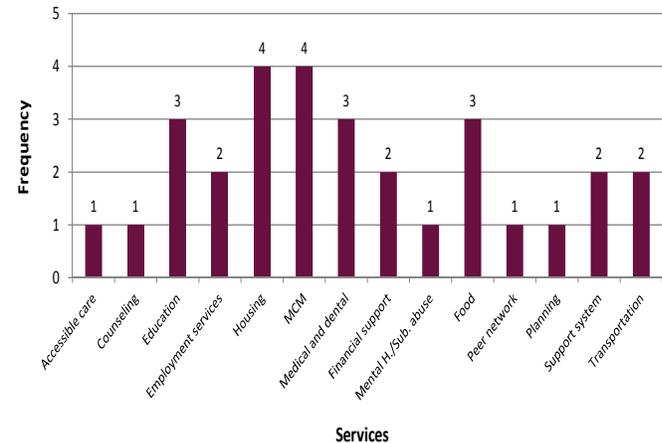
WHAT ARE THE FIVE MOST IMPORTANT SERVICES A PERSON NEEDS IN ORDER TO SUCCESSFULLY MANAGE AND LIVE WITH HIV DISEASE?

Medical case management (MCM) and housing were the most frequently listed services needed by a person to successfully manage HIV disease; these were each listed by four informants. Medical case management, including linking into resources and treatment adherence, were considered to be very important. Affordable and decent housing was also felt to be critical to a person successfully living with HIV. Interestingly, the four individuals listing housing were the individuals working in the clinics and community health centers; this is likely a reflection of the services their clients are lacking or have difficulty getting. Along the same lines of basic life needs, three informants listed food/nutrition services. These were three of the same informants listing housing.

Education was listed by three informants. Informants stated that education was necessary for both the HIV-positive individual, as well as for his family, and needed to include understanding the disease, how to manage it, building skills, and how to become actively engaged in one's HIV care. An informant of an AIDS service organization (ASO) said, "People are comfortably passive around those issues and sometimes that's okay and sometimes not okay, because it creates extra stress on the people and services. And that's not a good way to manage the disease because they are lacking complex knowledge, especially with new treatments. But that becomes an excuse for people. They could be trained to ask questions."

Adequate and comprehensive dental services were listed by three informants. Similarly, medical and prescription benefits/financial support were listed by two informants. One informant discussed the need for individuals to have sufficient insurance coverage or funding. She commented that some clients have insurance, but it does not cover all

Figure 19: The Most Important Services a Person Needs in order to Successfully Live with HIV Disease



It is important to note that one informant did not answer this question because she felt she could not presume the needs of other people since everyone is different.

of the service costs. She calls them “‘the working poor.’ They are out there working, but they make too much to qualify for the programs. And it might only be by like \$100, but they don’t qualify.”

Employment assistance was also listed by two informants. A way of increasing the employability of individuals would be beneficial for them to successfully live with HIV. “A lot of people are on disability, but they could still make something to contribute back to the community.” A support system, whether it is familial or community based, is also important for individuals living with HIV.

Other services listed by informants as being important for individuals living with HIV included transportation, accessible and open care, counseling, mental health and substance abuse services, a peer network, and planning.

HOW WOULD THE SYSTEM OF HIV CARE NEED TO CHANGE IN THE NEXT 3 TO 5 YEARS IN ORDER TO KEEP PERSONS HIV-NEGATIVE AND PROVIDE QUALITY CARE TO PERSONS WHO ARE HIV-POSITIVE?

The most common responses for how we would need to change the system of care to keep people HIV-negative and treat those who are HIV-positive were increasing education, reducing stigma, and integrating biomedical research and advances into the community. One informant mentioned sero-positive studies and the need to be able to incorporate results into care.

An informant from an ASO proposed that the way to keep people HIV-negative is by impacting those who are HIV-positive. Again he emphasized the importance of skills building. “The ability of HIV-positive people to prevent transmission is through skills, risk reduction, maintaining their health, getting the services they need.” The informant in the rural clinic said that staffing would need to be improved for them to successfully provide quality HIV care to persons who are already HIV-positive. She said, “We’ve gone from 85 to 120 patients. We can get them meds and to appointments, but not other things like social services. We don’t have the staffing to support all of their needs. Eventually we’re going to see a decline in patients.”

Additional changes proposed to improve the system of HIV care include increasing prevention and outreach, placing a greater focus on African American women, improving networking between medical providers so that they can more easily determine if a client has dropped out of care, having health care providers who are knowledgeable and experienced with HIV, not building parallel programs that chop up resources and waste money and people, and better integration of HIV services into social services (i.e. housing, food, education, job opportunities).

WHICH OF THE FOLLOWING POPULATIONS DO YOU BELIEVE IS MOST IMPORTANT TO HAVE THEIR HIV-RELATED NEEDS ASSESSED AT THIS TIME? THAT IS, WHICH POPULATIONS ARE THE MOST UNDERSERVED AND/OR DO WE KNOW THE LEAST ABOUT?

Informants were asked to choose three of the following groups:

Persons co-infected with Hepatitis C	Incarcerated/recently released	Persons with alcohol and substance abuse problems
Sex workers	The mentally ill	Homeless persons
Hispanics/Latinos	African Americans	Women
Men who have sex with men	Heterosexual men	Transgender persons
Youth age 13-24	Persons age 50 and older	Other (specify)

Each group was selected by at least one informant, with the exception of Transgender persons, which was not selected by anyone. There was no consensus as to what three groups most need to have their HIV-related needs assessed at this time. Each group was only selected by one or two informants. No informants listed a group that was not provided.

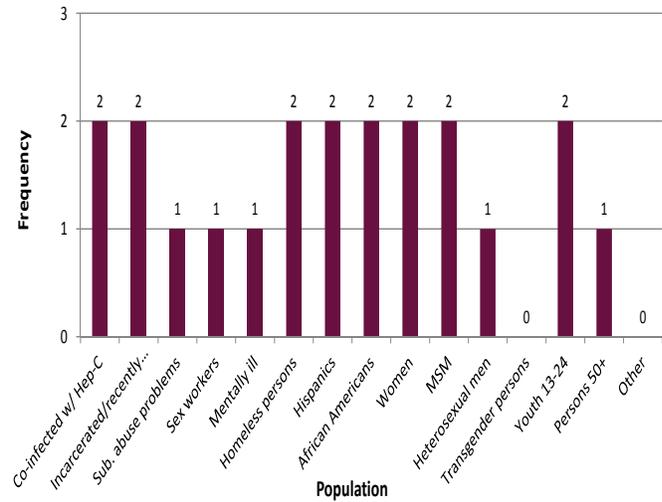
BRIEFLY DISCUSS THE SINGLE MOST IMPORTANT CHANGE ASIDE FROM INCREASED FUNDING, THAT YOU WOULD RECOMMEND FOR IMPROVING THE PROVISION OF HIV-RELATED CARE AND/OR SUPPORT SERVICES FOR PLWHA IN THE NASHVILLE TGA.

All of the key informants stated a different change that they would recommend for improving the provision of HIV-related care and support services for PLWHA. MCM was noted as a lynch pin within the system. The informant stated that while we need to identify primary activities for medical case managers, it should not be so monolithic. Also, we need to have a better understanding of where EIS ends and MCM begins. Another informant stated that social work and social services need to be more accessible, at least for individuals living in rural areas; and a different informant emphasized the importance of integrating HIV medical services into social services.

Other changes listed to help improve the provision of HIV services included treatment adherence, reducing inequality among community based organizations, education and outreach, and improving community attitudes towards HIV disease.

Two informants provided a second, additional change that they would recommend if they were allowed two changes. These included improving transportation in the rural areas and improving the infrastructure of services available outside of Davidson County.

Figure 20: Populations in Greatest Need of Having Their HIV-Related Needs Assessed at this Time



IS THERE ANYTHING ELSE YOU WOULD LIKE TO ADD REGARDING HIV DISEASE SERVICES IN THE NASHVILLE TGA, THE OVERALL SYSTEM OF CARE, OR SUGGESTIONS REGARDING IMPROVEMENTS TO THE SYSTEM?

A couple of informants added a few additional thoughts and concerns.

There is tremendous interest in the use of peers, however most organizations do not have the resources to reimburse them or have very limited resources for this.

There are many organizations that have staff members who are HIV-positive, but they have not thought about using them as peers. “Being HIV-positive yourself, regardless of whether a consumer or not, gives certain insight; how do we play that up and build it into the system? A lot of us make an effort to attract and hire HIV-positive individuals, but then don’t integrate them into the system or give them a unique role to put those skills to use.”

Testing needs to be expanded in the outlying, rural counties to identify those people who are positive and do not even know it.

Certain counties are served by the TGA and others are not. The rural area informant described the difficulties of serving clients that live within the TGA, as well as a significant number who do not. “There are certain counties that are served by the TGA, but there isn’t anyone to serve them and there are few people that even need services. Clarksville has a lot of people with HIV, but they aren’t eligible for your services.”

CONCLUSIONS

Overall it appears as if the key informants feel the services that are in place are doing a good job, however there are just not enough of them. Not surprisingly, many of the problems with the system of care go back to insufficient funding. However, as was suggested by a few informants, we need to find ways of improving the system without requiring additional funding; we need to more effectively and efficiently use the funding that is available.

The services mentioned the most often by informants as being critical to the system of HIV care are medical case management, housing, food, education, and transportation. Access to medical services, either through adequate health insurance or other funding, was also highly regarded.

These key informant interviews did not reveal a great deal of consensus. This is perhaps because each informant works in a different part of the HIV medical or social service field and therefore encounters different challenges related to the different types of clients they serve. However, it could also be presumed that the lack of strong consensus is the result of many areas of need existing within the HIV system of care.

