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



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FOOD AND TRANSPORTATION SURVEY

BACKGROUND

In 2012, the MPHD Research Analyst and the Community Access Committee created a Food and Transportation Survey to examine patterns of need regarding food and transportation services among HIV-positive persons in the Nashville TGA. The survey was aimed at determining whether people who are eligible for food and transportation services were receiving said services, to learn whether people were experiencing times of insufficient nutrition or unreliable transportation, and to ascertain what services were necessary to meet the food and transportation needs of PLWHA in the Nashville TGA.

METHODOLOGY

Survey Development: A previous study was conducted by the Research Analyst and Needs Assessment Committee in 2011 and found that 24.4% of HIV-positive respondents in the Nashville TGA reported not having enough food to eat for three or more days in a row. Also, 23.7% of respondents missed an appointment with their HIV doctor because they did not have transportation; 27.0% missed an appointment for an HIV support service due to not having transportation.

In order to determine some areas of focus regarding food and transportation among PLWHA, the Research Analyst conducted an in-depth analysis of the responses of the 2011 Ryan White Part A Service Needs and Gaps Survey. Responses were analyzed by looking at six different groups of respondents: all respondents (used as a baseline), persons reporting they did not have enough food, persons reporting they did have enough food, persons reporting they did not have adequate transportation, persons reporting they did have adequate transportation, and persons reporting they did not have enough food or adequate transportation. This analysis was used to determine potential problematic areas, as well as areas of disparity regarding demographics and service utilization.

Survey questions were created based on the Service Needs and Gaps Survey in-depth analysis, as well as being modified from *Hunger in America 2010*, a National Report Prepared for Feeding America, and an article from the National Rural Health Association, *Rural HIV Care: Transportation*.

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).

Before the survey was administered, it was submitted to the MPHD Institutional Review Board (IRB) to ensure that the survey complied with regulations regarding human subjects research ethics. The survey was approved by the IRB.

Confidentiality Measures: All peers and volunteers helping to execute the survey signed a confidentiality agreement stating that they would not share any information they may learn while assisting with the surveys. A peer or staff member informed each participant who completed a survey at a provider

site that the survey was voluntary and confidential. An optional question was included that asked for the respondents' name and phone number in the event that the participant was willing to share additional information at a later time; participants were not required to share this information. The Research Analyst was the only person to see respondents' names and phone numbers.

Survey Administration: Peers at provider sites administered the survey 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 Research Analyst trained the peers 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 Research Analyst trained the peers, they conducted surveys at their provider sites through convenience sampling. Provider sites used included the First Response Center, Nashville Cares, and Vanderbilt's Comprehensive Care Clinic. Nashville Cares' rural case managers also provided the survey to clients when conducting off-site visits in order to allow people not receiving services at the physical office to have the opportunity to participate in the study.

Data Entry and Data Cleaning: The Research Analyst created a corresponding survey using SurveyMonkey in order to allow for more accurate data entry. The Research Analyst was the only one to use this survey tool. The surveys were numbered and manually entered into SurveyMonkey following pre-established coding guidelines.

The Research Analyst conducted the data entry, entering data as surveys were received until all surveys were entered. The Research Analyst checked the data after data entry was completed to ensure data accuracy and to correct improper coding.

Limitations: Participant responses were based on the perceptions of the participant and therefore are only representative of his perceptions. In addition, 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 and so those 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 medical care and support services. However, because this survey was in part evaluating the food and transportation services that are provided by Ryan White Part A, it was not logical to implement the survey at non-Part A sites.

Analysis: Data were analyzed as of March 14, 2012.

Frequency counts were conducted on all demographic information, as well as general service information, in order to determine what the sample population looked like and how it compared with the greater HIV-positive population in the Nashville TGA.

Poverty level was determined by crossing the household monthly income with household size data and comparing it to the 2011 Federal Poverty Guidelines. However, because household income was collected in ranges, rather than an exact income, poverty levels could only be estimated.

Averages and ranges were calculated for length of time living with HIV disease, time to HIV medical and HIV-related support service appointments, how early one arrives to an appointment, and how late one must wait after an appointment.

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 data variable.

KEY FINDINGS

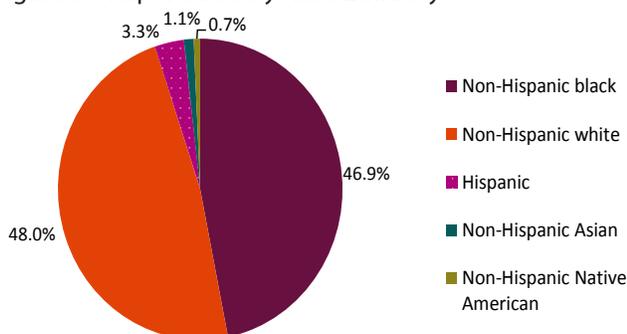
A total of 307 surveys were collected. Of these, 16 surveys were excluded from the study due to insufficient data provided, 16 surveys were excluded because the respondents did not live within the Nashville TGA, and one was excluded because the respondent was not HIV-positive. Therefore, a total of 274 valid surveys were submitted and analyzed. The number of useable surveys did not meet the appropriate sample size in order to maintain a margin of error of +/-5 percentage points with a 95% confidence level. However, obtaining a sample size of 274 only slightly increased the margin of error to +/-5.67 percentage points, while still maintaining a 95% confidence level.

It is important to note that some respondents may not have answered every question and therefore the n-value for each question is different.

DEMOGRAPHIC INFORMATION

Males represented 70.8% (194) of respondents, with females accounting for 28.5% (78), and transgender persons accounting for 0.7% (2). The largest portion of respondents identified as non-Hispanic white (48.0%, 130), followed by non-Hispanic black with 46.9% (127) of respondents. Non-Hispanic

Figure 1: Respondents by Race/Ethnicity



Asians accounted for 1.1% (3) and non-Hispanic Native Americans accounted for 0.7% (2). Only 3.3% (9) identified as Hispanic.

The majority (76.3%, 209) of persons participating in this survey were living with HIV, 17.9% (49) were living with AIDS, and 5.8% (16) were not sure if they had HIV or had progressed to AIDS. Over half (51.5%, 139) of the participants were between the ages of 45 and 64, while 40.0% (108) were between 25 and 44 years of age. Only 7.4% (20) and 1.1% (3) were 18 to 24 years old and 65 and older, respectively. No one younger than 18 years of age was eligible to participate in this survey.

The majority (88.8%, 229) of respondents resided in Davidson County. Twenty-nine (29) individuals lived outside of Davidson County, but were still located within the TGA; these persons accounted for 11.2% of survey respondents. The largest portions of people outside Davidson County resided in Rutherford County (34.5%, 10) and Sumner County (24.1%, 7). The most common zip codes were 37206 (22), 37207 (22), 37208 (20), and 37211 (20). Sixteen (16) persons did not provide their zip code.

Because only 11.2% of respondents lived in non-Davidson counties, and 23.1% of PLWHA in the Nashville TGA live in non-Davidson counties, the demographic make-up of the survey respondents may not be generalizable to persons residing outside of Davidson County. As a result, conclusions may not be as representative for persons living outside of Davidson County as they are for those living within Davidson County.

Respondents have been living with HIV disease for an average of 11 years, with lengths of time ranging from 1 month to 30 years.

Respondents were not asked exact household income, but rather for a range of household income; therefore, a precise poverty level could not be calculated for each respondent. However, based on the information collected, it is estimated that 56.4% of respondents were living at or below 100% of the poverty level.

SERVICE INFORMATION

Almost all respondents (96.0%, 263) reported that they were currently receiving medical care, while only 4.0% (11) of persons indicated that they were not receiving medical care for their HIV disease. Similarly, 91.1% (246) were currently taking medications for their HIV disease, while 8.9% (24) were not.

The majority (54.4%, 147) of respondents had seen their HIV case manager within the last 3 months, while 22.2% (60) and 14.1% (38) had seen their case manager within the last 4-6 months and 6-12 months, respectively. Few people (4.4%, 12) reported that they had a case manager, but had not seen him in over 12 months. Five percent (4.8%, 13) of respondents stated that they did not have a case manager.

FOOD SERVICES

Approximately 80% (215) of respondents were aware of food services prior to taking this survey, while 20.5% (56) were not aware of these services. Two-thirds (67.3%, 183) of the respondents reported that they were eligible to receive food services, while 8.1% (22) reported they were not eligible; 24.6% (67) did not know if they were eligible. Two-thirds (63.9%, 175) of respondents stated that they were currently receiving food services. Responses were evenly split between knowing or not knowing that food could be delivered if a person was not able to pick it up due to a medical or transportation issue; 47.8% (131) knew this and 47.1% (129) did not.

Figure 2: Food Services Received by Respondents



Note: Respondents may receive more than one food service, and therefore the frequency is not equal to the total number of persons receiving food services.

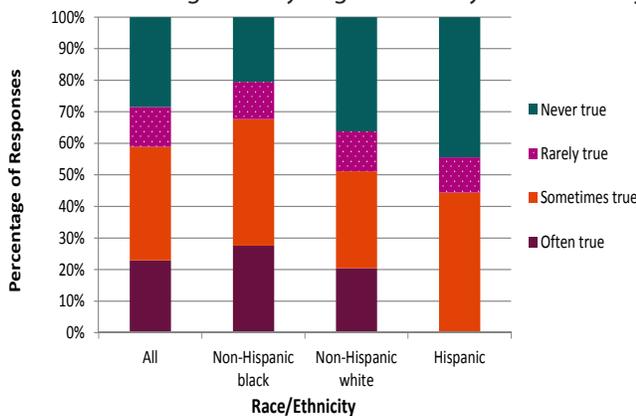
Respondents receiving food services have a variety of services available to them, with the most common one received being food bags (89.2%, 157), followed by food vouchers (35.8%, 63). A person may receive more than one type of food service and therefore the percentages do not total 100%. Ninety-eight (98, 35.8%) respondents reported that they were not currently receiving any food services and 88 (32.1%) respondents indicated that they had never received any food services. The non-Hispanic black respondents were 49% more likely to be currently receiving food services than were the non-Hispanic white respondents. In addition, the non-Hispanic white respondents were over 125% more likely to have never received food services than were the non-Hispanic black respondents. These two measures are significant reflections of socio-economic indicators because in order to receive food services a person must qualify based on their household income.

Of those persons who had ever received food services, 71.1% (113) received them on a monthly basis, 17.6% (28) received them twice a month, and 1.3% (2) received them weekly. The majority (61.1%, 96) of respondents received food services from only one provider, while 17.2% (27) received from two providers, 19.7% (31) from three providers, and 1.9% (3) from four providers. Over half (53.2%, 84) of food service recipients had received food services for over two years; 7.0% (11) for less than three months, 11.4% (18) for 3-6 months, 8.2% (13) for 6-12 months, and 20.3% (32) for 1-2 years.

For those respondents who had received food services, 54.5% (91) indicated that finding transportation to access food services was not difficult; however, 20.4% (34) and 25.1% (42) stated it was very difficult or somewhat difficult, respectively. In addition, 40.7% (68) of these individuals reported that lack of transportation has at times prevented them from receiving food services.

Survey respondents reported a variety of experiences regarding food and its availability to them within the last year. When asked whether their food just did not last and they did not have enough money to get more, 23.0% (62) of respondents indicated this was often true. Over one-third

Figure 3: Responses to “The food I had just didn’t last and I didn’t have enough money to get more.” by Race/Ethnicity



(35.9%, 97) reported this statement was sometimes true, 12.6% (34) rarely true, and 28.5% (77) never true.

When asked whether the respondent or any other adults in the household have ever cut the size of meals within the last year because there was not enough money or food, over one-fourth of respondents stated this occurred either every month (12.9%, 34) or most months (13.6%, 36). And while 36.3% (45) of non-Hispanic black respondents stated this happened no months, 57.7% (71) of non-Hispanic white respondents gave this response.

When asked if the respondent ever ate less than he felt he should because there was not enough money or food, 48.1% (129) reported yes. Also, 34.9% (90) of respondents reported that within the last 12 months there were times they were hungry but did not eat because they could not afford enough food. Significant differences were present between the responses of non-Hispanic whites and non-Hispanic blacks. Non-Hispanic black respondents were over 35% more likely to report having eaten less than they felt they should because there was not enough money to buy food than were non-Hispanic white respondents; non-Hispanic blacks were also 13% more likely to report having been hungry, but did not eat because they could not afford enough food.

Respondents reported a variety of foods that they could not get enough of. And while the most common foods respondents could not access were meats (60.9%, 142) and fresh produce (fruits or vegetables; 47.7%, 110), there were notable differences between non-Hispanic whites and non-Hispanic blacks. Non-Hispanic whites were most likely to state fresh produce was the most difficult food to access (54.6%, 53) and non-Hispanic blacks were most likely to state meats were the most difficult food to access (71.7%, 86).

Non-Hispanic blacks were 40% more likely than non-Hispanic whites to receive food that they do not eat. It is possible this difference could be attributed to non-Hispanic blacks being more likely to receive food services and therefore having less control over the foods they receive. Sixty-two

Figure 4: Types of Food Most Difficult to Access by Race/Ethnicity

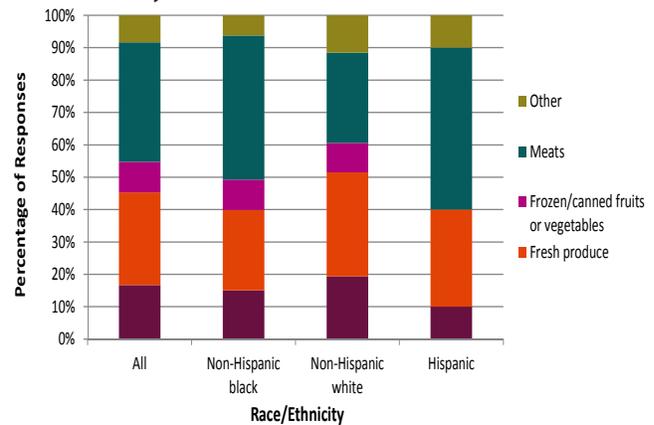
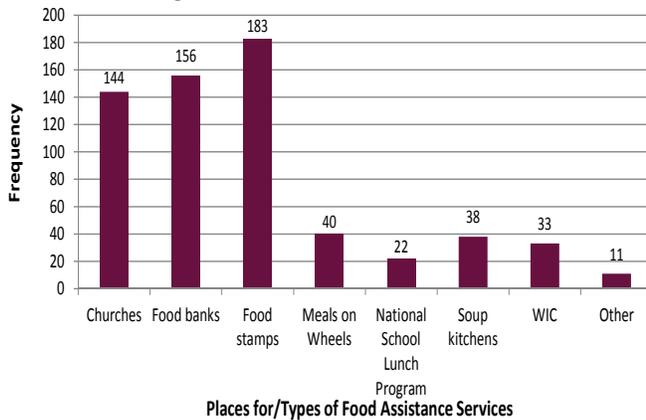
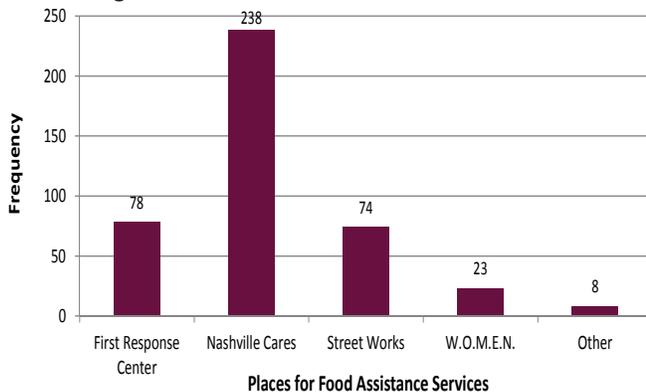


Figure 5: Places to Receive Food Assistance Services: Non-AIDS Service Organizations



(62) of the 91 respondents who indicated that they have received food that they do not eat reported what they do with the items. The most common response was to share or give the items away to family, friends, neighbors, homeless persons, or anyone in need (40.3%, 25). Others stock piled the items (14.5%, 9), traded them (9.7%, 6), returned the items or did not take them in the first place (6.5%, 4), or threw them away (4.8%, 3). Rather than listing what was done with the items, some respondents noted what the items were that they do not eat, including peanut butter, rice, canned goods, pastas, some meats, and vegetables.

Figure 6: Places to Receive Food Assistance Services: AIDS Service Organizations



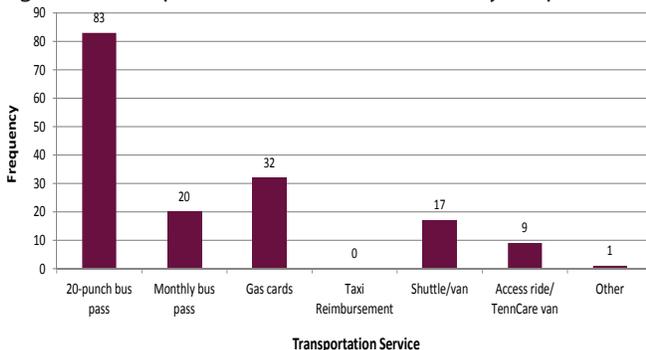
Respondents were aware of numerous places in which a person could receive food assistance. The most common services/places respondents were aware of include food stamps (75.6%, 183), food banks (64.5%, 156), and churches (59.5%, 144). The most commonly known AIDS service organization in which food services could be received from was Nashville Cares (94.4 %, 238), followed by First Response Center (31.0%, 78), Street Works (29.4%, 74), and W.O.M.E.N. (9.1%, 23).

Note: Respondents could select more than one organization or type of organization in Figures 5 and 6. Therefore, the frequencies do not equal the total number responding to the question.

TRANSPORTATION SERVICES

The majority (72.8%, 198) of respondents were aware of transportation services prior to participating in this survey; 25.0% (68) were not aware of this type of service. Over half (53.3%, 144) reported that they were eligible for transportation services, 15.6% (42) reported they were not eligible, and 31.1% (84) did not know if they were eligible. Less than half (46.7%, 128) of the respondents were currently receiving transportation services and over half (55.5%, 147) had never received transportation services.

Figure 7: Transportation Services Received by Respondents



Note: Respondents may receive more than one transportation service. Therefore, the frequency is not equal to the total number of persons receiving transportation services.

The most common transportation service currently being received by respondents was 20-punch bus passes (60.6%, 83), followed by gas cards (23.4%, 32), monthly bus passes (14.6%, 20), a shuttle/van service (12.4%, 17), and Access ride/TennCare van (6.6%, 9). Non-Hispanic white respondents were over 100% more likely to not be receiving any transportation services than were non-Hispanic black respondents. Over half (52.9%, 145) of respondents got to their HIV-related appointments with their own car, 33.2% (91) used the bus, and

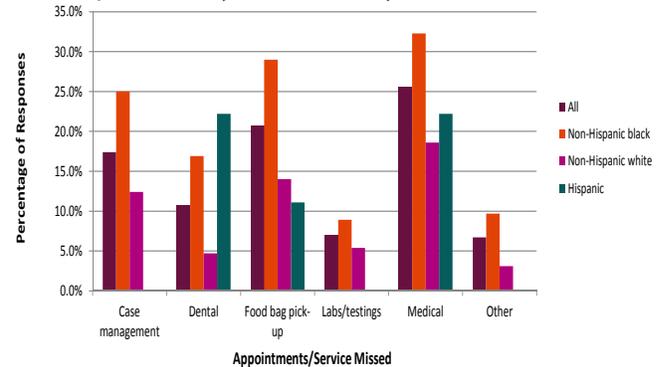
15.7% (43) got a ride with a family member/friend. Other means of transportation included Access ride, TennCare van, getting a ride with their case manager, and walking. Non-Hispanic white respondents were 87% more likely than non-Hispanic black respondents to get to their appointments in their own car.

Over half (54.6%, 149) of all respondents reported they never miss HIV-related appointments due to lack of transportation. However, significant differences were present between the responses of non-Hispanic black and non-Hispanic white respondents. Non-Hispanic black respondents were 40% more likely to miss HIV-related appointments than were non-Hispanic white respondents. And while both groups were equally likely to frequently miss appointments, non-Hispanic blacks were over 140% more likely to sometimes miss HIV-related appointments. The most common services missed due to lack of transportation were medical appointments (60.5%, 69), food bag pick-up (49.1%, 56), and case management appointments (41.2%, 47).

Respondents reported an average travel time of 57.0 minutes to get to an HIV medical appointment, with times ranging from 5 minutes to 3 hours. An average travel time of 42.5 minutes was reported for getting to an HIV-related support service provider; responses ranged from 0 minutes, because the provider would come to the client, to 3 hours. For times that were provided in a range, the greater time was used for the analysis.

Respondents using the public bus system reported an average of two transfers to get to HIV-related appointments, with responses ranging from zero to four transfers (meaning one to five buses). Due to the structure of the public bus system in the Nashville area, it is unlikely that persons would need to take five different buses to get to one appointment. It is therefore likely that some respondents counted the number of transfers to get to an appointment, as well as home from an appointment, or that they counted the number of buses they may need to take as the number of transfers. Both of these misinterpretations would lead to over-reporting of bus usage and

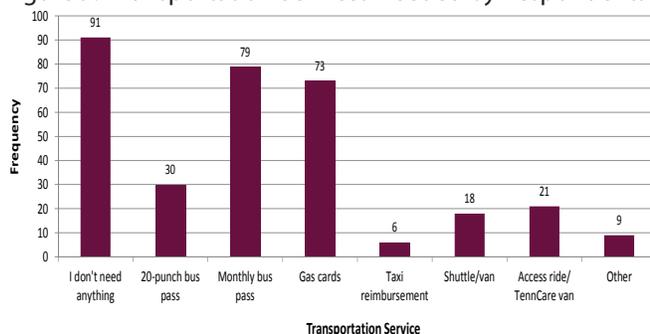
Figure 8: Types of Appointments/Services Missed because of Transportation by Race/Ethnicity



consequently over-reporting of the necessary number of bus passes per appointment.

Respondents who do not drive themselves to their HIV-related appointments, reported arriving an average of 37.8 minutes prior to their scheduled appointment time. Times ranged from two hours early to being on time; three individuals stated they arrive late for their appointments. Respondents had an average wait time of 42.8 minutes for their ride after their appointment. The times ranged from zero minutes to three hours. For respondents who reported their times in a range, the greater time was used for the analysis.

Figure 9: Transportation Services Needed by Respondents



Note: Respondents could select more than one service that would help them to more reliably and consistently get to their HIV-related appointments. Therefore, the number of responses does not equal the number of respondents.

Respondents were asked what they would need regarding transportation so that they could reliably and consistently get to their HIV-related appointments. The largest proportion of respondents (34.9%, 91) stated that they do not need anything. Others reported needing monthly bus passes (30.3%, 79), gas cards (28.0%, 73), 20-punch bus passes (11.5%, 30), Access ride/TennCare van (8.0%, 21), a shuttle/van (6.9%, 18), and taxi reimbursement (2.3%, 6).

Non-Hispanic black and non-Hispanic white respondents had significantly different needs regarding the types of services they reported that would help them get to their HIV-related appointments. While 52.5% (64) of non-Hispanic white respondents stated they did not need anything, only 16.8% (21) of non-Hispanic black respondents provided this response. Also, while 44.8% (56) and 19.2% (24) of non-Hispanic blacks said monthly bus passes and 20-punch bus passes, respectively, would help them, only 18.0% (22) and 2.5% (3) of non-Hispanic white respondents noted these services.

SUMMARY

The majority of respondents who were eligible for food and transportation services were receiving said services at the time of this survey. Of those respondents self-reporting that they were eligible for food services (183), 86.3% (158) stated that they were receiving food services and 89.6% (164) had received food services within the last year. Of the

144 respondents self-reporting that they qualified for transportation services, 83.3% (120) of them were receiving transportation services.

Despite receiving transportation services, many respondents have experienced times of unreliable transportation causing them to miss appointments frequently (12.0%) or sometimes (36.0%). Only 36.3% of the respondents receiving transportation services reported never missing appointments due to transportation issues.

Persons having their own car were 189% more likely to report never missing an appointment than were persons not having their own car. And persons having their own car and not receiving any transportation services were 25% more likely to report never missing an appointment than were persons who had their own car, but were receiving gas cards. The majority (83.6%) of respondents with their own car and not receiving transportation services never missed appointments, while only 66.7% of persons with their own car, but receiving gas cards never missed appointments. Only 28.9% of respondents not having their own car reported that they never missed appointments. In addition, no respondents having their own car reported frequently missing appointments, whether they received gas cards or not, yet 13.3% of respondents not having their own car stated they frequently missed appointments. Non-Hispanic whites were also more likely to have their own car (67.7%, 88), and therefore more likely to never miss appointments due to transportation (86.4%, 76) than were non-Hispanic blacks, in which 36.2% (46) had their own car and 65.2% (30) reported never missing appointments because of transportation.

Overall, the respondents had increased access to constant and dependable transportation due to the transportation services funded by the Ryan White Part A Program. And while 35% of respondents stated that they did not need anything else in order to reliably and consistently get to their HIV-related appointments, the remaining 65% reported needing additional assistance. The most commonly reported transportation services noted were monthly bus passes, gas cards, 20-punch bus passes and Access ride/TennCare van. Moreover, many people commented that the 20-punch bus passes did not last long enough and therefore, many of these people felt monthly bus passes would be better. Also, persons receiving gas cards remarked that the gas cards did not have enough money on them, especially for those persons living further out from the city.

The majority of respondents receiving food services reported that they have often (24.2%, 44) or sometimes (41.8%, 76) within the last year experienced times in which the food they had did not last and they did not have money to get more. In addition, 53.9% (97) of respondents receiving food services reported that they have eaten less than they felt they should because there was not enough money to buy food. Meanwhile 39.2% (69) of these persons noted that they have been hungry within the last year, but did not eat because they could not afford enough food. Although it is unclear as to whether these reported food insufficiencies occurred prior to a person receiving food services or once they were already receiving food services, 75.0% of those receiving food services have been receiving them for over one year, indicating a prolonged need for these services.

The respondents have increased access to food due to the food services available to them; however, they have reported still having difficulty in accessing certain types of food, primarily fresh produce and meats. Overall, the foods respondents were the most dissatisfied with were those that are part of most food bags (pastas, rice, and peanut butter). Moreover, although a high percentage of those receiving food services have reported not having enough food and not having enough money to buy more food, 43.8% stated that they receive foods they do not eat. Some persons were not able to eat all types of food

included in food bags, such as those who are diabetic or have heart disease. Therefore, having food bags available for persons with certain medically prescribed diets would likely prove to be beneficial.

CONCLUSIONS

Some people are not aware of services, do not know what they qualify for, or do not know how to get the services. Of those who specifically mentioned this, 83% have a case manager, so they should not be having these problems. Therefore, the case managers are either not asking the clients if they need additional services or the clients are not telling their case managers that they need more help. For those clients not having a case manager, the first step for them would be getting a case manager to inform them of services and assist them in linking to services.

Significant differences appeared in the responses of non-Hispanic whites and non-Hispanic blacks. In general, non-Hispanic blacks were more likely to report experiencing food deficiencies, as well as inconsistent and unreliable access to transportation for HIV-related appointments. This is likely a reflection of the differences in socio-economic statuses among persons of different racial groups in this region. Locating food and transportation services available to and easily accessible to areas of predominantly non-Hispanic blacks may ensure that more persons who qualify for services are able to access the services.

Regarding food services, persons would benefit from receiving education on the intent of the food services Ryan White funds; understanding that food bags are only meant to supplement one's diet may help motivate people to seek out other food resources. Providing persons with ideas on different ways to prepare common foods would help reduce the number of persons who are not eating these foods because they have grown tired of them. Teaching people how to purchase groceries that are healthy and economical would also be beneficial for the health of people living with HIV disease, in addition to reducing the financial requirements of this service placed on the Ryan White program.

OUTPATIENT CLIENT SATISFACTION SURVEY

BACKGROUND

In 2012, the MPHD Research Analyst and the Needs Assessment Committee created a Client Satisfaction Survey on HIV Medical Care. It has been found that patients with higher satisfaction levels tend to have improved health outcomes. Therefore, in order to most effectively serve HIV-positive persons in our community, and improve health outcomes, it is essential to get a better understanding of how clients perceive the medical care they receive from Ryan White Part A providers. The purpose of this evaluation of client satisfaction is to determine any areas in which clients are dissatisfied with their HIV medical care: access to care, waiting for appointments, experiences during the medical visit, and overall quality of HIV care.

METHODOLOGY

Survey Development: An appropriate sample size was determined to be at least 346 people living with HIV disease in the TGA, in order to maintain a margin of error of +/-5 percentage points with a 95% confidence level for a population of 3,465 (the number of PLWHA who received HIV services at a Ryan White Part A funded provider in 2011).

The survey was created by the MPHD Research Analyst and reviewed by the Needs Assessment Committee. The survey was adapted from the Patient Satisfaction Survey for HIV Ambulatory Care produced by the New York State Department of Health AIDS Institute.

A Spanish version of the survey was also created in order to expand participation accessibility to persons either not speaking English or being uncomfortable completing a survey not in their preferred language.

Before the survey was administered, it was submitted to the MPHD Institutional Review Board (IRB) to confirm that the survey complied with regulations regarding human subjects research ethics. The survey was approved by the IRB.

Confidentiality Measures: All peers helping to implement the survey signed a confidentiality agreement stating that they would not share any information they may learn while assisting with the surveys. A peer or staff member informed each participant who completed a survey at a provider site that the survey was voluntary and confidential.

The Research Analyst was the only person to have access to completed surveys, although no identifiable information was collected on the surveys so there was consequently no manner in which surveys could be connected with a specific individual.

Survey Administration: Peers at provider sites were used to administer the surveys 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 Research Analyst trained the peers 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 Research Analyst trained the peers, they conducted surveys at their provider sites. Medical provider sites used included the First Response Center, the Meharry Wellness Center, and Vanderbilt's Comprehensive Care Clinic (CCC). Surveys were also completed at Nashville Cares in order to gain access to persons who may not have had a medical appointment during the surveying period.

It is important to note that respondents answered the survey questions according to their perceptions of HIV medical care provided by their HIV medical provider, regardless of the site in which they completed the survey.

Data Entry and Data Cleaning: The Research Analyst created a corresponding survey using SurveyMonkey in order to allow for more accurate data entry. The Research Analyst was the only one to use this survey tool. The surveys were cleaned, numbered, and manually entered into SurveyMonkey following pre-established coding guidelines.

The Research Analyst conducted the data entry, entering data as surveys were received until all surveys were entered. The Research Analyst checked the data after data entry was completed to ensure data accuracy and to correct improper coding.

It is important to note that almost all of the questions, except three, could have only one response, and therefore the number of responses for each question is indicative of the number of respondents answering that question. However, respondents could mark more than one HIV provider whom he had received services from within the last year, could select multiple words to describe the care from their medical provider, and could note as many reasons for being treated poorly as they felt appropriate. For these questions, the total number of responses is not indicative of the total number of respondents.

Limitations: Participant responses were based on the perceptions of the participant and therefore are only representative of his/her perceptions. In addition, 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. Although surveys were only conducted at Ryan White Part A funded medical providers and Nashville Cares (also funded by Part A), the purpose of the survey was to evaluate client satisfaction of these specific medical providers and therefore the perceptions of persons not receiving services from these medical providers are not necessary to be captured in this survey. However, persons who are currently clients of these medical providers, but did not receive services from these providers during the surveying time period did not have the opportunity to disclose their perceptions of HIV medical care.

Analysis: Data was analyzed as of May 7, 2012. A total of 389 surveys were collected for this study: 373 were considered complete and useable, 13 were excluded due to incompleteness, and 3 were excluded because the respondents were not HIV-positive. Of the 373 useable surveys, 344 were completed by

individuals residing within the Nashville TGA, while 29 of the respondents lived outside of the TGA; also, 11 of the completed surveys were of the Spanish version. Surveys completed by those residing outside the TGA were included in the analysis because even though these people do not qualify to have their services paid for by Ryan White Part A, they receive the same medical services and have the same needs as those residing within the TGA. There were not enough surveys completed by persons residing outside of the TGA to skew the results of the survey.

KEY FINDINGS
GENERAL INFORMATION

Survey respondents ranged in age from 18 to over 65 years of age. The majority of respondents were 45-64 years of age (58.9%, 218) and 25-44 (34.1%, 126). There were also small numbers of respondents 18-24 years of age (4.6%, 17), and over 65 years of age (2.4%, 9).

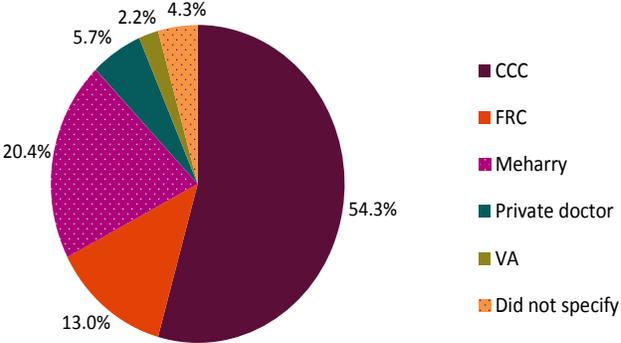
People living with AIDS were underrepresented in this survey, accounting for only 20.9% (78) of respondents. This could be attributed to persons not knowing their up-to-date diagnosis or believing that once their CD4 level rises above 200 cells/ μ L that they no longer have AIDS, and have reverted back to HIV; however, once a person is diagnosed with AIDS his diagnosis does not change.

Females were overrepresented in this study, having accounted for 36.2% (135) of respondents, compared to males who were underrepresented with 63.3% (238). Only two transgender persons participated in this survey.

Non-Hispanic blacks represented the largest racial/ethnic group, accounting for 58.0% (203). Non-Hispanic whites were underrepresented in terms of those persons who access medical services from a Ryan White Part A medical provider (36.9%, 129). Hispanics accounted for 4.0% (14) and non-Hispanic others accounted for 1.1% (4) of respondents, including persons reporting their race as Asian, Native American, and multi-racial.

Respondents had been living with HIV disease for a range of less than one year to over 30 years. On

Figure 10: Respondents' Medical Providers



average, the respondents had been living with the disease for 12 years.

The majority of respondents (98.4%, 360) reported that they were currently receiving HIV medical care, while only six individuals (1.6%) stated they were not receiving HIV medical care at that time. Of those receiving medical care, 55.6% (200) were receiving their medical care from Vanderbilt's Comprehensive Care Clinic (CCC). Others reported receiving their care from the Meharry Wellness Center (20.8%, 75), First Response Center (13.3%, 48), a private doctor (5.8%, 21), and the Veteran's Administration Hospital (2.2%, 8). Sixteen individuals (4.4%) reported that they were currently receiving HIV medical care, however they did not specify from where. Individuals may have indicated receiving medical care from more than one place, of which eight individuals did so; these cases are likely to be persons who changed providers during the last year.

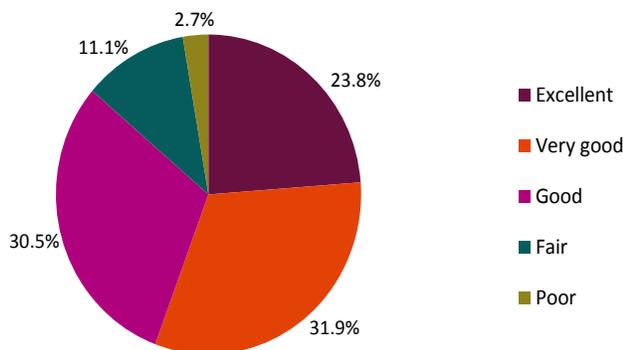
The largest portion of respondents (39.6%, 143) had been receiving HIV medical care at their reported medical facility for over five years. Others received care for 3-5 years (22.2%, 80), 1-2 years (19.9%, 72), and less than 1 year (18.3%, 66). Over half of respondents (50.6%, 183) had their last HIV medical visit within 2 months, 42.0% (152) within the last 2-6 months, and 4.1% (15) within 6-12 months. Twelve individuals (3.3%, 12) had not had an HIV medical visit in over 12 months.

Eighty-seven percent (87.2%, 312) of respondents reported having had a general medical check-up within the last 12 months. The largest portion of respondents (31.9%, 118) rated their overall health as very good; 2.7% (10) reported their health as poor.

ACCESS TO HIV CARE

Overall, respondents were able to access HIV care. The majority of respondents (83.4%, 306) were always or mostly able to get an appointment soon enough for their needs. Also, 88.7% (331) of respondents stated that their HIV providers talked with them always or mostly about the importance of keeping their appointments. Almost everyone (92.0%, 333) reported receiving services in their

Figure 11: Overall Rating of Health Self-Reported by Respondents



language of preference all of the time or most of the time.

There were lower rates of access to care regarding persons who could always or mostly reach someone at the office when the clinic was closed (55.1%, 201), as well as being able to always or mostly reach someone on the phone to discuss a medical question (69.5%, 256).

Almost ten percent (9.9%, 36) of respondents reported that they always or mostly were not able to receive the medical services they needed because they could not pay for them.

WAITING FOR YOUR APPOINTMENT

A significant portion of respondents stated that the staff was always or mostly friendly towards them (94.6%, 351) and that HIV-related educational materials were always or mostly available (93.2%, 340). Fewer people reported being able to see their doctor within 30 minutes of their scheduled appointment time (71.7%, 261).

YOUR HIV MEDICAL VISIT

The majority of persons reported that their provider always or most of the time made sure they understood their lab results (87.9%, 326) and side effects of HIV medications (78.0%, 284), explained how to avoid getting sick (82.5%, 301), and talked about safer sex practices and risk reduction (82.2%, 303).

Other elements of care respondents reported receiving all the time or most of the time included: “being satisfied with the amount of time my provider spent with me” (88.7%, 329), “feeling the staff and my providers kept my HIV status confidential” (92.6%, 339), “being asked about my life situation by staff and providers and receiving referrals as necessary” (65.5%, 238), and “getting the services my provider referred me to” (76.8%, 281).

Nearly one-quarter (22.4%, 81) of respondents had questions they wanted to ask their doctor, but did not. Additionally, 17.6% (64) of respondents felt uncomfortable discussing personal or intimate issues with their provider and 13.0% (47) of respondents felt their providers felt uncomfortable asking

Figure 12: Experiences with Medical Providers: HIV Medical Visit(a)

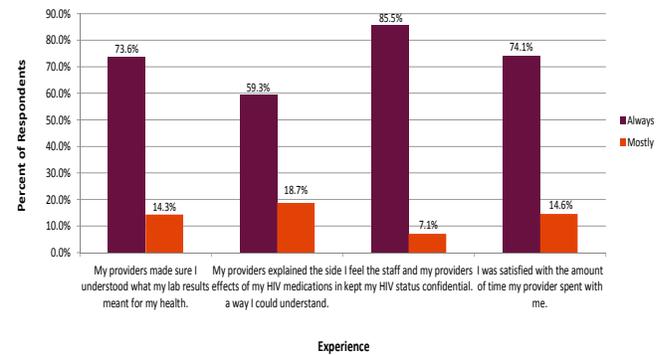


Figure 13: Experiences with Medical Providers: HIV Medical Visit(b)

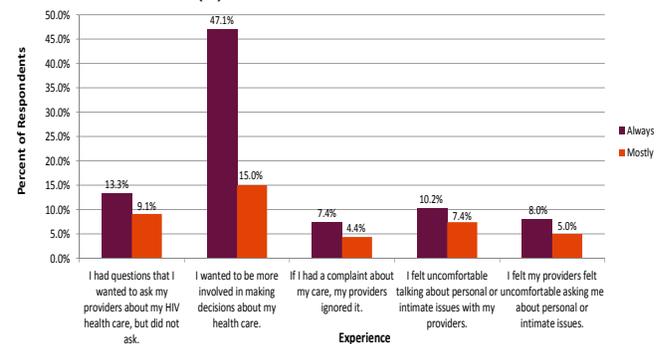


Figure 14: "I would rate the quality of care at this clinic in comparison to other clinics I know about as..."

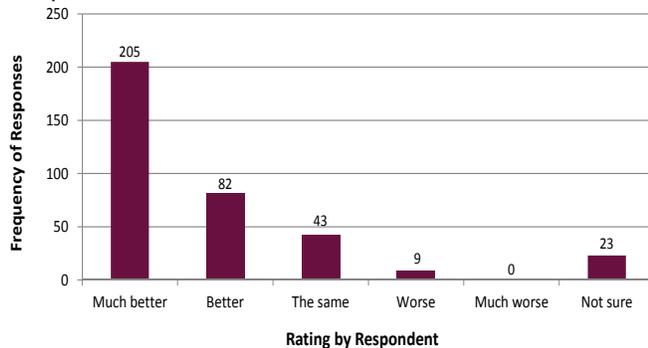


Figure 15: "When I think about my care at this clinic, these words come to mind..."(a)

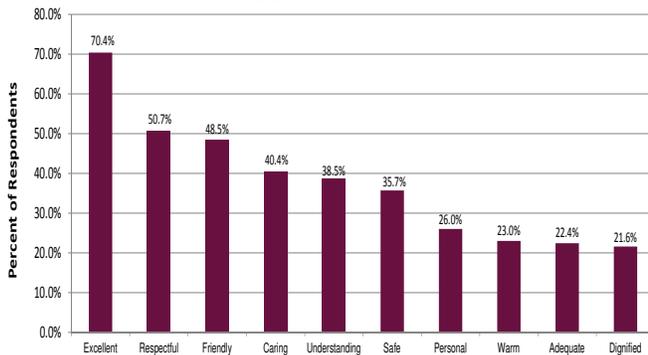
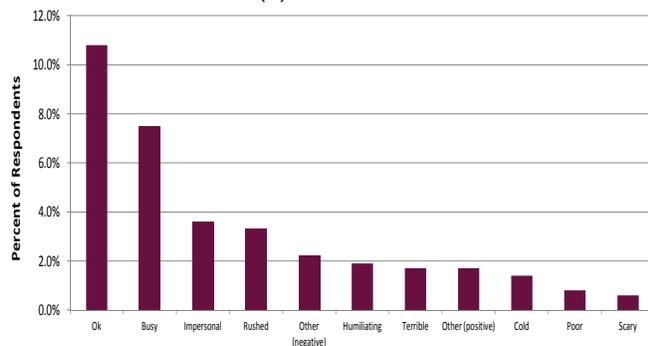


Figure 16: "When I think about my care at this clinic, these words come to mind..."(b)



about personal or intimate issues. Persons who did ask their doctors questions, reported that it was hard to understand their answers (11.2%, 40). Over half (62.1%, 224) of respondents reported always or most of the time wanting to be more involved in making decisions about their health care.

Twelve percent (11.8%, 43) of respondents felt their providers ignored their complaints about their care.

OVERALL QUALITY OF HIV CARE

Most of the respondents rated their provider's knowledge of the newest developments in HIV medical standards as excellent (61.5%, 227) or very good (27.4%, 101), however a small portion rated their knowledge as fair (2.4%, 9) or poor (0.8%, 3). Over half (65.6%, 205) of respondents rated the quality of care at their clinic in comparison to others as much better; nine individuals (2.5%) rated their clinic as worse.

Respondents most frequently selected the following words to describe the care at their clinic: excellent (70.4%, 254), respectful (50.7%, 187), friendly (48.5%, 175), caring (40.4%, 146), and understanding (38.5%, 139). Other words less frequently selected include adequate (22.4%, 81), ok (10.8%, 39), busy (7.5%, 27), and impersonal (3.6%, 13).

Nine percent (8.9%, 31) of respondents reported having felt they were treated poorly at their HIV medical clinic. Reasons they believed they were treated poorly included their race (11), age (6), drug use (6), income (5), gender (4), language (4), and sexual orientation (2). Other reasons provided by respondents included mental health (3) and pain management/medication needs (2). Three people claimed poor treatment, but did not indicate a reason for such treatment.

The majority (81.0%, 278) of respondents stated that they would definitely recommend their HIV medical clinic to HIV-positive friends with similar needs. Fourteen percent (14.3%, 49) said they may recommend their clinic and 3.2% (11) said they were not sure. Five respondents (1.5%) indicated they would definitely not recommend their clinic to HIV-positive friends.

Nineteen individuals (5.6%, 19) stated that they left an HIV medical provider because they were dissatisfied with the services and/or care they were receiving. At least one respondent left each of the following providers because of dissatisfaction within the last 12 months: CCC, Meharry Wellness Center, First Response Center, and the VA.

Many respondents added additional comments about the medical care they are receiving for their HIV disease. A client at CCC wrote “I greatly appreciate all the help I’ve gotten and continue to get.” Another said, “Doctors and staff are world-class. It is difficult to imagine a better comprehensive facility anywhere.” Other respondents noted: “They are very understanding and trustworthy and well educated about this disease.” (Meharry); “My doctor is compassionate, to the point, and displays knowledge and wisdom.” (CCC); and “They are very good to me.” (FRC) Other comments included “Front staff have become very impersonal and mostly rude” and “It would be nice to talk to someone who really knows what you’re going through and can relate.”

CONCLUSION

The Nashville TGA Part A Program last conducted a Client Satisfaction Survey in 2009. Based on survey results, it appears as though many aspects of HIV medical care have improved since 2009. While 81% of respondents in 2009 strongly agreed or agreed that the medical provider made sure the client understood his lab results, 88% agreed with this in the 2012 survey. And while 87% of respondents felt the staff and providers kept their HIV status confidential in 2009, 93% felt this way in 2012. However, 85% of the 2009 respondents stated that the doctor discussed lifestyle choices for improving one’s health, but fewer agreed with this in 2012 (83%). The majority of 2009 respondents (88%) reported that they are involved in making decisions about the care and services they received, however in 2012 47% of respondents stated that they wanted to be more involved in the decision-making about their healthcare; although this does not necessarily mean that they were not involved at all, it does indicate that clients would like to have greater input in their care.

Overall, respondents of the 2012 Client Satisfaction Survey were satisfied with the care they are receiving at the Ryan White Part A-funded medical clinics. People reported being able to get the services they needed when they needed them. They also reported getting a clear understanding of what their labs, medications, and lifestyle mean for their HIV disease. Less people reported feeling comfortable enough with their doctor to ask questions or discuss personal and intimate issues. However, there were people who reported not being able to receive services or access staff to ask questions; these are key elements that contribute to people dropping out of care and to poorer health outcomes.

Persons with higher satisfaction tend to have improved health outcomes and therefore having anyone with low satisfaction is undesirable. In order to reduce the number of individuals being lost to care, there needs to be high satisfaction across the board, which will be obtained by addressing different areas of improvement at each medical provider.

RESOURCE AUDIT

BACKGROUND

In 2012, a resource audit was created by the MPHD Research Analyst and the Needs Assessment Committee to gain a comprehensive picture of the continuum of care of the organizations and individuals providing services to HIV-positive persons, regardless of whether the provider sees itself as an HIV/AIDS service provider. The audit consisted of two primary components that are essential in determining resources available to HIV-positive persons: (a) the resource inventory portion depicts the HIV services currently available and (b) the profile of provider capacity and capability portion provides detailed information about the availability, accessibility, and appropriateness of services for PLWHA.

METHODOLOGY

Survey Development: The resource audit was created by the MPHD Research Analyst and reviewed by the Needs Assessment Committee of the Planning Council. Some questions in the audit were adapted from other resource audits/surveys, including the Central Florida Ryan White CARE Act 2005 Needs Assessment: Title I and Title II Provider Survey; Final Results: Indiana Provider Survey, a Component of the 2009 HIV Services Needs Assessment; and the Las Vegas TGA Needs Assessment Provider Survey for Agencies Serving People Living with HIV/AIDS.

Before the survey was administered, it was submitted to the MPHD Institutional Review Board (IRB) to be sure that the survey complied with regulations regarding human subjects research ethics. The IRB concluded that the resource audit was not human subjects research.

Confidentiality Measures: The information collected in this resource audit was public knowledge; no personal information was gathered. Therefore, no precautionary measures were necessary to reduce potential risks. However, because the audit was implemented through SurveyMonkey, SSL encryption was enabled in order to encrypt the results as they were sent between the respondents and SurveyMonkey.

Survey Administration: A convenience sample was obtained by implementing the resource audit through SurveyMonkey, an online survey software program, as a means of allowing more agencies to access the audit. An explanation of the survey purpose, as well as a link to the resource audit, was emailed to select agencies through GivingMatters.com, a community foundation of non-profit organizations in Middle Tennessee. Agencies were selected by GivingMatters.com based on the types of services they provide, the geographic location of the agency, and the geographic location of their clients' residences. A total of 241 pertinent agencies were invited to participate in the resource audit.

The survey was scheduled to be open for three weeks, however due to some unforeseen problems in emailing the survey link and a low response rate, the survey deadline was extended for an additional ten days.

A GivingMatters.com associate emailed the resource audit to selected organizations. Because the organizations being sought out already had contact with GivingMatters.com, it was believed that this relationship would help promote survey participation. The surveying period was 4.5 weeks and

agencies received reminder emails during this time period to elicit greater participation.

At the end of the surveying period, 88 surveys were taken. However, two were removed due to insufficient data for proper analysis and five were removed because of being duplicates within an agency. Therefore, 81 surveys were included in the data analysis.

Limitations: Participation in the resource audit was limited to those organizations that received an email notice of the survey. The purpose of using GivingMatters.com was to increase the scope of those organizations asked to participate by not limiting the participation list to only organizations known by the Research Analyst and members of the Needs Assessment Committee. However, many organizations do not recognize the link between their work and the needs of HIV-positive persons, and consequently did not participate in the survey.

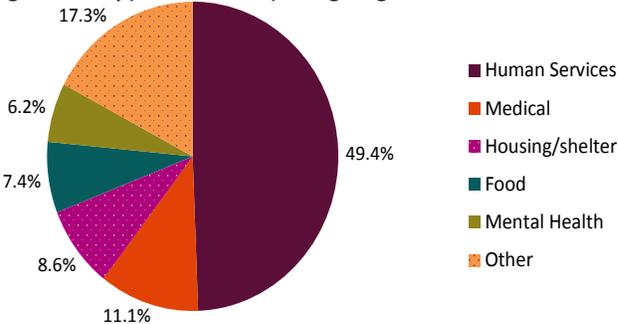
The results of this resource audit are not representative of all the non-profit organizations in Middle Tennessee, nor are they representative of the organizations providing services to HIV-positive persons. The data gathered through this audit serves as a source to a detailed understanding of the framework and services provided by those agencies that participated. The summary analysis functions to give a general picture of those agencies participating in the resource audit and the resources they have available to HIV-positive persons. Responses were based on self-reports by agency staff and have not been independently verified.

KEY FINDINGS

BASIC INFORMATION ABOUT PROVIDER AGENCIES

Almost half of respondents (49.4%) were human services organizations, providing such services as education, childcare, veterans’ affairs, and assistance for the physically and developmentally disabled. Other types of organizations participating in this audit included medical providers (11.1%), housing/shelter providers (8.6%), food organizations (7.4%), and mental health centers (6.2%). Other organizations accounted for 17.3%.

Figure 17: Types of Participating Organizations



FINANCIAL RESOURCES

Almost all participating organizations (91.0%) received contributions/donations within the last year. Over half (56.4%) received funding from the state government.

The total annual budget for participating agencies ranged from less than \$100,000 to over \$20,000,000, with 64.2% having received \$100,000 to \$5,000,000.

Less than twenty percent (19.8%) of agencies had an HIV/AIDS budget of up to \$1,000,000. Three agencies had HIV/AIDS budgets ranging from \$1,000,001 to \$15,000,000. Almost two-thirds (62.7%) of agencies do not provide services specific to HIV/AIDS and therefore do not have a set budget for HIV/AIDS services; this does not mean however that these agencies do not serve PLWHA.

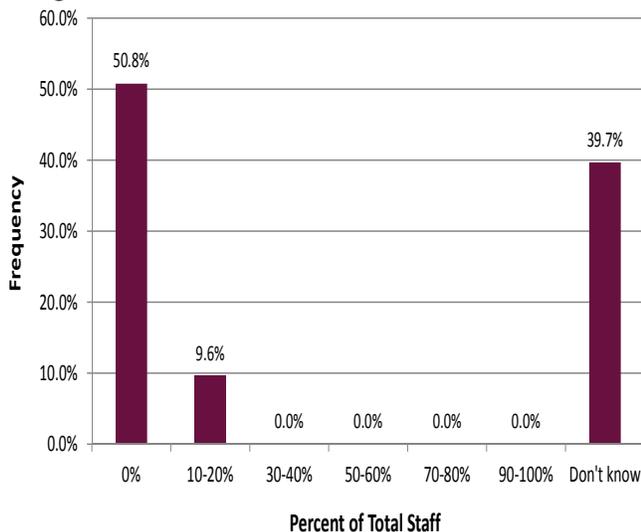
STAFF RESOURCES

Staff composition was over 50% female in 91.4% of the participating agencies, with 22.9% of all the agencies having only female staff members. Over one-third (33.8%) of the agencies have 10-30% racial/ethnic minority staff members. Many agencies (19.1%) claimed 0% racial/ethnic minority make-up. Over half (50.8%) of the agencies have no staff members living with HIV/AIDS, while only 9.5% reportedly have 10-20% of staff living with the disease; 39.7% did not know how many of their staff members are living with HIV/AIDS. LGBT staff made up 0% (42.4%), 10-20% (21.2%) and 30-50% (4.5%). One-third (31.8%) of agencies did not know the percentage of staff members who are LGBT.

Sixteen (16) agencies reported having full-time staff members working in HIV/AIDS, ranging from one to 333 people. Twelve agencies had part-time staff members working in HIV/AIDS; this ranged from one to 13 people. Ten agencies reported having volunteers who work in HIV/AIDS medical care or support services; the number of volunteers ranged from one to 400 persons.

The most common staff training among agencies was cultural competence in racial/ethnic minorities (66.7%), followed by cultural competence in underserved populations (60.9%), and cultural

Figure 18: Demographic Composition of Staff: Percent Living with HIV Disease



competence in people with disabilities (49.3%). Staff with specialized trainings in HIV/AIDS occurred in 20.3-24.6% of the participating agencies, depending on the specific HIV/AIDS training area.

TARGETED POPULATIONS SERVED

The most commonly targeted population was adults (35.6%), followed closely by females (31.5%) and youth (27.4%). HIV-positive persons are targeted by 15.1% of the agencies. Other notable targeted groups include: homeless persons (19.2%), persons with alcohol or other substance dependencies (17.8%), persons with serious mental illness (13.7%), men who have sex with men (6.8%), and injection drug users (6.8%). Non-Hispanic blacks and Hispanics were targeted by 19.2% and 17.8% of agencies, respectively.

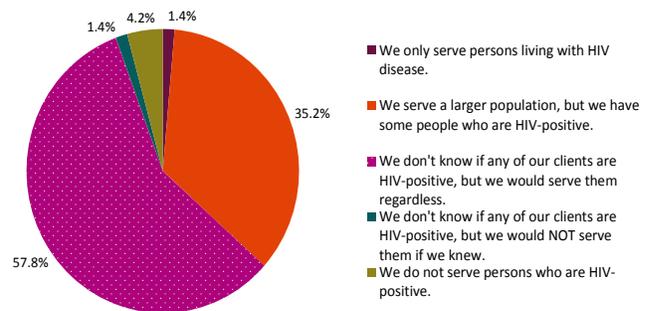
PROGRAM FOCUS

Over half (57.7%) of the responding agencies reported that they do not know if their clients are HIV-positive; however, they would serve them regardless. Over one-third (35.2%) of the agencies serve a larger population, but have some people who are HIV-positive. Three agencies (4.2%) do not serve HIV-positive persons and one (1.4%) said they do not know if any of their clients are HIV-positive, but they would not serve them if they knew. Only one agency (1.4%) reported that they only serve persons who are HIV-positive.

The most common medical services provided by participating agencies, whether to the general population or a specific population, included mental health treatment (42.4%), medication (29.8%), substance abuse-outpatient (23.2%), disease screening (22.8%), and HIV testing (22.8%). The most common support services provided, including services to the general population as well as a special population, include referral (80.0%), community outreach (69.5%), supportive counseling (64.2%), advocacy (62.7%), case management (59.6%), outreach (55.8%), and child/family support (53.8%). The most common financial service provided was utility payments (31.6%).

No agencies reported eliminating any services within the last year. Seven agencies reported

Figure 19: "Who does your organization provide services to?"



adding services in this time period; some of these additions included a psychiatric medical clinic, increasing presence at health fairs targeting HIV-positive populations, counseling and economic support for PLWHA, an outreach worker to provide testing, and increasing peer delivered services.

PROJECT SERVICE AREA

The majority (83.6%) of responding agencies has a main or branch office in Davidson County, followed by Rutherford County (14.9%), Williamson County (13.4%), and Sumner County (7.5%). Each of the 13 counties in the TGA had at least one agency with a main or branch office participate in this resource audit.

While 28.6% of the agencies do not provide services outside of the office, people residing in each TGA county could receive face-to-face services outside of an office setting from a number of agencies.

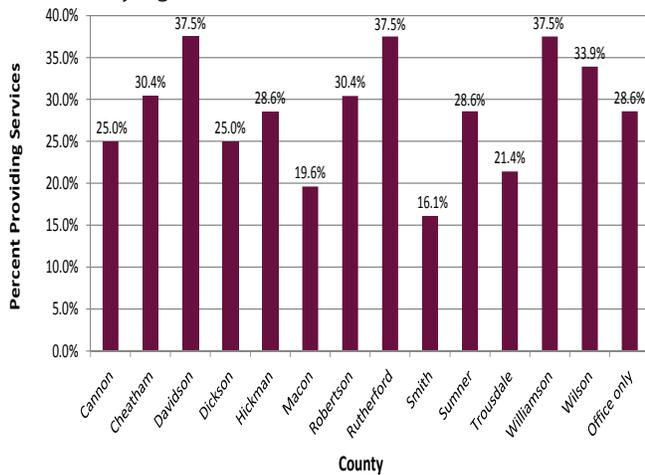
Ninety-one percent (91.0%) of the agencies served clients residing in Davidson County. Agencies' clients resided in each of the 13 TGA counties, ranging from Williamson County (62.7%) to Smith County (29.9%).

SERVICE CAPACITY

Same day/walk-in services were most commonly available for the first medical visit in the following areas: HIV testing (17.7%), medication (11.5%), lab work (8.2%), outpatient medical care (8.2%), disease screening (8.2%), and mental health treatment (8.1%). An average waiting time of a few days was reported in the following areas: mental health treatment (14.5%), substance abuse-outpatient (9.8%), and lab work (6.6%). One agency reported that it would take over two months for a client to receive HIV testing.

The support services with the shortest wait time (same day/walk-in) to a person's first support service include referral (58.3%), supportive counseling (28.6%), outreach (27.6%), advocacy (26.8%), food bags/vouchers (22.8%), and transportation (21.8%). Case management and community outreach had a slightly longer wait time of a few days (29.1% and 24.6%, respectively).

Figure 20: Counties Where Face-to-Face Services are Provided by Agencies Outside of the Office



Wait time for a client's first financial service greatly ranged depending on the service and the agency. However, utility payments had the shortest wait time with 6.8% for same day/walk-in and 6.8% within a few days.

No more than two agencies offering any service reported an average wait of over two months for that service.

Half of the responding agencies reported having no waiting lists for services, although 55.3% of the services have a waiting list at a minimum of one agency. The most common services to necessitate waiting lists were transitional housing (11.3%), permanent housing (9.7%), and childcare (8.1%). Other services with waiting lists included dental/oral care, mental health treatment, substance abuse-residential, advocacy, and financial support; each of these services was reported at 4.8%.

Capacity building training needs were similar across training categories. However, those training areas needed by the most agencies, regardless of training level, included program evaluation (59.7%), media/public relations (59.7%), motivational training (53.2%), and community planning (49.2%). The most commonly needed HIV/AIDS and STD-related capacity building trainings were HIV/AIDS general training (40.3%), providing HIV/AIDS linkages (33.9%), and STD general training (33.9%).

Because many agencies do not know if their clients are HIV-positive, they were not able to identify how many HIV-positive clients they served within the past year or how many HIV-positive clients they could potentially serve. Of those agencies that were aware of their HIV-positive population, 38.5% claimed to have an unlimited capacity, 30.8% are close to reaching their capacity, 15.4% are at capacity, 7.7% are over capacity, and 7.7% are not near reaching their capacity.

Over one-quarter (26.2%) of agencies stated they do not need anything to increase capacity to serve PLWHA because it is a population they are not able to serve. Nineteen percent (18.5%) of agencies reported that they do not need anything more to

increase their capacity for this population. Of those agencies reporting gaps in serving PLWHA, the most commonly reported needs were increased partnerships with HIV/AIDS specialty agencies (29.2%), training in HIV/AIDS social issues (27.7%), and funds to develop new capacity (27.7%).

SERVICE ACCESSIBILITY

Almost two-thirds (64.6%) of the agencies reported that public buses run within one-quarter mile of all of their organization’s locations. Seventeen percent (16.9%) do not have a public bus within one-quarter mile of any of their locations.

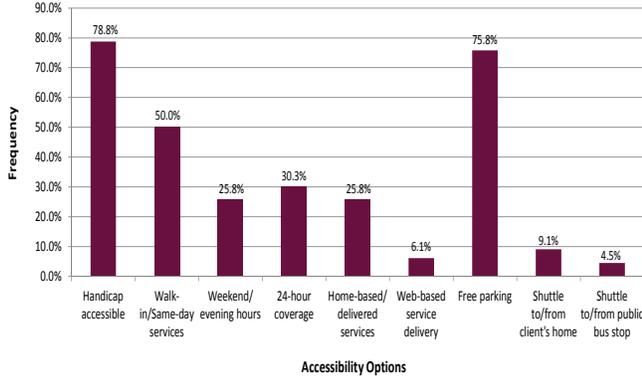
The majority (76.1%) of organizations have week-day hours, roughly 8am-5pm. Thirteen percent (13.4%) have weekday evening hours, after 5pm, and 11.9% have weekend hours. Twenty-one percent (20.9%) are open 24 hours/7 days a week or have someone on call at all times.

Handicap accessibility features are at 78.8% of the agencies and free parking at 75.8% of the agencies.

Different agencies allow different payment plans for the same services; and sometimes within the same agency they will allow multiple payment plans for different services. Two-thirds (67.7%) of the agencies provide free services, 27.7% use a sliding fee scale, 24.6% have insurance reimbursement (including private insurance, Medicare, Medicaid), and 10.8% charge a minimal fee. Some people (18.5%) pay the full payment of services.

In order to serve clients who do not speak English or do not speak English well, over half (51.5%) of the agencies have staff members who speak other languages in addition to English. Half (50.0%) of the agencies ensure that translators/interpreters are available when needed and 33.3% of the agencies translate patient materials into different languages. Some agencies also reported having clients bring someone in with them who can translate for them, using internet translation, and making referrals to agencies with staff/volunteers who speak other languages. Ten of the organizations (15.2%) are not able to serve persons who do not speak English.

Figure 21: Accessibility Options Offered by Organizations



Only nine agencies reported having difficulties meeting the language needs of all of their clients. The languages included African languages, Arabic, Hindi, Karen, Kurdish, Laotian, languages of Somalia, Spanish, Sudanese, and Vietnamese.

BARRIERS TO CARE

Forty percent (40.0%) of responding agencies reported encountering barriers other than lack of funding in providing services to HIV-positive persons. The most common barriers were that the agency does not provide all of the services a person needs (21.5%), staff training in HIV/AIDS is limited (16.9%), there are not enough resources at the agency (15.4%), there is an insufficient number of specialty care providers (12.3%), and missed appointments (12.3%). Twenty percent (20.0%) of respondents stated that they have not encountered any barriers; and 40.0% stated that the question was not applicable to them.

Other barriers specified by respondents included transportation, stigma, limited referral options for substance abusers, a lack of understanding among clients about what services they are eligible for, immigration issues associated with clients being illegal aliens, as well as a range of housing related barriers, including lack of affordable housing, homelessness, unstable housing, and limited shelters.

THE SYSTEM OF HIV/AIDS CARE

Varying opinions were given about which three special populations living with HIV disease are in greatest need of having their HIV-related needs assessed at this time. The most frequently noted group was youth age 13-24 (38.2%), followed by persons with alcohol and/or substance abuse problems (32.4%), African Americans/Blacks (29.4%), and persons with a mental illness (29.4%). Persons aged 50 and older (26.5%) and homeless persons (26.5%) were also frequently mentioned. Recommendations for ways to improve the provision of HIV-related care and support services included increasing HIV education for the general population to reduce stigma, broadening and expanding support services so that they are more easily accessible, and creating a more unified, coordinated system of care.

TOWN HALL MEETINGS

BACKGROUND

In 2012, the MPHD Research Analyst and Needs Assessment Committee created questions for Town Hall meetings on access to HIV testing and treatment. It is recognized that people from all different sectors of the community are impacted by, at risk of, or infected with HIV disease. In order to better serve this community, it was desirable to gain an improved understanding of the community's awareness of HIV testing and treatment services. Therefore, with the number of new infections still rising and many people unaware of their HIV-positive status, it is important for members of this community to get tested for HIV and for those people who are HIV-positive to enter into and remain in care. By hearing from members of this community, a more comprehensive understanding of the knowledge, attitudes, and experiences of the community can be used to improve access to testing and treatment services.

METHODOLOGY

Question Development: The town hall questions were created by the Research Analyst and reviewed by the Needs Assessment Committee. The questions were adapted from the Town Hall Meeting Series Summary Report generated by the New Jersey HIV/AIDS Planning Group. A guide was then developed to assure parity between the town hall meetings.

Locations: Two town hall meetings were held by the Ryan White Part A Program, one in each of two geographic regions in the Nashville TGA:

- Nashville
- Murfreesboro

Recruitment: People of any background were invited to attend the town hall meetings, including people aware of their HIV-positive status, those working in the HIV field, persons interested in HIV, as well as anyone from the general public wishing to contribute attitudes and experiences or gain additional knowledge. The Ryan White Part A Program created and delivered town hall flyers for advertisement at Ryan White Part A providers. The program also sent email invitations out to non-profit and private organizations providing services that may be applicable to HIV-positive individuals. Lastly, members of the Planning Council were asked to personally invite persons to the meetings.

Moderation: The town hall meetings were run by two different Planning Council members. Joseph Interrante moderated the Nashville meeting and Jessica Lyons conducted the Murfreesboro meeting.

Participants: A total of 21 individuals participated in the two town hall meetings, 19 at the Nashville meeting and 2 at the Murfreesboro meeting. From observation, participants were 52.4% (11) female and 47.6% (10) male. They were also 57.1% (12) white and 42.9% (9) black; ethnicity data was not observed.

ANALYSIS

WHY DO YOU THINK PEOPLE MAY NOT GO FOR HIV TESTING? AND, WHAT FACTORS DO YOU THINK CONTRIBUTE TO A PERSON DECIDING TO GET HIV TESTED?

A common theme as to why people choose to not get tested for HIV disease is that they actually do not want to know if they are HIV-positive. People believe in the thought “what I don’t know won’t hurt me.” People do not want to face the disease, so if they do not know they are HIV-positive then they do not have to acknowledge it. They are also afraid to tell partners and family members, so if they are not tested then they do not have to disclose anything to these people. Many people, especially young people, do not recognize the risk factors; in not seeing the behaviors putting them at risk for the disease they do not see a reason to be tested. Education plays a role in this attitude. People who are not sufficiently educated about the disease may not know that they are at risk. For instance, if they think HIV is generally spread through sexual contact and they are not promiscuous, they feel they are not at risk and therefore do not think they need to be tested. What they do not realize is that HIV is spread through many other means unrelated to sexual contact, but that even sexual contact with only one person has its risks. They may think that vaginal sex is the only mode of transmission through sexual contact, so they engage in oral or anal sex instead, not realizing that they are still at risk. These two divergent thought processes, denial compared to lack of education, can lead people down the same path—not getting tested for HIV disease.

Another common belief is the idea of “the other”. People often feel that things like HIV disease happen to “other” people and not to people like them. They feel that by engaging in risky behaviors only one time or infrequently that they will not contract the disease.

There is a lack of understanding about the testing process as well, that while it may not deter people from being tested, is not promoting testing either. Many people do not know that they can receive their test results within 15 minutes; people do not like the idea of having to return to the testing location a second time. It is also not widely known that free testing is available. Many people do not want to spend possibly the little money they have on being tested for a disease that they feel they are not at risk of. Therefore, they simply choose to not be tested.

Lastly, being in the Bible belt, there is a great deal of stigma surrounding HIV disease, as well as lifestyle factors that may place people at greater risk for the disease. Asking someone if they would like to be tested can be considered offensive because it is suggesting that the person might have HIV or that they engage in behaviors of an alternative lifestyle.

On the other hand, many people do not want to be thinking “what could have been” once they have HIV disease and are seriously ill. People who are educated about the disease, understand the symptoms and that they do not always appear or may only appear after the disease has progressed, may decide to get tested. They do not want to be faced with the realization once it is too late, that there was something they could have done to protect themselves.

Another common theme was that people do not usually get tested because they are trying to be preventive, but rather because someone reminds them to do it. Visibility of the disease and testing for it can gain someone’s attention. Therefore, it may not be that people are deciding to not get tested, but that they are not being tested because they do not think about it. They may only make a conscious decision to be tested once they are presented with the idea. This theme was acknowledged by multiple people. They feel that people just do not think about the disease and so they are not tested for it—whether it is that their doctor does not ask them if they want to be tested or they are not faced with

education that reminds them of the importance of doing so—but as a result they do not get tested. However, once they are presented with the idea, they are understanding of the importance of being tested, and only do so at that point.

WHERE WOULD YOU SEND SOMEONE TO GET HIV TESTING OR TREATMENT SERVICES?

The most common responses were the health department, Nashville Cares, the VA, and college/university health centers. However, because many of the participants of the town hall meetings were people who are involved in the HIV care system already (staff, consumers), they may have knowledge that general community members do not.

It was acknowledged that young people often have significant barriers with testing, particularly because they do not trust as many people, do not have access, and do not know how to access services. Stigma and financial status may affect the decisions of anyone as to where to get testing or treatment services. If a person feels he does not have the financial means to pay for the services, he may decide to not receive them rather than attempting to access financial assistance which would then allow him to utilize the services. Regarding stigma, a person may not want to get tested by or receive treatment services from his primary care physician if he does not trust that the doctor will keep his status confidential; this seemed to be a bigger issue in small communities where a person's doctor may know the client's family and friends.

WHY MAY INDIVIDUALS DECIDE NOT TO RECEIVE TREATMENT FOR THEIR HIV? OR WHY MAY THEY NOT STAY IN TREATMENT?

There were three main themes given for why people do not enter HIV care once they learn they are HIV-positive: emotions, finances, and stigma.

The first theme, emotions, can significantly impact whether or not a person enters into HIV treatment. Many people are emotionally shocked when they first learn they are HIV-positive. If they are not ready to deal with the disease or are in disbelief that they even have it, they are less likely to enter into care. The moment an individual enters into care, is the moment he has to admit something is wrong and face the disease. The person who tells the individual that he is HIV-positive has a great deal of influence on whether or not the person enters into care. If the tester offers support and education and can answer the individual's questions, it is more likely that the person will enter into care.

Financial reasons also significantly affect whether or not a person enters into treatment. Many people do not realize that programs are available for persons with low-incomes and therefore if they feel they cannot afford the services they simply do not engage in the system of care. If people were aware of the resources available to assist them in getting care, possibly free care and medications, they would be more likely to enter into treatment.

Again, stigma plays a big role in whether or not someone enters into treatment services. If a person lives in a small community, stigma and fear are likely to play a bigger role. People worry that others will see them going in for a doctor's appointment and will then be identified as being HIV-positive. They do not want to be targeted or presumed as being HIV-positive and so feel avoiding anything related to HIV disease is the answer. People also worry because they do not trust the system and think that once they enroll in care that they will be placed on a "list".

Some people enter into care, but then drop out. A common reason suggested by town hall participants was that people do not like the medications—they make them feel ill, they have side effects, they do

not appear to make a difference. Some people will stop taking their medications and going to their doctor because they do not want to deal with it and then only re-engage in the system once they start to feel sick again.

People often get angry, frustrated, and exhausted with the treatment process. It can be an emotional roller coaster. It can also be difficult to understand the system of care and its functionality, making them frustrated when the system does not work as quickly as they would like it to.

Access to services may also impact a person dropping out of care. If doctors' offices are not open at times that work with an individual's schedule, or if the office is located in an inconvenient or far away place, people are more likely to fall out of care. And if the individual is busy and is not able to regularly commit to appointments or stay on top of his care, receiving treatment may fall to the wayside.

WHAT WOULD YOU RECOMMEND TO HELP US GET PEOPLE HIV TESTED? DO YOU HAVE ANY IDEAS HOW TO GET HIV-POSITIVE PEOPLE INTO HIV CARE?

Improving access to testing and treatment services was a common theme expressed at the town hall meetings. Having offices open in the evenings and on weekends when people with 9am-5pm jobs can more easily attend appointments would be helpful. Also, having a Center of Excellence and more HIV doctors in the rural areas could improve engagement in the system. For rural people, transportation can be a major barrier. Currently the bus system is very limited for people in rural areas and with gas prices being so high having another person drive the individual to appointments is not always an option. Therefore, improving transportation services is essential in getting people from the rural areas to get tested, enter into care, and stay in care.

Another significant theme discussed was education. Education on the disease can help people to recognize the importance of knowing one's status, as well as the difference that can be made by entering into care if a person is HIV-positive. This can teach people that they can live longer and healthier lives if they get into care; it can also open up the conversation more and help to reduce stigma associated with the disease. Education about services is also important. Many people are not aware of all the services available to them, nor are they aware that many services are free for person's with low incomes.

CONCLUSIONS

While nothing significantly new was proposed in the town hall meetings, it was learned that stigma and education are still problems in this community. More education is needed for the community on HIV disease and the HIV system of care. Many people do not have a sufficient level of knowledge of HIV disease and therefore do not recognize the importance of reducing one's risk factors, getting tested, and entering into and remaining in care if they are HIV-positive. However, because stigma is so high in this community, many people are not willing to discuss HIV; they also have the belief that only people engaging in alternative lifestyle behaviors are at risk. If stigma in this community can be reduced and therefore education about HIV disease be improved, it is likely that more people will get tested and enter into treatment if they are found to be HIV-positive.

Persons living in the rural areas are also at an increased disadvantage because not only does stigma tend to be greater, but they have less access to the HIV system of care. There are fewer HIV providers and agencies in the rural areas, in part due to stigma, which leads many people to come into Davidson County for services; however, because transportation from these areas is scant and infrequent, many opportunities to engage people in the system are lost. By working to improve transportation services

from these areas, as well as bring new providers into these areas, more people are likely to receive care and remain in care.

Many of the issues surrounding HIV testing and treatment in this community stem from stigma. If this can be addressed, even one person at a time, differences can be made that will impact education and knowledge and accessibility of services. This in part will then help lead more people to be tested for HIV disease, as it will help get more people into care and stay in care if they learn they are HIV-positive.

