2014 Austin Area Comprehensive HIV/AIDS

Needs Assessment

June 2014

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Executive Summary

The fundamental purpose of a periodic needs assessment is to ensure that the Planning Council continues to have a clear and comprehensive understanding of the needs of People Living with HIV/AIDS (PLWHA) within the Austin Transitional Grant Area (TGA). This report provides the findings of the 2014 Needs Assessment Project, which includes a written survey and focus group discussions. In general the needs identified as a result of the 2014 Needs Assessment does not reflect dramatic shifts in the needs of the HIV community nor the challenges faced by the community. To a large extent the findings are consistent with previous needs assessment findings. While some shifts in needs, barriers and attitudes were identified those differences must be considered from the context of how the questions were asked and the profile of the individuals who participated in the survey.

The Needs Assessment also explored questions related to the changing landscape resulting from implementation of the Affordable Care Act (ACA). One subject not previously addressed is determining how many consumers are undocumented (citizenship is an eligibility condition for ACA insurance). This needs assessment provides insight into the number of undocumented PLWHA and their current insurance coverage. Survey questions explored the scope and range of current insurance coverage. A surprising finding is that significantly more PLWHA are covered by Medicare and Medicaid than in the past. Perhaps the most concerning ACA related finding came from focus group participants. At the conclusion of each focus group session participants were asked if they were aware of ACA and if they had been afforded the opportunity to apply. The findings suggest consumers remain uninformed about ACA. More concerning is the indication that what they were told has been focused more on exemption from a tax penalty than on than on the opportunity for better health coverage.

The most revealing findings from the 2014 Needs Assessment comes from the focus group discussions. Focus group participants were recruited based upon priority populations identified by the Needs Assessment Committee as target groups/issues the Committee felt were most essential to gain additional insight into. Discussion points were developed for each focus group with the intent of exploring the needs and challenges of that specific group. For example Ryan White consumers who are currently homeless were recruited for the homeless focus group and questions were developed to stimulate discussion related to being homeless and living with HIV/AIDS. However what became apparent with each focus group is regardless of the profile of the individuals participating, the needs and issues of each group was often interrelated. It became apparent that attempting to isolate a single problem for discussion misses the point because the problems faced by the focus group participants are not single isolated problems that create barriers to HIV care. Rather, many of the fundamental issues being explored impact all the groups. Homelessness, for example, is not a single isolated barrier that if resolved would enable the individual to get their life in order and enable them to focus on HIV care. Mental health, substance abuse and a number of other socioeconomic barriers all contribute to the circumstances faced by the individuals in the focus group. The conclusion that can be drawn from the focus groups is that while it is necessary and logical for the Planning Council to examine needs from the standpoint of each service category eligible to be funded, the needs of consumers is complex and needs must be considered holistically rather than as individual issues.

Introduction

The Austin Area HIV Planning Council is responsible for allocating Ryan White Program funding within the five county Transitional Grant Area (TGA) which consists of Travis, Williamson, Hays, Bastrop and Caldwell counties. In order to effectively set priorities for allocating funding across eligible Ryan White service categories, the Planning Council needs a clear understanding of the needs of people living with HIV/AIDS (PLWHA) who reside within the TGA. This comprehensive Needs Assessment was designed to provide this essential information to assist the Planning Council in decision making.

This report documents the methodology used to conduct the needs assessment and the resultant findings of the 2014 Needs Assessment.

Purpose and Objectives

The Health Resources and Services Administration (HRSA) is the federal agency responsible for administering the Ryan White HIV/AIDS Program. HRSA program regulations require the Planning Council to complete a number of specific tasks and deliverables in accordance with the roles and responsibilities of the Planning Council. A key deliverable the Planning Council is responsible for producing is a Comprehensive Plan for the organization and delivery of health and support services in conjunction with a coordinated community strategy[1]. A key component of the Comprehensive Plan is to complete a needs assessment. The Austin Area HIV Planning Council conducts a needs assessment on a periodic basis to ensure that the Planning Council has a clear understanding of the scope of the epidemic and the need for HIV/AIDS services within the TGA[2]. The needs assessment is required to include:

- The size and demographics of the population of individuals diagnosed with HIV/AIDS
- The size and demographics of the population who is unaware of their HIV/AIDS status
- The needs of the HIV/AIDS population within the TGA, with particular attention to:
    - Individuals who know their status but are out of care
    - Disparities in access to service among affected subpopulations who are historically underserved
    - Individuals with HIV/AIDS who do not know their status
- Ryan White legislation also requires the planning council to establish methods for obtaining input from the community regarding needs and priorities.

[1] The Austin Area HIV Planning Council develops a Comprehensive Plan on a three year cycle. The current Comprehensive Plan was developed in 2012.

[2] A Comprehensive HIV Needs Assessment was completed in 2005 by New Solutions Inc. under contract to the Austin TGA and in 2010 by the University Of Texas School Of Social Work. HRSA recommends comprehensive needs assessment every 3 years with an annual update.

Methodology

The Austin Area HIV Planning Council's Comprehensive Planning and Needs Assessment Committee is responsible for defining the plan for completion of the needs assessment as well as for providing direction and oversight of the needs assessment effort. The 2014 Needs Assessment was conducted by City of Austin Health and Human Services staff providing administrative support for the Planning Council. Planning Council staff administered the needs assessment in accordance with an approved project plan and following the ongoing direction and input of the Committee.

The Needs Assessment Plan consisted of the following components:

- A written survey administered to PLWHA within the TGA
- Focus groups consisting of PLWHA representing specific subpopulations
- Demographic and statistical data from:
  - AIDS Regional Information and Evaluation System (ARIES[3]) and
  - The Texas Department of State Health Services (DSHS) Epidemiological Profile[4].

Written Survey

A written survey developed by the Needs Assessment Committee was the primary tool used to complete the needs assessment. (See Appendix A for a copy of the survey). The survey was developed by the Needs Assessment Committee with assistance of Planning Council staff. Staff researched surveys from a number of Ryan White EMA/TGAs to identify survey formats and questions. The Committee created a hybrid survey based upon these samples, including the past two Austin TGA needs assessment surveys. The final list of questions was a composite of the samples and the specific information needs determined by the Committee. The focus on survey development was to keep the survey as brief as possible while ensuring that the scope covered all areas deemed essential by the Committee. Technically there are only 43 mostly multiple choice questions. However there are also four "grid" questions dealing with key service areas that consist of three to seven service topics. For each of the grid questions there are five separate sub questions: *Did you know about the service, did you need the service, ranking importance of service on a 5 point scale, did you ask for the service and did you receive the service*. The written survey was available in English and Spanish.

One of the problems inherent in designing a survey of Ryan White Program needs is that the actual range or type of service available under a given Ryan White service category is not always clear from the title. This means you run the risk of having survey responses that are based upon the respondent's general understanding of a service need rather than measuring their need for the more narrow service Ryan White provides. (Respite Care and Legal Services are prime examples of Ryan White services that

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[3] ARIES is the primary reporting system tracking utilization of Ryan White Program services in Texas. Detailed utilization and demographic reports are produced on an annual basis reflecting utilization by Ryan White Part A grant year. The data cited in the report reflects ARIES data for the grant year ending February 2014.

[4] The 2012 DSHS Epidemiologic Profile revised February 2014 and supplemental data for 2013 from Part A Continuum of Care – DSHS HIV/STD Prevention and Care Branch.

are quite different than the service implied by the title). Because of this Ryan White surveys often ask questions related to consumer priority so as to make it easy to determine the consumer's priority ranking for each service. The downside to this approach is that the responses don't always measure the true need for services within the community. The Needs Assessment Committee selected questions based upon the needs the Committee felt were most important to gain information about regardless of current funding status. Thus the survey questions do not always align directly to the list of currently available Ryan White services.

The written survey proved highly successful in terms of obtaining a statistically significant sample of PLWHA within the TGA in order to draw conclusion regarding the needs of the HIV community. A total of 346 surveys were completed. Nine percent were completed in Spanish. It took respondents an average of 25 minutes to complete the survey. The surveys were administered using two methodologies:

- All Ryan White Part A service providers were provided surveys and were requested to make the survey available to their clients as they came in for service. Posters and flyers were used to advertise the availability in addition to being verbally informed by provider staff. Additionally, physicians at four clinics in the Austin area who specialize in treatment of HIV/AIDS were sent letters requesting support with the written surveys. These physicians also received personal contacts from members of the Needs Assessment Committee.

- Survey sessions were scheduled at the two largest service provider facilities on designated times and dates. Two survey sessions were scheduled at the Roosevelt House, which provides housing for PLWHA. Six sessions were scheduled at AIDS Services of Austin in conjunction with the Food Bank schedule, which yielded the majority of the surveys. Additional sessions were held in conjunction with support group meetings. A total of eleven sessions were conducted. Planning Council staff managed these sessions, issuing and collecting surveys, assisting respondents with logistics and answering questions about the surveys. Ten dollar gift cards were provided to respondents as an incentive for completing the survey.

Survey Monkey

The written survey questions were also available via Survey Monkey for respondents who opted to take the survey electronically. This option did not prove popular. Only seven responses were received and only two of those respondents completed the entire survey. It was hoped that the on-line version of the survey would be desirable for those PLWHA who wished to remain anonymous and were thus reluctant to take the survey in person. However, the fact that a gift card was not available for respondents via Survey Monkey put the on-line option at a disadvantage.

Focus Groups

Focus groups were conducted to obtain insight into needs of the HIV community that cannot be obtained from written surveys. Information obtained from written surveys is largely quantitative and statistical in nature. Focus group insight compliments survey data in two ways (a) by enabling the

facilitator to explore the "why" behind survey responses and (b) focus groups allow PLWHA to say what is on their minds and to discuss what is important to them as opposed to simply responding to pre-scripted questions. Recruitment is essential to success because the participants must not only be members of the topic population but also willing and able to speak freely and candidly about the topic. Focus groups were not overly scripted in terms of discussion points. The facilitator began with a list of questions intended to generate discussion on the topic. However when the participants are comfortable with their peers and facilitator the discussion generally deviates from the script to explore the thoughts of the group. The target size for focus groups was six to ten people. Recruitment yielded four to eight people for the focus groups that were conducted.

The Needs Assessment Committee identified nine topics/populations deemed by the Committee to be the most important for exploration through focus groups. Planning Council staff conducted recruitment for these focus groups through distribution of flyers and the assistance of service provider staff. Gift cards in the amount of $30 were provided as an incentive to participate. Criteria for participation included the requirement to be a PLWHA and member of the topic specific population.

A total of six focus groups were conducted focusing on target populations and issues:

- Aged (55+)
- Homeless
- Substance abuse and mental health
- African American/Black
- Hispanic/Latino

As with the gift cards for the written survey, the focus group gift cards were absolutely essential to recruit participants. It proved difficult to recruit participants for several of the topics despite the incentive (especially the homeless and Hispanic/Latino focus groups).

The list of priority topics also included:

- Newly diagnosed
- Young MSM
- Out-of-care

Efforts to recruit participants for these three groups were not successful. While not surprising based upon outreach experience with these groups, the difficulty in recruiting underscores the fact these groups are difficult to reach and generally underserved.

Limitations of Methodology

Eighty-two percent of the written surveys were completed by respondents during the survey sessions. The success of the scheduled sessions was due primarily to the $10 incentive and also due to the fact that the Food Bank provided a large number of PLWHA in a concentrated time frame. This enabled staff to accomplish a key objective by collecting a sample of PLWHA in excess of the goal of 5% of the HIV/AIDS population within the TGA. However, the demographic profile of respondents is somewhat skewed relative to the profile of Ryan White consumers (ARIES profile). The survey sample is somewhat older than the AIRES profile, with minimal representation of those under 25 years of age. The sample also reflects a moderate over representation of females, African Americans and heterosexuals relative to the ARIES profile.

Consumers completing the survey were asked to certify that they were in fact HIV positive and that they have not taken the survey more than once (a risk because the gift card was a significant incentive to low income consumers). The fact that consumers had to sign for the gift card, the location where survey sessions were conducted and the assistance of provider staff all tended to minimize the risk of people who are not HIV+ taking the survey.

The goal of the needs assessment project design was to obtain a statistically significant cross sampling of PLWHA within the TGA, including those out of care, those residing in rural areas, PLWHA who are not Ryan White Program recipients (e.g., those in private medical care) historically underserved minority populations, undocumented and the homeless. With only one Planning Council staff person to conduct most of the survey sessions, use of gift cards and reliance upon service provider scheduled events was necessary to leverage these opportunities to achieve results. Nevertheless, findings should be considered in context to known limitations of the methodology and resulting respondent profile.

Comparing Findings to Previous Needs Assessments

The findings from previous Austin TGA needs assessments were reviewed to identify areas where findings are either consistent with current findings or where the findings differ significantly. Despite the fact that previous needs assessment projects have some differences in methodology and content of questions, it is helpful to consider past findings when drawing conclusions regarding current data. This is especially thru where findings are consistent with previous findings in terms of confidence in the validity of findings. References are made to previous needs assessment findings throughout the Needs Assessment Findings section of the report where meaningful.

Part B Needs Assessment

The Brazos Valley Council of Governments (BVCOG)[5] commissioned a Central Texas HIV/AIDS Client Needs Assessment for Ryan White Part B in late 2013 just prior to completion of the Austin TGA Needs Assessment. The BVCOG Needs Assessment includes a supplemental report for the ten counties which make up the Austin Health Services Delivery Area (HSDA). The Austin HSDA includes the five counties that make up the Austin TGA. Findings and conclusions cited in the supplemental report (*Central Texas HIV/AIDS Client Needs Assessment Supplemental Report: Austin HSDA*) are referenced in the findings section of this report where information in the BCCOG report are deemed noteworthy in contrast to the findings of this Needs Assessment. The BVCOG findings are particularly important when considering the needs of rural consumers since the BVCOG respondents are primarily residents of areas outside Austin. As a general statement it should be noted that survey findings from the two needs assessments are generally consistent. It should also be noted that the methodology and scope are quite different.

[5] BVCOG serves as the administrative agency for HIV services funded by the Texas Department of State Health Services through Part B of the Ryan White Program.

Demographic Profile of Austin Area TGA

Basic demographics are presented in the section as a point of reference for needs assessment findings. More comprehensive demographic profiles are available via links on the Austin Area HIV Planning Council website: http://austintexas.gov/department/austin-area-comprehensive-hiv-planning-council

Population Distribution within the Five County TGA

According to the most recent population data from the US Census Bureau[6], the population of the five county Austin TGA is 1,883,051. The distribution of the population within the Austin TGA is as follows:

Table 1: Distribution of Austin TGA population by race/ethnicity and county 2013

Race/Ethnicity	County				
	Travis	Williamson	Hays	Bastrop	Caldwell
White	533,056	284,219	100,343	43,357	17,183
Hispanic/Latino	371,188	110,791	62,639	26,961	19,319
African American	85,206	27,154	5,429	5,810	2,535
Other	88,442	34,047	5,267	2,133	868
Total	1,077,892	456,211	173,678	78,261	39,902

Number of Persons Living with HIV/AIDS within the Austin TGA

As of December 31, 2013 there were 5,254 PLWHA within the Austin TGA[7]. This total includes 2,260 living with HIV and 2,994 living with AIDS.

Table 2: Distribution of Austin TGA RW population by race/ethnicity and county over last 5 years

Race/Ethnicity	Year				
	2009	2010	2011	2012	2013
White	2,036	2,121	2,245	2,302	2,334
Hispanic/Latino	1,104	1,161	1,256	1,502	1,587
African American	980	1,010	1,082	1,117	1,142
Other	37	40	50	47	53
Total	4,177	4,352	4,676	5,084	5,254*

*For 2013 an additional 138 are of unknown race/ethnicity

Note: The following demographic profiles (tables 3 and 4) are taken from the 2013 Austin TGA Ryan White Grant Application (data as of December 2012):

[6] US Census Bureau.gov 2013

[7] HARS data (as of July 2014)Texas Department of State Health Services, HIV/STD Prevention and Care Branch

Table 3: Number of persons living with HIV by age group and gender

Age	Female	Male	Total
≤ 2	0	1	1
2 - 12	6	5	11
13 - 24	35	172	207
25 - 34	110	744	854
35 - 44	213	1,134	1,347
45 - 54	254	1,484	1,738
≥ 55	131	795	926

Table 4: Number of persons living with HIV by gender, race/ethnicity and exposure category

Gender	Race	MSM	IDU	MSM/IDU	Hetero	Pediatric	Other	Total
Male	White not Hispanic	1,812	67	189	44	8	2	2,122
	Hispanic	1,051	79	84	89	8	1	1,312
	African American	423	133	90	120	5	1	712
	Other	28	2	3	4	1	0	38
	Unknown	74	3	9	3	2	0	91
	Subtotal	3,389	284	375	259	24	4	4,335
Female	White not Hispanic		66		113	1	0	180
	Hispanic		34		239	11	1	190
	African American		95		152	3	0	345
	Other		2		6	1	0	9
	Unknown		7		18	0	0	25
	Subtotal	0	205	0	527	16	1	749
Total		3,389	490	375	786	40	5	5,084

Table 5: Number of PLWHA receiving one or more Part A Funded Services by Ryan White Grant Year

County	GY 2012-13	GY 2011-12	GY 2010-11	GY 2009-10	GY 2008-09
Travis	2,101	2,180	2,074	1,948	1,821
Williamson	162	162	146	140	127
Hays	81	73	85	90	70
Bastrop	66	77	69	66	65
Caldwell	22	24	22	18	16
Totals	2,539	2,516	2,396	2,262	2,099

Comparing Table 2 to Table 5 contrast the number of PLWHA who receive one or more Ryan White Part A services for the last five grant years to the total number of PLWHA residing in the Austin TGA. Table 5 also illustrates the comparative number of PLWHA in each of the five TGA counties.

Table 6 Utilization by Ryan White Service Category GY 2012-13

Ryan White Service	All Funding	Part A	MAI
AIDS Pharmaceutical	1,477	1,117	
Non-medical case management	861	345	165
Emergency Financial Assistance	1		
Food Bank	500	367	
Health Insurance Assistance	50	25	
Home and Community Based Health	4		
Hospice	26	16	
Housing Placement Assistance	6		
Housing Subsidy	214		
Insurance - Medical	75	52	
Insurance – Prescription Drugs	16	10	
Medical Case Management	1,382	146	10
Medical Nutrition Therapy	343	174	
Medicare/Medicaid Supplement	68	38	
Mental Health Services	511	314	
Oral Health Care	1,304	1,111	
Other Services	17		
Outpatient Ambulatory Medical Care	2,335	1,388	
Outreach Services	38	38	
Psychosocial Support Services	73	30	
Rental Assistance	79		
Substance Abuse Services - Outpatient	191	182	
Substance Abuse - Residential	16	16	
Supportive Services	10		
Transportation	652	467	
Treatment Adherence Counseling	72		
Total Cost	$8,959,134	$3,192,785	$174,034

Table 6 provides a breakdown of the utilization of services by consumers[8] within the Austin TGA for Ryan White Grant Year 2012-13 (March 2012 thru February 2013).

Note that “All Funding” refers to all funding sources tracked by the ARIES system (Part A, Part B, Minority AIDS Initiative (MAI), Part C, HOPWA, and City/County General Fund). There are many other funding sources not tracked by ARIES, including Center for Disease Control (CDS), various federal and state grants, funding from foundations and funding from charitable contributions. Note also that there are differences in the service definitions (taxonomy) and scope for the various Ryan White parts.

[8] Unduplicated client count by enrollment status

Unmet Need

Table 7 provides estimates of unmet need[9] within the Austin TGA for 2013. The definition for unmet need is based upon HRSA guidelines: A person living with HIV is said to have an unmet need for medical care if there is no evidence of a CD4 count, a viral load test, antiretroviral therapy or an outpatient/ambulatory medical care visit during the defined 12 months period.

Table 7: Unmet Need Within Austin TGA

Demographic	Austin TGA				State	
	Unmet Need		Met Need		Unmet Need	
	#	Percent	#	Percent	#	Percent
HIV	487	22	1773	78	11025	32
AIDS	408	14	2586	86	8000	19
Gender						
Female	124	16	658	84	3904	23
Male	771	17	3701	83	15121	25
Race/Ethnicity						
White not Hispanic	358	15	1976	85	4496	21
Black	208	18	934	82	7846	27
Hispanic	299	19	1288	81	6160	27
Other	15	28	38	72	258	33
Unknown	15	11	123	89	265	11
Age						
0-1	15	11	123	89	-	-
2-12	-	-	-	-	58	28
13-24	2	17	10	83	1000	25
25-34	36	18	159	82	3923	28
35-44	209	23	687	77	5161	26
45-54	249	18	1113	82	5455	22
55+	250	14	1495	86	3428	24
Sexual Orientation						
MSM	587	17	2950	83	10376	23
IDU	149	14	895	86	2634	30
MSM/IDU	54	15	310	85	1082	25
Heterosexual	150	18	670	82	4694	26
Pediatric	7	18	33	83	209	27
Adult other	-	-	5	100	30	24
STD Co-infections						
STD Co-infection	11	10	101	90	18915	25

[9] 2013 eHARS data provided by Texas Department of State Health Services, HIV/STD Prevention and Care Branch

Table 7 also provides State level data for unmet need for comparison to Austin TGA outcomes. Data is sorted by various demographic factors to provide a comprehensive picture of unmet need. These demographic sorts allow a detailed analysis of unmet need in order to pinpoint where unmet need is the highest.

As can be seen from this comparison, the Austin TGA has lower rates of unmet need than the statewide average in every category measured. DSHS analysis of this data includes the following points of particular note for the Austin TGA:

- The 8% differential in unmet need between HIV and AIDS within the Austin TGA is the lowest of any region in the state. While lower, the difference is nevertheless a significant indicator of disparity in unmet need.

- While Blacks and Hispanics show a higher than average disparity in unmet need across the state, the disparity is likewise much lower within the Austin TGA. While the "Other" sample size is small, the 28% rate for the Austin TGA is notably higher (although still lower than the statewide number).

- It is also notable that while the statewide age group with the highest unmet need is 25-34, the Austin TGA peak is 35-44. In fact, the spike in that age group is statistically significant.

- Additional sorts of the data (<u>not</u> displayed in Table 7 above) show that Hispanic heterosexual males have an unmet need rate of 29% and Hispanic IDU males have an unmet need rate of 30%. DSHS specifically identified these two groups as having a disproportionate impact.

DSHS also sorted unmet need data by ZIP code. Within the Austin TGA eight ZIP codes stood out as geographic areas showing the highest unmet need within the TGA:

ZIP Code	Percentage of Unmet Need
78753	15.44%
78741	18.18%
78759	18.33%
78758	19.71%
78754	21.51%
78702	21.71%
78721	23.46%
78764	23.53%

Note: DSHS has stated that the estimates of unmet need should be considered liberal estimates for several reasons: (1) The estimates do not include HIV care provided by the Veterans Administration, Medicare and all private providers and (2) Matches between eHARS, ARIES, and some private payers were based upon a unique identifier or limited data elements which may underestimate the true number of clients with met need from these data sources.

Needs Assessment Findings

The results of the written survey are presented in this section.

Demographic Questions

The demographic profile of PLWHA who completed the written survey is provided in the tables below. Comparisons are made between the statistical profile of PLWHA who completed the written survey (respondents) and profiles of PLWHA available from reports provided by the Department of State Health Services (eHARS) as well as ARIES.

Table 8: Age of Survey Respondents

		Count	Column N %
Age Category	TOTALS	346	100%
	20 and Under	1	0%
	21 to 25	3	1%
	26 to 30	8	2%
	31 to 35	16	5%
	36 to 40	21	6%
	41 to 45	37	11%
	46 to 50	75	22%
	51 to 55	61	18%
	56 to 60	45	13%
	61 to 65	20	6%
	66 to 70	7	2%
	Over 70	2	1%
	Illegible/Incomplete	0	
	No Response	50	14%

Respondents completing the written survey tended to be older than the age profile for PLWHA in the TGA. According to 2012 eHARS data, 5.3% of PLWHA are under the age of 25, 17.9% are between 25 and 34 years old, 29.4% are between 35 and 44, 32.6% between 45 and 54, and 14.8 % are over the age of 55.

Respondent demographics for the Part B survey were remarkably similar to the profile found in this survey. The Part B assessment also found that respondents were older and reflected more females than indicated through ARIES and DSHS data. The only area where Part B differed is in the area of race/ethnicity. While 50% of respondents in this survey indicated their race is African American/Black, Part B respondents had 20% indicating African American/Black. The number reporting their race/ethnicity as Hispanic/Latino was 26% and 27% respectively. However, an additional 23% of Part B respondents selected “other” as their race and specified “Mexican” in the comments section.

Table 9: Race and Ethnicity of Survey Respondents

Race/Ethnicity	TOTALS	346	100%
	White/Caucasian	64	18%
	Black/African American	174	50%
	Hispanic/Latino	89	26%
	Native American	2	1%
	Asian/Pacific Islander	4	1%
	Multi-Racial	9	3%
	Other	2	1%
	Illegible/Incomplete	0	
	No Response	2	1%

African Americans were over represented in the survey with fully 50% of respondents indicating they were African American/Black. According to eHARS data only 23% of PLWHA in the Austin TGA are African American/Black.

Table 10: Gender of Survey Respondents

Gender	TOTALS	346	100%
	Male	211	61%
	Female	104	30%
	Transgender	22	6%
	Other	2	1%
	Illegible Incomplete	0	
	No Response	7	2%

Females were also over represented in the written survey with 30% of survey respondents being female. According to eHARS 15.6% of PLWHA in the TGA are female.

Table 11: Sexual Orientation of Survey Respondents

Sexual Orientation	TOTALS	346	100%
	Heterosexual	151	44%
	Gay/Lesbian	111	32%
	Bisexual	32	9%
	Other/Unsure/Prefer not to say	38	11%
	Illegible/Incomplete	0	
	No Response	14	4%

Heterosexuals appeared to be over represented in the written survey with 44% identifying as heterosexual. According to eHARS 24% of PLWHA are heterosexual. Note that 15% choose not to respond to the question.

Table 12: Citizenship Status of Survey Respondents

U. S. Citizen	TOTALS	346	100%
	Yes	306	88%
	No	38	11%
	No Response	2	1%
Documented Immigrant?	TOTALS	346	100%
	Yes	13	4%
	No	8	2%
	Not Applicable	307	89%
	Illegible/Incomplete	1	0%
	Prefer not to Answer	9	3%
	No Response	8	2%

This question is of particular importance because very little factual information is available regarding the numbers or status of PLWHA whose immigration status is undocumented. In fact limited information is available estimating the number of undocumented people residing within the Austin TGA. The Travis County Health and Human Services Department[10] estimates there are approximately 110,000 undocumented immigrants in Travis County. Assuming the rate of PLWHA who are undocumented is relatively consistent with the DSHS projection rate for the Austin TGA of 254 cases per 100,000[11], an estimate of 250 – 280 PLWHA in the Austin TGA is a reasonable assumption. However any conclusions drawn regarding the number of undocumented PLWHA within the TGA based upon the survey sample must be considered in the context of the available data.

Quantifying the number of PLWHA who are undocumented is an important objective for two reasons:

- Undocumented persons are not eligible for Medicaid[12] or eligible to purchase insurance under the Affordable Care Act. Under current laws, even if Texas changed position regarding Medicaid expansion under ACA the undocumented population would still be ineligible for Medicaid and thus remain dependent upon Ryan White for medical care.
- People who are undocumented are apprehensive about being identified and thus subject to deportation. Consequently they live largely "in the shadows" and tend not to seek or utilize services. This adds an additional barrier to HIV care.

While only 2% of respondents indicated they are not documented immigrants, an additional 3% selected "Prefer not to answer" and 2% did not respond to the question. It is reasonable to assume that somewhere between 7 and 11% of survey respondents are undocumented.

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[10] Travis County Immigrant Assessment 2007

[11] 2010 Texas Integrated Epidemiologic Profile

[12] Lawfully admitted children and pregnant women are eligible as a state option

The profile of respondents who indicate they are not citizens or documented immigrants is notably different from overall survey statistics in several ways. Eighty-four percent are male and 82% indicate their race is Latino/Hispanic. Eleven percent of undocumented respondents indicated their race as Asian. Sixty-eight percent of undocumented respondents indicate they are heterosexual, which is notably higher than the overall population of respondents. The average age of undocumented respondents was 46, which is notably younger than the average age of overall respondents. Spanish is the language 68% feel most comfortable speaking. The education level of undocumented respondents was also notably below that of the overall survey, with 38% indicating 8th grade or less and an additional 26% reporting a high school or GED level of education. Twenty-three percent of undocumented respondents indicate they have no insurance and 44% report MAP insurance which indicates an uninsured rate significantly higher than the overall respondent population. A significant majority of undocumented respondents left questions related to mental health and substance abuse blank and only 15% of those respondents reported the need for mental health and/or substance abuse services. In fact undocumented respondents tended to leave personal questions blank at a much higher frequency that the overall respondent population suggesting they are more guarded or cautious in discussing personal issues. This also tended to be true with questions regarding their need for medical care and support services. The number of undocumented respondents who indicated they were aware of given services and who indicated they ask for service was notably below the rate of responses for the general population of respondents. It is unclear to what extent this reflects a true lack of knowledge of available services, reluctance to seek services, or simply a consequence of the confusion experienced with the "grid" question format being further complicated by language barriers. It is likely that all of these factors contributed to the response findings for undocumented respondents. Regardless of the reasons for the lower response rates by undocumented respondents, the survey findings suggest that being undocumented is an additional barrier to care for PLWHA.

Table 13: Language of Survey Respondents

Language Most Comfortable Speaking	TOTALS	346	100%
	English	291	84%
	Spanish	32	9%
	Multi-Lingual	18	5%
	Other	0	
	Illegible/Incomplete	1	0%
	No Response	4	1%

It is noteworthy that of the 5% of respondents selected both Spanish and English as the language they are most comfortable speaking.

Table 14: Education Level of Survey Respondents

Highest Education Attained	TOTALS	346	100%
	8th grade or less	45	13%
	High school or GED	140	40%
	Vocational training	20	6%
	Some college	88	25%
	College degree	47	14%
	Some high school	2	1%
	No response	4	1%

Table 15: AIDS Diagnosis of Survey Respondents

Ever Diagnosed with AIDS?	TOTALS	346	100%
	Yes	179	52%
	No	147	42%
	Don't know	17	5%
	Illegible/Incomplete	1	0%
	No response	2	1%

Table 16: Number of Years Survey Respondents has been HIV Positive

Year Category of HIV Discovery	TOTALS	346	100%
	<=1980	1	0%
	1981 to 1985	18	5%
	1986 to 1990	32	9%
	1991 to 1995	46	13%
	1996 to 2000	69	20%
	2001 to 2005	39	11%
	2006 to 2010	41	12%
	After 2010	31	9%
	Illegible/Incomplete	3	1%
	Does not Know	1	0%
	No Response	65	19%

Table 17: Tobacco Use by Survey Respondents

Uses Tobacco	TOTALS	346	100%
	Yes	134	39%
	No	176	51%
	No Response	36	10%

The percentage of consumers using tobacco appears to be significantly higher than the general population. According to the American Cancer Society tobacco use has declined in the United States

from 42% in 1965 to 18%[13] in 2012. However according to CDC estimates that rate has not declined for HIV+ persons in the United States[14]. Smoking is among the most prevalent problems affecting HIV-infected patients. According to the Center for Disease Control (CDC) smoking is the leading cause of coronary heart disease, respiratory illness, cancer and diabetes. For HIV-infected smokers, antiretroviral therapy shifts the risk of death dramatically away from HIV and towards smoking-related causes. Equally concerning for PLWHA is the fact that CDC studies show that smoking weakens the immune system by depressing antibodies (something PLWHA can ill afford). Consequently this is one of the more significant findings of the needs assessment survey.

In addition to smoking being an indicator of general health, this question is of high significance because of the direct impact tobacco use has on eligibility for insurance under the Affordable Care Act (ACA). Smoking has a dramatic impact on the cost of premiums under ACA. Ryan White Program legislation mandates that Ryan White be a "*payer of last resort*" requiring that consumers utilize other available resources before utilizing Ryan White to pay for HIV services. Consumer eligibility for ACA insurance and the determination of cost effectiveness of ACA insurance are negatively impacted by tobacco use. As the Ryan White Program evolves under ACA the program will potentially direct more core service dollars toward the Health Insurance Premium and Cost Sharing Assistance service category. The question of cost effectiveness of using Ryan White funds to pay premiums vs. paying for direct medical care is directly impacted by tobacco use.

Table 18: Access to Electronic Media

Has Texting, Phone and/or Internet Note: Respondents could select more than one option	TOTALS	346	100%
	Has Phone	319	92%
	Has Text Messaging	159	46%
	Has Internet Access	122	35%
	None of the Above	12	3%

This question was asked as a result of the dramatic impact social networking has had in recent years as a source of information and communication. The question is an attempt to ascertain the extent to which PLWHA are utilizing electronic media and thus the viability of leveraging social networks for prevention and HIV service messages. The question did not distinguish between cell phone and land line service, however, interaction with respondents at survey locations makes it clear that an overwhelmingly majority have a cell phone. It is important to note that while 92% of respondents report having a cell phone, many noted that they have limited service minutes under their plan. "Cricket" is the most popular cell provider. Note that only 46% have text capability and many respondents pointed out that they are guarded in use of text capability because of the cost associated with texting. Thus these numbers may be deceptive in suggesting that a large number of PLWHA would be candidates for communication of HIV related messages.

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[13] Rates cited by the American Cancer Society are higher in the South (20%) and Midwest (21%). Smoking rates for minority populations are generally higher, with 26.5% of African Americans using tobacco in 2012

[14] The CDC estimates that in 2009, 42% of HIV infected Americans in care smoked cigarettes.

Table 19: Respondent Residence by ZIP Code

ZIP Code	TOTALS	346	100%
	78501	1	0%
	78602	7	2%
	78610	1	0%
	78612	2	1%
	78621	5	1%
	78634	1	0%
	78640	4	1%
	78641	1	0%
	78648	2	1%
	78653	3	1%
	78659	1	0%
	78660	1	0%
	78664	1	0%
	78666	5	1%
	78676	1	0%
	78701	6	2%
	78702	21	6%
	78704	15	4%
	78705	1	0%
	78721	7	2%
	78722	1	0%
	78723	32	9%
	78724	7	2%
	78725	2	1%
	78727	4	1%
	78728	2	1%
	78729	1	0%
	78735	1	0%
	78741	24	7%
	78744	12	3%
	78745	8	2%
	78749	1	0%
	78751	4	1%
	78752	29	8%
	78753	13	4%
	78754	3	1%
	78755	1	0%
	78756	31	9%
	78757	4	1%
	78758	22	6%
	78759	2	1%
	78768	1	0%
	78778	1	0%
	78942	2	1%
	78947	1	0%
	78957	1	0%
	Homeless	2	1%
	Illegible/Incomplete	3	1%
	No Response	45	13%

The list of zip codes makes it appear that respondents are spread out across the Austin TGA. However, when viewing a zip code map it is clear that most respondents reside in the general geographic area of east central Travis County. The top nine zip codes based upon the number of respondents are:

Zip Code	Respondents
78732	32
78756	31
78752	26
78741	24
78758	22
78702	21
78704	15
78753	13
78744	12

Collectively these zip codes represent 56% of the total survey responses. This concentration is consistent with ARIES data.

Respondents residing in zip codes in the four TGA counties outside Austin (Hays, Bastrop, Williamson and Caldwell) represent 10% of responses. This proportion is consistent with ARIES residence from an overall standpoint. Communities included in these zip codes include Bastrop, Buda, Elgin, Hutto, San Marcos, Leander, Luling, Pflugerville, Round Rock and Wimberly. However, given the population of Round Rock, this area appears to be underrepresented. It should also be noted that the majority of respondents from outlying counties reside in urban communities such as Round Rock and San Marcos and do not reflect the needs of rural consumers.

Analysis of Responses by ZIP Code

Survey responses were sorted by zip code to determine if the profile of respondents in the "other" four Austin TGA counties differed from the responses of respondents residing in metropolitan Austin. No statistically significant differences were noted in the responses to survey questions with the single exception of transportation. Consumers residing in areas not served by Capitol Metro (Austin area bus system) have very different transportation challenges. Those issues are well documented in a previous Needs Assessment Report[15]. Residents in the four outlying counties are served by CARTS. However consumers who reside in a truly rural setting have not realistic option for public transportation. Thus rural consumers have significant challenges in obtaining transportation both for medical services and also for picking up prescriptions.

[15] Needs Assessment Research Project, June 2012 available on Austin TGA website

Employment and Income

Table 20: Income of Respondents

Total Income Last Month	TOTALS	346	100%
	Less than $500	87	25%
	$501 to $1,000	145	42%
	$1,001 to $1,500	56	16%
	$1,501 to $2,000	24	7%
	More than $2,000	14	4%
	No Response	20	6%

Understanding the economic status of PLWHA within the Austin TGA is an essential component in assessing the needs of the consumers who rely upon Ryan White. Evidence strongly suggests a link between socioeconomic status and health[16]. The information presented in Table 19 is of particular importance given the fact that very limited income information is available from other sources[17].

Based upon the incomes presented in Table 19, 67% of respondent households have incomes of less than $1,000 per month and 84% less than $1,500 per month. A lesson learned from survey design is that this question should have aligned the income levels with the federal poverty level given the significance of the FPL for program eligibility. The current FPL for a one person household is $972.50 per month ($11,670 annually). The income data must be considered in context of household size since this question reflects household income. As can be seen from Table 22 below, 45% of respondent household consist of 2 or more persons. Correlating the responses to question 15 (total income) with question 16 (number of people supported by declared income) reveals that 86% of respondent households live at or below the federal poverty line[18].

The survey data does not show any significant differences in income based upon race and ethnicity. Thirty-one percent of respondents who report their race as Hispanic/Latino report their household income as less than $500 per month and 60% report incomes less than $1,000. (Note that 15% of Hispanic/Latino respondents did not respond to the income question). Among African Americans, 24% of respondents report household incomes of less than $500 and 70% report household incomes less than $1,000. Twenty-one percent of White/Caucasian respondents report income of less than $500 and 73% less than $1,000.

No significant differences were found in reported household incomes when sorted by gender with the exception of respondents who indicate their gender as transgender. Transgender respondents report

[16] Link & Phlean (1995) *Social Conditions as a fundamental cause of disease*, Journal of Health and Behavior.

[17] ARIES tracks household income as a percentage of the federal poverty level in increments of 100. This information is collected periodically by service providers and the currency of this information is unclear.

[18] This percentage is qualified by three limitations (1) The $1,000 income break is slightly more than the $972.50 one person FPL, (2) a number of respondents provided incomplete or conflicting information regarding the number of persons residing in their household and (3) some respondents who reported they were employed also responded to questions about the reason they were unemployed.

36% with household incomes under $500 per month and 77% with incomes under $1,000 per month. No statistically significant differences in income were noted when sorting by sexual orientation and age.

Table 21: Employment Status of Respondents

.		Count	Column N %
Employment Status (more than one may apply)	TOTALS	346	100%
	Working Full-time	35	10%
	Working Part-time	35	10%
	Self-Employed	8	2%
	Working Off-and-On	17	5%
	Not Working	249	72%
	No Response	3	1%
Reason(s) Not Working (more than one may apply; some clients responded to this question even though they were employed)	TOTALS	249	100%
	Student	4	2%
	Looking for Work	24	10%
	Disabled	165	66%
	Retired	17	7%
	No Response	51	20%

As can be seen from Table 20, less than one quarter of respondents are employed and of that number only 10% are working full time. Only 10% report that they are looking for work. Out of the 72% who indicate they are not working, the overwhelming majority (66%) report that they are disabled with another 7% indicating they are retired. It is significant that 20% of respondents did not answer the question regarding the reason they are not working. Anecdotal information provided by focus groups suggest the list of reasons should have included HIV specific barriers as a reason for unemployment ("*who would hire us*"?).

Correlating surveys where respondents indicated they are working full time with responses to household income confirms that the overwhelming majority of respondents reporting incomes in the $1,500 and above range are those households working full time. A few respondents asked if the question on employment was intended to indicate their employment status or also that of a partner. While the questions were intended to survey the HIV + respondents own employment status and total household income (as worded) it is possible that the employment status responses may include the status of another household member.

Table 22: Unearned Income

Benefit(s) Received (more than one may apply)	TOTALS	346	100%
	SSI	125	36%
	Disability/SSDI	121	35%
	Unemployment	11	3%
	Food Stamps	89	26%
	Other Benefits	18	5%
	None of the Above	73	21%

As seen in Table 21, the primary source of income for respondent households is unearned income from Supplemental Security Income (SSI) or Social Security (SSDI). This is consistent with the percent of

respondents who report they are disabled and/or retired. Unfortunately respondents who checked "Other Benefits" did not specify what that benefit is. However the more significant unanswered question is the 21% who selected "None of the above". Note that the wording for this question specified to "*answer for yourself and not the household*". Based upon questions from respondents during survey questions it is known that "other benefits" includes Veteran's Benefits and retirement checks from other household members.

Food Stamps (Supplemental Nutrition Assistance Program-SNAP) were included in the question despite the fact that it is not a cash income source. It is important to consider the percentage of respondents reporting SNAP assistance in the context of SNAP eligibility rules (income limits and exclusion of non-disabled adults).

Table 23: Income by Household Size

Total Persons in Household Supported Solely by Respondent Income	TOTALS	346	100%
	One (1)	191	55%
	Two (2)	61	18%
	Three (3)	27	8%
	Four (4)	15	4%
	Five (5)	1	0%
	Six (6)	2	1%
	Seven (7)	1	0%
	Illegible/Incomplete	4	1%
	Prefer not to Answer	0	
	No Response	44	13%
Total in Household Under 18	TOTALS	346	100%
	None (0)	242	70%
	One (1)	31	9%
	Two (2)	20	6%
	Three (3)	3	1%
	Illegible/Incomplete	1	0%
	Prefer not to Answer	0	
	No Response	49	14%

While this question was directly focused on the number of people supported by the household's income (Table 22) the question also indirectly profiles whether or not the consumer lives alone or with others. As seen in Table 22, 55% of respondents live alone and 32% live with others (13% did not respond). Of the 32% who live with others, half of those households (16%) include minor children.

Ironically the last two needs assessments both asked the living situation question but presented results only in the context of specific priority populations and in the context of housing status (e.g., living with parents). The 2005 needs assessment found that PLWHA who live with a spouse were more likely to be in care and conversely those living with relatives or a partner were out of care at a higher rate. The negative impact on medical care appears to be related to concern that others not find out about the HIV status of the consumer.

The current survey results do not reflect any notable difference between respondents who live with others and the response to question 32 (medical care in last 6 months) nor question 35 (are you taking medications as prescribed). However some insight into this issue was obtained via focus groups where female respondents with dependent children or grandchildren expressed a reluctance to have older children be aware of their status.

Insurance

Table 24: Insurance Coverage

		Count	Column N %
Insurance Type *More than one may apply. Therefore column total will be less than the sum of the individual insurance types.*	**TOTALS (Unduplicated)**	**346**	**100%**
	No Insurance	30	9%
	MAP (Medical Assistance Program)	77	22%
	Employer-sponsored Insurance	10	3%
	COBRA	2	1%
	Private Insurance	12	3%
	Medicare	129	37%
	Medicaid	146	42%
	State High Risk Insurance Pool	0	
	VA (Veterans Administration)	4	1%
	Other Insurance	6	2%
	No Response	8	2%
Health Insurance Covers HIV Care?	**TOTALS**	**346**	**100%**
	Yes	246	71%
	No	20	6%
	Some	20	6%
	I Don't Know	16	5%
	Not Applicable (doesn't have insurance)	30	9%
	Other	2	1%
	No Response	12	3%

Only 9% of respondents report no insurance coverage. This percentage is markedly lower than the findings of past needs assessment surveys. The 2005 survey reported 48% of respondents without insurance. (Data is not available for the 2010 survey). The primary reason for this dramatic difference appears to be related to the percentage of PLWHA who are covered by Medicare and Medicaid. In 2005 only 6% of survey respondents reported Medicare and an additional 5% reported Medicaid. That finding is in sharp contrast to the 37% now reporting Medicare and the 42% now reporting Medicaid. One reason for this significant change may be related to the fact that more people are living long term with HIV/AIDS. A number of focus group participants described protracted legal "battles" with Social Security before their disability application was approved. Given the fact that the HIV population is aging and living longer with the disease, it is reasonable to assume that a larger percentage of PLWHA are deemed medically disabled (and thus eligible for federal disability). This assumption is also supported by the fact that a larger number of people describe themselves as disabled (see table 33) than in the past. However this may be due to the way in which the question is asked in each survey. For example, in 2005 the survey asked "*Do you have any mental or physical disabilities other than HIV/AIDS*". In contrast, the current survey asked the disability question in the context of ability to seek employment. Regardless of the reason, the current needs assessment clearly shows a notable increase in the number of PLWHA who are covered by Medicare and Medicaid. This is a significant finding that has direct implications for future priority setting decisions. It does not appear that this trend in medical coverage has been pointed out by other studies.

Incarceration History

Table 25: Incarceration History of Respondents

		Count	Column N %
Incarcerated during the Past 12 Months	**TOTALS**	**346**	**100%**
	Yes	***42***	***12%***
	No	290	84%
	Illegible/Incomplete	1	0%
	No Response	13	4%
Did jail staff know you were HIV positive?	**TOTALS**	**42**	**100%**
	Yes	38	90%
	No	3	7%
	No Response	1	2%
Did you receive HIV medications while in jail?	**TOTALS**	**42**	**100%**
	Yes	31	74%
	No	9	21%
	Not Applicable (no prescriptions)	1	2%
	Illegible/Incomplete	1	2%

This question was designed to evaluate the transition of care for PLWHA who were recently incarcerated. As can be seen from table 24, 90% of respondents who were incarcerated during the preceding 12 months report that jail staff was aware of their HIV status and that 74% of those individuals received medications while incarcerated. These numbers are consistent with past needs assessment which found that jail staff were aware of the inmates HIV status 83% of the time and that 63% of those inmates received medical care (previous surveys asked if the inmate received medical care rather than medication).

Table 26: Follow up services upon release from prison

Received the Following Services as Part of Jail/Prison Release			*Received from the Jail*	*Received from Other Organization*
Housing Information	18	43%	*10*	*7*
Referral to Medical Care	19	45%	*15*	*5*
Referral to Case Management	16	38%	*9*	*6*
Received Medications upon Release	15	36%	*10*	*3*

These findings are likewise comparable to previous needs assessment findings. While incarceration was not a focus group topic, discussion with participants who reported history with incarceration suggests that there is a difference between the level of medical care given to an inmate in a penitentiary who resides there for months or years and the level of care provided to a person in a county jail for a relatively brief period. Future needs assessment surveys should attempt to distinguish between the two levels of incarceration.

Analyzing survey findings by demographic criteria shows a disproportionate number of African Americans reported incarceration. Fifty-seven percent of respondents who reported being incarcerated

were African American, compared to 14% for White respondents and 19% for Hispanic/Latino respondents. Not surprisingly 79% of respondents who report incarceration were male. It is also notable that the age range 46 to 50 represented 33% of those respondents reporting incarceration while age ranges 41-45 and 51-55 were only 10% of reported incarcerations. Even when adjusting for the fact that survey respondents were older than the average age of consumers per eHARS, it is unclear why this age range shows such a dramatic spike.

Housing

Table 27: Housing Status of Respondents

	Number and Percent of Total Respondents (346) with the Indicated Housing Situation(s)			
	Housing Situation "Now"		Housing Situation Six Months Ago	
Apartment/House Rental	196	57%	100	29%
Apartment/House Own	35	10%	25	7%
Parents/relative	27	8%	26	8%
Someone else's apartment/house	33	10%	25	7%
Boarding house/group home	10	3%	10	3%
Supportive/assisted living facility	13	4%	6	2%
Half-way house	5	1%	5	1%
Psychiatric facility	3	1%	5	1%
Substance abuse facility	5	1%	6	2%
Nursing home/physical rehab	2	1%	3	1%
Homeless on the streets	9	3%	17	5%
Homeless shelter	6	2%	7	2%
Domestic violence shelter	2	1%	3	1%
Public housing, including Section 8	15	4%	13	4%
Hospice	4	1%	7	2%
Jail/prison	0	0%	12	3%
Hotel/motel	6	2%	6	2%
Other	3	1%	0	0%

It is a well-established fact that adherence to care is negatively impacted by PLWHA who are economically disadvantaged and struggling with basic needs. Housing is unquestionably at the top of the list in terms of unmet consumer need. This survey question was asked in terms of the current housing situation ("now") and the situation 6 months ago in an effort to get a more comprehensive picture of the housing status of PLWHA within the TGA. As can be seen from Table 27, respondents reported a broad range of living situations with a significant majority reporting that they live in a rental apartment/house (57% Now) followed by an owned apartment/house (10%), Someone else's apartment/house (10%) and residing with parents/relatives (8%). These numbers are consistent with past needs assessment findings and also with ARIES data[19]. Note that a number of respondents selected more than one option from each column. Based upon questions from respondents during survey sessions it is clear that respondents who selected more than one option were indicating that they resided briefly in a temporary situation such as a shelter, hotel or jail, and more permanently in another residential setting.

However what is surprising about current survey findings is the fact that six months ago only 29% resided in an apartment/house. One of the pitfalls of multi-column questions is that respondents tend not to answer the second part completely. This was definitely true for this survey and specifically for the housing question. Nevertheless, the significant difference is not entirely explained by incomplete

[19] Current ARIES living situation data shows 52% of Ryan White consumers reside in a rental apartment or home, 14% in a home they own and 29% reside in a home or apartment of a friend or relative.

responses. Some insight into this issue came from focus group discussions in that focus group participants reported that a significant amount of instability in their living situation. Lack of consistent HOPWA funding, housing policies that limit length of stay and various stigma related barriers were all cited by focus group participants as contributing factors to having long term stable housing.

The Part B survey results suggest somewhat more stable housing for the more rural counties relative to this survey. Seventy-five percent of Part B respondents report residing in a house or apartment they own or rent, and 14% indicate they are residing with parents or relatives. Only 1% report indicates they are living in someone else's apartment and 1% indicate they reside in a homeless shelter. This difference would seem consistent with known differences in rural and urban demographics.

Table 288: Respondent Difficulty in Obtaining Housing

		Count	Column N %
Had difficulty obtaining housing	**TOTALS**	**346**	**100%**
	Yes	***83***	***24%***
	No	238	69%
	Not Applicable	3	1%
	Other	1	0%
	Illegible/Incomplete	2	1%
	No Response	19	5%

Table29: Barriers to Housing

		Count	Column N %
Issues that kept you from getting housing (respondents may have selected more than one category)	**TOTALS**	**83**	**100%**
	No money for deposit	30	36%
	Could not find affordable housing	38	46%
	No transportation to search for housing	16	19%
	Bad credit	33	40%
	Criminal record	37	45%
	Wait list	27	33%
	Not qualified for housing assistance	14	17%
	Physical and/or mental disability	11	13%
	Substance abuse issues	7	8%
	Other	5	6%
	No response	2	2%

Table 27 points to one of the dilemmas encountered in assessing the relative importance consumers place on housing. For those (69%) who have stable housing the need is not ranked high as a consumer priority, while for those who do not have stable housing consumers rank housing as a high need and the list of barriers they have encountered is significant. Note that most respondents selected multiple issues owning to the fact that they have encountered multiple barriers to securing housing.

It is important to note in a tight housing market with rising rents these barriers are exacerbated. Note also that issues such as criminal record or bad credit ratings are barriers that cannot be addressed by funding or through greater availability of housing. Discrimination as a result of HIV status was not one

of the survey options. However a number of focus group participants indicated that their HIV status was believed to be a barrier because landlords are reluctant to rent to an HIV positive tenant.

Table 290: Housing Issues Impacting HIV Care

		Count	Column N %
Issues that kept you from taking care of your HIV-AIDS (respondents may have selected more than one category)	**TOTALS**	**346**	**100%**
	No safe/private room	30	9%
	No storage place for medicines	18	5%
	No telephone	20	6%
	Not enough food	43	12%
	No money for rent	44	13%
	No heat and/or AC	13	4%
	Does not want anyone to know HIV status	46	13%
	Does not feel safe	18	5%
	Other	17	5%
	None of the above	175	51%
	No affect/not applicable	6	2%
	No answer	47	14%

Table 28 points to the consequences of unstable housing in terms of the impact housing have on remaining in medical care. Note that 51% of respondents selected “None of the above” suggesting that the list of reasons is missing one or more key reasons. The focus groups did not provide any specific insight into what other housing issues may be missing that contribute to disruptions in care. One comment by a focus group participant simply noted “*when you don’t have a place to stay or enough to eat you aren’t thinking about taking medicine*”. Thus the particular reasons why unstable housing negatively impacts continuity of care is perhaps less important than the recognition that it is an impact.

Part B survey responses identified similar responses. Forty percent of Part B respondents selected “other” in response the question “housing situations that prevent participants from caring for their HIV” despite the fact that that survey had a comparable list of reasons. The number one reason cited by Part B respondents was “afraid of others knowing you are HIV positive” (17%) followed by “not enough money to pay rent” (9%) and “do not have enough food to eat” (8%).

Mental Health

Table 301: Mental Health History

		Count	Column N %
Received mental health related treatment or counseling during past six months	**TOTALS**	**346**	**100%**
	Yes	122	35%
	No	213	62%
	Illegible/Incomplete	1	0%
	No Response	10	3%
Prescribed mental health medications during past six months	**TOTALS**	**346**	**100%**
	Yes	117	34%
	No	210	61%
	Illegible/Incomplete	1	0%
	No Response	18	5%
If prescribed mental health medications, did you receive them	**TOTALS**	**117**	**100%**
	Yes	89	76%
	No	4	3%
	Not Applicable	1	1%
	No Response	23	20%
If you did not receive your mental health medications, why not *(clients can select more than one response)*	**TOTALS**	**4**	**100%**
	Could not afford them	2	50%
	Did not know where to get them	3	75%
	No transportation	1	25%
	Other	0	0%
	No Response	0	0%

This question was worded to measure the number of PLWHA who are currently or recently receiving mental health care. While that information is significant for evaluating need from the context of projecting the number of PLWHA who may seek mental health services, the 35% finding does not provide insight into the number of people who need mental health care. Previous needs assessments have reported as many as two-thirds of PLWHA report a mental health condition with 59% indicating they experience depression. Mental health was an issue frequently brought up by focus group participants during the current needs assessment. As can be seen from Table 43, the current survey revealed that 63% of consumers are aware of the availability of mental health services and 38% indicated they needed mental health care. The reasons for the disparity between the number who express a need for mental health care and the number who actually seek service are not entirely clear. The only insight from focus group participants was the indication that consumers have not found available counseling and medications to be effective in addressing mental health problems. One focus group participant stated "*I go to a support group and take my medication but the reasons I am depressed are still there*". Thus the assessment of need for mental health service may be more about the effectiveness of outcomes than simply the availability of menthe health service.

Part B mental health findings differ somewhat from the findings of this survey. Sixty-two percent of Part B respondents reported they were currently experiencing one or more mental health conditions, with anxiety and depression being the most common conditions cited. While there is clearly a difference in asking about current experience and need for service, the difference suggests mental health needs are

still not well understood. The key may be found in the reluctance of consumers who are experiencing mental health issues to pursue mental health care. In fact, the number of people who reported receiving mental health care in the last six months in this survey is 35% while 41% of Part B respondents indicate they received mental health care in the last two years. The Part B report states "*The discrepancy between the percentage of participants currently reporting a mental health condition and the percentage reporting utilization of mental health counseling is worth noting. This may indicate the need for increased service coverage and/or outreach*."

Substance Abuse

Table 312: Impacts of Substance Abuse on Continuity of Care

Effect of alcohol/drugs during past six months *(clients can select more than one response)*	**TOTALS**	**346**	**100%**
	Trouble keeping medical appointments	40	12%
	Trouble following doctor's instructions	22	6%
	Trouble taking medications as prescribed	30	9%
	Tried quitting alcohol/drugs	34	10%
	Feel guilty about drug/alcohol use	39	11%
	Have abused drugs/alcohol in the past year	45	13%
	Other	0	0%
	No affect/issue (not applicable)	28	8%
	Did not answer this question	195	56%

The findings from this question are consistent with previous needs assessment findings showing that for those PLWHA who are struggling with substance abuse the negative impact on continuity of medical care is significant as are the personal struggles reflected by the responses. As noted previously in this report, mental health, housing and socioeconomic issues are intertwined. The value of examining individual needs and barriers is predicated upon the extent to which the individual issue is considered in the context of an overall picture of needs.

This question attempts to measure the impacts of substance abuse on continuity of care rather than quantifying the scope of substance abuse among PLWHA. Note that Table 44 provides a response to the question of how many PLWHA perceive a need for substance abuse service (21%). This is consistent with the approach and findings in previous needs assessments where approximately 80% of respondents indicate “no need” for substance abuse service. Note that 56% of respondents chose not to answer this question. Based upon focus group comments it is clear this is a sensitive subject that many PLWHA do not wish to discuss. However, a frequent point of feedback regarding the survey design was that many questions lacked a “not applicable” option. While this question does have “No affect/issue (not applicable) as the next to last option, based upon the number of questions during survey sessions it is believed that the placement of this option and the wording may have contributed significantly to the large number of respondents who did not answer the question.

The Part B needs assessment survey found that 45% of participants reported a history of street drug alcohol abuse. The Part B report states “*The majority of participants who report current drug or alcohol use indicated they were not interested in any type of treatment program and did not need to improve*.”

Access and Barriers to HIV Medical Care

Table 323: Overall Health of Respondents

		Count	Column N %
Level of overall health	**TOTALS**	**346**	**100%**
	Very Good	86	25%
	Good	134	39%
	Fair	93	27%
	Poor	20	6%
	Illegible/Incomplete	1	0%
	No Response	12	3%

The positive result of HIV care is evidenced in the response to the question of overall health, with 64% of respondents describing their health as good to very good. This measure should be considered in the context of the fact that survey respondents were largely in care (only 5% of survey respondents indicated they did not receive medical care).

Table 334: Medical Care Status of Respondents

Received medical care during the last six months	**TOTALS**	**346**	**100%**
	Yes, I received all the medical care I needed	286	83%
	I needed more medical care than I received	23	7%
	I did not receive medical care	**19**	**5%**
	Illegible/Incomplete	4	1%
	No Response	14	4%
Reason you did not receive or seek HIV medical care in the past six months	**TOTALS**	**19**	**100%**
	Did not know where to go	0	
	Could not get an appointment	1	5%
	Could not find transportation	0	
	Could not afford it	0	
	Could not find child care	0	
	Other things on my mind, other priorities	2	11%
	Did not want anyone to know I was HIV+	0	
	Did not feel sick	4	21%
	Other reason for not seeking/receiving HIV care	8	42%
	No Response	4	21%
Where do you regularly receive your HIV medical care	**TOTALS**	**346**	**100%**
	HIV clinic for HIV+ clients, such as David Powell	234	68%
	Emergency room, hospital	14	4%
	Community clinic	54	16%
	Private doctor	36	10%
	Private clinic	19	5%
	VA clinic, hospital	4	1%
	N/A - Did not receive HIV-related medical care	6	2%
	Other	1	0%
	No response	9	3%

The proportion of PLWHA who receive their medical care from various sources is consistent with previous needs assessment findings. In 2005 13.9% of respondents indicated they received care from a private doctor compared to 15% (10% private doctor and 5% private clinic) in this survey.

No specific insight was obtained via focus groups into the reason 7% of respondents said they needed more medical care than they received. However general input from focus groups suggests that barriers such as homelessness, mental health and substance abuse were contributing factors rather than any direct limit in availability of medical care.

Table 345: Prescription Adherence by Respondents

Currently taking HIV medications prescribed by doctor	**TOTALS**	**346**	**100%**
	Yes	310	90%
	No	**23**	**7%**
	No Response	13	4%
Doses of medication missed in the last three days	**TOTALS**	**346**	**100%**
	(0) None	211	61%
	(1) One	47	14%
	(2) Two	27	8%
	(3) Three	14	4%
	More than (3) three	11	3%
	Not Applicable - Not taking Meds	22	6%
	Illegible/Incomplete	2	1%
	No Response	12	3%
Reason you are not taking prescribed HIV medications	**TOTALS**	**23**	**100%**
	Not currently prescribed HIV medications	8	35%
	Do not know where to get prescription filled	0	
	Difficulty getting a refill	1	4%
	Cannot afford the medications		
	Cannot afford medication copays	2	9%
	I feel healthy	5	22%
	The medications make me feel sick	1	4%
	Self-directed drug holiday	2	9%
	Doctor-directed drug holiday	1	4%
	Worried someone will find out that I have HIV	0	
	Have trouble remembering when to take the medications	0	
	Other	1	4%
	No affect, N/A	0	
	No response	4	17%

This question was an attempt to gain insight into the rate of adherence for prescriptions. The finding that 61% of PLWHA is consistent with evidence from the local statistics for the Treatment Cascade, which suggest that Austin TGA consumers are doing a relatively good job with adherence. While no survey respondents reported that they simply forgot to take medication, this was an issue reported by a number of focus group participants. Additionally, while only one participant reported difficulty in getting a prescription refilled this has consistently been an issue reported by rural focus group participants. The rural experience is more about ability to travel to the pharmacy (including multiple trips to obtain a prescription) than it is about unwillingness of the pharmacy to fill a prescription.

There is no indication from the needs assessment that lack of availability of medical care or medication is prohibiting consumers from obtaining medical care.

Dental Care

Table 356: Dental Care

		Count	Column N %
Received HIV dental care in the last year	TOTALS	346	100%
	Yes, I received all the dental care I needed	206	60%
	I needed more dental care than I received	34	10%
	I did not receive dental care	***86***	***25%***
	Illegible/Incomplete	2	1%
	No Response	18	5%
Reason you did not seek or receive HIV dental care in last 12 months (Clients can indicate more than one response)	TOTALS	86	100%
	Did not know where to go	12	14%
	Could not get an appointment	10	12%
	Could not find transportation	6	7%
	Could not afford it	12	14%
	Could not get child care	1	1%
	Had other things on my mind, other priorities	19	22%
	I did not want anyone to know I was HIV+	1	1%
	Did not feel sick	5	6%
	Did not need dental care	28	33%
	Other reason for no dental care	6	7%
	No affect, not applicable	0	0%
	No Answer	3	3%

The survey findings suggest that dental care is generally available to those consumers who want the service. While 10% of respondents indicated that they “needed more dental care than they received”, based upon focus groups comments this finding may be related to the need for services beyond basic dental care (periodontal gum disease, restorations etc.) and reluctance by consumers to follow through with more involved dental procedures than it is to availability of service. Note that 22% indicate they “had other things on their mind” and 33% indicated they did not need dental care.

Need for Services

The final portion of the written survey was designed to measure the need for services and the extent to which this need was met. For each of the following service areas, a "grid" asked the same 5 questions:

- Did the consumer know about the service
- Did the consumer need the service
- Importance of the service to the consumer on a 5 point scale
- Did the consumer ask for the service
- Did the consumer receive the service

As noted in the Introduction section of this report, there tended to be some trail off of responses for the grid questions. Perhaps one in 10 respondents needed assistance in following the format of the grid but with rare exception respondents followed the concept once they answered the first set of questions on the gird.

There is also some inconsistency between the responses to questions presented in sections above with the number of people who indicate they received the (same) service. For example only 198 respondents said they received drug assistance, while in the previous question 310 reported taking their prescription in conjunction with medical care. Thus the numbers in this section have value from the standpoint of measuring relative importance of services rather than a true quantification of service usage.

This survey did not attempt to have consumers rank all services in a competing manner. Rather the survey simply asked the respondent to rank the importance of the survey on a scale of one to five. A well-documented limitation of needs assessment surveys is the fact that consumers tend to take for granted the service needs that are met and to rank higher those service needs than are unmet. That trend was evident with this survey.

It is also important to keep in mind that the Ryan White Program definition of a service (what services are covered) is in some cases quite different from what a consumer has in mind when they think about a service category. A key example is legal services. The scope of what Ryan White will cover in legal services is relatively limited while the scope of needs of consumers for legal assistance is quite broad. The ranking list must be considered in this context.

Table 367: Consumer Ranking of Services

SERVICE	AVERAGE IMPORTANCE RATING	TOTAL RESPONSES WITH RATINGS
HIV medical care	4.75	139
Drug Assistance	4.55	131
Dental Care	4.52	130
Food Bank	4.48	136
Case management - help to get to appointment	4.22	139
Case Management - short term assistance on one issue	4.21	130
Health Insurance Assistance	4.16	119
Housing	4.12	130
Transportation	4.07	130
Nutritionist Services	3.98	122
Mental Health Services	3.69	122
Case management - medication reminders	3.67	129
Legal Services	3.64	121
Outpatient substance abuse service	3.32	122
Hospice	3.26	108
Residential Substance Abuse	3.21	114
Personal Care at Home	3.09	120
Translation Service	3.05	119
Child Care	2.84	105

Table 37 provides the relative ranking of services based upon survey responses. Note that respondents were not asked to rank services (relative to other Ryan White services) but rather to rate the importance of each service individually.

An alternative method of evaluating need is to consider the number of respondents who said they need the service and compare that number to the percentage of unmet need. Ironically the top ten services remain the same, with some variation in order.

Number of Consumers who Said they Need Service

1. Medical Care 243
2. Food Bank 234
3. Case Management 210 (help with appointment)
4. Drug Assistance 209
5. Dental Assistance 199
6. Transportation 173
7. Housing 167
8. Health Insurance 153
9. Nutrition Service 143
10. Mental Health 132

Services with Largest Gap in Need

1. Housing 16%
2. Transportation 12%
3. Health Insurance 9%

4. Health Insurance 9%
5. Legal Assistance 9%
6. Food Assistance 8%
7. Case Management 8%
8. Medical Care 5%
9. Mental Health 3%
10. Nutrition 3%

Primary Care Services

Medical Care

Table 38 shows the responses to questions regarding the need for primary medical care. The responses verify that need for medical care is being met. It should be noted that during survey sessions a number of respondents pointed out that they did not need to ask for medical care because their case manager/nurse routinely schedule them for their next appointment without the need to ask. Since 91% of respondents indicated they are currently receiving medical care, it is unclear why on 75% reported they received medical care services. Based upon questions during survey sessions there appears to be some confusion regarding this question.

Table 378: Need for Medical Care

	Know about this Service		Need This Service		Asked for This Service		Received this Service	
	Count	Column N %	Count	Column N %	Count	Column N %	Count	Column N %
HIV Medical Care	299	86%	243	70%	238	69%	260	75%

Drug Assistance

As with the response to medical care, there was clearly confusion with the response to this question. As noted in Table 33, 310 (90%) respondents indicate they are taking prescribed medications. Based upon question from respondents during survey sessions the understanding of this question related to <u>applying</u> for drug assistance. Respondents in ongoing medical are who receive medications without physically going to a service provider to actively apply for assistance did not perceive this question as relating to their supply of medication.

Table 3938: Need for Drug Assistance

	Know about this Service		Need This Service		Asked for This Service		Received this Service	
	Count	Column N %	Count	Column N %	Count	Column N %	Count	Column N %
Drug Assistance	249	72%	209	60%	189	55%	198	57%

Dental Services

Table 390: Need for Dental Services

	Know about this Service		Need This Service		Asked for This Service		Received this Service	
	Count	Column N %	Count	Column N %	Count	Column N %	Count	Column N %
Dental Services	261	75%	199	58%	190	55%	180	52%

Health Insurance

As is the case with other "need" questions, responses to this question must be viewed in the context of what respondents perceived the questions to mean. Only consumers who encounter co-payments as a result of private insurance or Medicare have occasion to apply for assistance in covering unmet costs of medical care or prescriptions. Based upon questions during survey sessions it does not appear that those consumers who reported insurance coverage from sources that do not entail personal contributions considered this question from a Ryan White service perspective.

Table 401: Need for Health Insurance

	Know about this Service		Need This Service		Asked for This Service		Received this Service	
	Count	Column N %	Count	Column N %	Count	Column N %	Count	Column N %
Health Insurance Assistance	180	52%	153	44%	129	37%	121	35%

Table 412: Need for Mental Health Care

	Know about this Service		Need This Service		Asked for This Service		Received this Service	
	Count	Column N %	Count	Column N %	Count	Column N %	Count	Column N %
Mental Health Services	217	63%	132	38%	127	37%	120	35%

Survey findings indicate that the need for mental health services is quite high, with nearly 4 out of every 10 consumers reporting a need for mental health service. The number of PLWHA who indicate they need mental health services (38%) is identical to the responses to previous needs assessments. What is notably different is the finding that only 3% of respondents who indicated they needed the service report that they did not receive service.

Hospice

Table 423: Need for Hospice Care

	Know about this Service		Need This Service		Asked for This Service		Received this Service	
	Count	Column N %	Count	Column N %	Count	Column N %	Count	Column N %
Hospice/End of Life Services	129	37%	40	12%	40	12%	39	11%

The 12% of consumers who report needing hospice service is notably higher than found by previous needs assessment surveys, which averaged 4%. Surveying the need for hospice service is a challenge. First, many PLWHA are not familiar with the service definition. “End of life” was added to the description in an effort to clarify. Nevertheless survey session questions continued to point to confusion. Second, a portion of PLWHA who in fact utilized hospice service were terminal and thus not part of the survey. While the eligibility criteria for hospice service includes a requirement that a doctor certify that the consumer is terminal, the reality is that a significant portion of consumers who receive hospice service experience significant improvement in their medical condition and are no longer classified as terminal. This outcome is the result of the fact that many of the consumers who enter hospice service have either never received medical care or have been out of care long term. Once these “terminal” consumers begin receiving medication, they respond positively to the medical care. It is unclear how many of the 39 respondents who say they received hospice service fall into this category. A recommendation for future surveys is to ask a follow up question.

Nutrition Service

Table 434: Need for Nutrition Service

	Know about this Service		Need This Service		Asked for This Service		Received this Service	
	Count	Column N %	Count	Column N %	Count	Column N %	Count	Column N %
Nutritionist Services	225	65%	143	41%	130	38%	131	38%

Forty-one percent of respondents reported a need for nutritionist service with 38% reporting they asked for the service and the same percentage indicating need was met. The findings suggest this service need is being met. Previous needs assessments have found 58% of consumers reported a need for nutrition counseling. It is unclear if asking about the need for a nutritionist instead of nutritional counseling had a bearing on the responses. The survey includes a significant number of respondents who utilize the food bank of a key provider which has a nutritionist on staff. However only 65% of respondents indicated they know about nutritionist service. This finding suggests the need to better advertise the availability of nutritional counseling.

Case Management

Table 445: Need for Case Management

	Know about this Service		Need This Service		Asked for This Service		Received this Service	
	Count	Column N %	Count	Column N %	Count	Column N %	Count	Column N %
Help to get you an appointment	262	76%	210	61%	185	53%	183	53%
Remind you to take your medications	178	51%	114	33%	92	27%	106	31%
Provide you with short-term help with a single issue	208	60%	178	51%	148	43%	149	43%

Case management is a service for which consumers are well familiar. The only confusion comes when discussing the various funding sources associated with case management. Consumers are not familiar with distinctions between medical and not-medical case management. Consequently, consistent with previous needs assessments the survey simply asked about case management. However, unlike previous needs assessments which only asked about case management from an overall service standpoint, the current survey asked three specific questions about specific case management services: (1) did a case manager *help you get an appointment* (2) Did a case manager *Remind you to take your medications* and (3) Did a case manager *provide your with short-term help with a single issue*. The findings provide insight into the types and level of case management services being received and most importantly the relative importance consumers place on the need for each type of service. (See Table 37 for respondent rankings). Note that while help with appointments and assistance with a single issue ranked 5th and 6th respectively, respondent ranked *reminder to take medication* much lower.

Without doubt the survey question that resulted in the most questions and confusion by respondents was the question "*Provide you with short term help with a single issue*". Even when the question was explained to those who asked about the question, it was clear that some consumers were never comfortable with the wording and unsure on the intent of the question.

ARIES utilization indicates that 72.2% of consumers received case management service (*all funding* level statistic). The finding that only 53% of consumers received case management service is not consistent with the known level of utilization. However this is undoubtedly due to the fact that the survey broke services into types rather than asking only if the respondent received case management. Thus a direct comparison between the 72% receiving case management and the 53% responding is not valid as a direct comparison.

While case management was not a topic of focus groups, the assistance consumers receive from case managers was a point that frequently came up during discussions. Based upon the comments made by participants it is quite clear that they see the assistance of case managers as a vital component of their care. Specifically, focus group discussions emphasized the importance of case manager interaction as a source of information regarding availability of services and linking to services. Statements alluding to a

high degree of dependence upon case managers for information and direction were made by several focus group participants.

It is noteworthy that 84% of Part B respondents reported use of case management services and 30% indicated the need for additional services (increased communication, a 24 hour crisis line and changes in income eligibility to enable higher income consumers to receive case management service).

Substance Abuse

Table 456: Need for Substance Abuse Service

	Know about this Service		Need This Service		Asked for This Service		Received this Service	
	Count	Column N %	Count	Column N %	Count	Column N %	Count	Column N %
Outpatient substance abuse counseling	177	51%	72	21%	56	16%	61	18%
Residential substance abuse treatment	134	39%	49	14%	40	12%	36	10%

Responses to the substance abuse question are curious when considered in the context of ARIES utilization data. According to the ARIES reports for the year ending February 2013 only 7% of consumers received outpatient substance abuse service and .007% received residential substance abuse service. Thus the numbers of consumers who report receiving both inpatient and outpatient service appears somewhat high given the survey sample size, even considering additional funding sources beyond Ryan White. However, respondents may not have formal substance abuse service in mind when they answered the survey question. Based upon interaction with respondents during survey sessions and focus group discussions, it appears that consumers may be including support they receive from various support groups and case management discussions that touch upon substance abuse.

Supportive Services

Several key support services were included in the grid portion of the survey in an effort to better understand the consumers need for these services.

Medical Transportation

Table 467: Need for medical transportation

	Know about this Service		Need This Service		Asked for This Service		Received this Service	
	Count	Column N %	Count	Column N %	Count	Column N %	Count	Column N %
Medical transportation	239	69%	173	50%	142	41%	131	38%

Transportation is one of the better understood service needs. While the survey question specifies medical transportation, respondents are influenced in their responses by the fact that large numbers of consumers have basic unmet transportation needs. Respondents do not necessarily separate out transportation for medical appointments from other travel. Also, consumer concerns with Cap Metro and Metro Access (transportation for the disabled) continue to be a well-documented and emotional issue. (The Cap Metro issue goes well beyond funding Ryan White service). The needs assessment findings reinforce two key points:

- This service need cannot be resolved simply through additional funding.
- The needs and challenges of rural consumers are quite different than those served by Cap Metro.

Note that transportation continues to be a frequently cited reason for missed appointments. Input from focus groups reinforced a key issue regarding medical appointments – PLWHA often have good and bad days from a medical aspect. Bad days cannot be predicted. There are times when consumers miss an appointment because they are just unable to make it on the scheduled day. The inability to travel on a "bad" day is influenced to a large degree by the effort required to travel via Metro Access. This is not a funding issue.

While there are clearly differences in the transportation needs and challenges of more rural clients, it is worth noting that 88% of Part B survey respondents reported utilizing transportation services and half (44%) reported adequate transportation service was unavailable.

Child Care

Table 478: Need for Child Care Services

	Know about this Service		Need This Service		Asked for This Service		Received this Service	
	Count	Column N %	Count	Column N %	Count	Column N %	Count	Column N %
Child care	76	22%	28	8%	21	6%	19	5%

Since this is not currently a funded Ryan White service and based upon checks with service providers no formal child care service is being provided (related to or medical care appointments), it is unclear what child care service the 19 respondents who say they receive the service are referencing. Survey demographic data shows approximately 15% of households include of one or more minors. This percentage is consistent with ARIES data. A previous needs assessment studied the need for child care in depth and confirms a need for child care service. Based upon this previous study, approximately 9% of households have a minor of an age that precludes the child from being left alone while the consumer travels to a Ryan White service appointment. Thus there is a clearly established need for child care service by a small population of consumers. While the numbers of consumers in need is relatively small, the implications of child care as a barrier to medical care is quite clear, especially for mothers and grandmothers who place the needs of the child above their own needs. However, this is a complex problem that much like transportation cannot be resolved simply by finding this service. Essentially,

finding a service provider willing to deliver child care service is challenging. But more problematic is the fact that for consumers who must travel by public transportation to reach a medical appointment, adding the logistics of getting the child to the child care provider makes the process unrealistic in the view of most consumers. Thus while the need for this service is established, a practical service solution has not been identified that would allow the Planning Council to fund this service.

Food Bank

Table 49: Need for Food Bank Service

	Know about this Service		Need This Service		Asked for This Service		Received this Service	
	Count	Column N %	Count	Column N %	Count	Column N %	Count	Column N %
Food bank	284	82%	234	68%	200	58%	207	60%

The need for food bank service is well established as demonstrated by the findings shown in table 49 above. Note that respondents ranked food bank as the top support service (4th overall). Food and housing are two of the basic needs consumers consistently cite that create barriers to care when those needs are unmet. Because non-disabled adults are not eligible for the Supplemental Security Nutrition Program (Food Stamps) the food bank provides a vital service to consumers within the TGA. It should be noted that a number of non-profit and faith based organizations operate food banks within the TGA, and (as confirmed by participants during focus groups) consumers frequently utilize more than one food bank service. What is more difficult to measure is how the collective need of low income citizens balances against the availability of food within the community. Regardless of the number of sources, the need for Ryan White funded food bank service is well established. It is important to note that food banks funded by Ryan White are linked to Nutrition Service and supplement diets appropriate for PLWHA. Also, food banks provide essential personal hygiene items.

Legal Services

Table 480: Need for Legal Service

	Know about this Service		Need This Service		Asked for This Service		Received this Service	
	Count	Column N %	Count	Column N %	Count	Column N %	Count	Column N %
Legal services	176	51%	121	35%	98	28%	82	24%

This service category is not currently funded by Ryan White. The service is being provided via other funding sources. Respondents rated the need for legal services as 13th on the priority rating. The number of people who indicated they need legal service is 35%, which suggest this is an area of significant need. However, as stated previously in this report, when consumers are interviewed to learn the nature of their legal needs, the majority have legal needs that are not within the scope of the Ryan White service category. The most important legal need as it relates to HIV care is the need for assistance with appeals of Social Security and/or SSI denials. Based upon interviews with respondents it appears that this specific legal need is being addressed.

Translation Services

Table 491: Need for Translation Service Needs

	Know about this Service		Need This Service		Asked for This Service		Received this Service	
	Count	Column N %	Count	Column N %	Count	Column N %	Count	Column N %
Translation services	126	36%	71	21%	64	18%	50	14%

Translation service is not currently funded by Ryan White. According to the information provided by Ryan White service providers, translation service is being provided via services such as Language Line and through use of bi-lingual staff. Since translation service is not being billed as a separate service the cost is being "absorbed" as part of service provider indirect costs. The needs assessment findings indicate that 21% of respondents have a need for this service. Thus the need for translation service appears to be significant but the need is being addressed.

Housing

Table 502: Need for Housing Service

	Know about this Service		Need This Service		Asked for This Service		Received this Service	
	Count	Column N %	Count	Column N %	Count	Column N %	Count	Column N %
Housing services	186	54%	167	48%	146	42%	109	32%

The fact that 48% of consumers reported a need for housing assistance is indicative of the level of unmet need for this critical service. While Ryan White Part A is not currently funding housing, HOPWA, City of Austin General Fund, and numerous other agencies and funding sources provide housing assistance. Nevertheless it is clear that the available funding and service infrastructure is inadequate to satisfy need. It is equally clear that housing and food stand out as vital needs that (when unmet) constitute formidable barriers for continuity of care. The level of need reflected here must be considered in the context of the barriers to housing described above. For consumers who face barriers as a result of their background (incarceration, bad credit, sex offender etc.) this need cannot be met simply through additional funding for housing.

The Part B survey found that 44% of respondents had a need for short term housing and utility assistance, making housing the top need for "other" services among Part B respondents.

Home Care

Table 513: Need for Home Care

	Know about this Service		Need This Service		Asked for This Service		Received this Service	
	Count	Column N %	Count	Column N %	Count	Column N %	Count	Column N %
Person who takes care of you at home	101	29%	53	15%	38	11%	33	10%

The 15% of respondents who report a need for home health care is consistent with previous needs assessments that found 13% of consumers need the service. Home Health Care is not currently funded by Ryan White. While daily in home medical care is not a service offered by local HIV providers, non-profit volunteer organizations such as The Care Communities do provide basic in home (non- medical) assistance. It is unclear what home care service respondents are reporting that they received but undoubtedly includes assistance from The Care Communities and also case management related home visits and “wrap around” support services associated with developing independent living skills. Note that respondents had neither a definition nor scope description for home care, nor any knowledge of eligibility criteria to qualify for home care.

Focus Group Findings

Focus groups were conducted to obtain insight into needs of the HIV community that cannot be obtained from written surveys. While the information obtained from focus groups is subjective, the insight gained from focus groups is an essential compliment to written survey data. The insight into key issues provided by focus group participants is invaluable in understanding the challenges and perspectives faced by key priority populations. As discussed in the Methodology section of this report, invariably the discussion in every targeted focus group touched upon to the same basic needs and challenges: housing, food, transportation, stigma and social isolation. Perhaps even more revealing was the fact that in every group a sense of frustration and hopelessness was expressed. One participant said "*Sometimes you just get tired of dealing with it and just want to give up*".

A total of six focus groups were conducted focusing on target populations and issues:

- Aged (55+)
- Homeless
- Substance abuse and mental health
- African American
- Hispanic

A summary of the discussions for each group is presented. Points made by focus group members are generally summary statements resulting from group discussions. Individual quotes are provided for emphasis where the quote provides unique insight into an issue.

It is important to consider human nature and the dynamics of focus group discussions when reviewing comments in this section of the report. It is human nature to vent about problems consumers face and to focus on needs that are not met. Indeed participants in two focus groups expressed the feeling that the session had been therapeutic by allowing them to talk and feeling like someone cared about what they thought. Nevertheless, consumers did express gratitude for services they receive and for the provider community that delivers those services.

Aged (PLWHA+55) Focus Group

This focus group consisted on one Hispanic male, three Black males and three Black females ranging in age from 55 to 68. All of the participants have been HIV+ for more than 20 years and all but one of the participants have a long term AIDS diagnosis.

- Two participants indicated that despite their long term HIV status they have not told friends or relatives. The group discussed experiences resulting from revealing their status and the stigma and rejection they have encountered. One participant shared an experience where he was fed Thanksgiving dinner on a paper plate while all other family present ate on china. The psychological scar of his experience was quite apparent. One participant stated "I*t's different now than when it first started, but a lot of people are still ignorant*".

- Participants discussed the impact of stigma to their mental health. One participant reported taking medication to deal with apprehension and depression. Several participants reported

significant stress and depression. Several of the participants who are Black indicated that racial prejudice is compounded by HIV status "*Racial prejudice is part of the stigma that frustrates you*".

- Several participants discussed the fact that they can't afford to get sick as a result of their compromised immune system. They indicated they must be constantly on alert to avoid people who are sick. "*Just catching a cold can put me in the hospital or kill me*". One participant indicated he is aware that he is developing dementia as a long term impact of living with AIDS.
- One participant spoke of the complexity of managing his care in light of numerous medical issues. He indicated he is overwhelmed with the responsibility of managing medications and instructions from multiple specialists and frustrated by the pressure he is receiving from his case manager be more independent.
- Several participants expressed a sense of personal responsibility for living a lifestyle that resulted in acquiring AIDS. "*I guess I am being punished for my past*". They also expressed frustration and anger with those who knew they were HIV positive and engaged in unprotected sex in callous disregard for others.
- Several participants expressed frustration with HIV service providers. Comments indicated a complicated relationship with their case managers, characterized by a sense of dependency while also expressing frustration with how they are treated. "*They tell you what they want you to know*". "*They never have the time to talk to you – they are just worried about filling out their forms*". There was a consistent feeling expressed that agencies don't care if you understand or not: "*They talk at you, no to you*".
- Participants discussed the varied quality of service they receive from specific providers. There was a clear consensus that some agencies are "*in their own world*" and focused on "*what they do and the way the want to do it*". The implication being that several HIV providers are in a silo with respect to being aware of the overall needs of the community.
- It was clear from discussions that several participants do not understand the eligibility rules and policies related to specific agencies and frustration in not being told in a clear and understandable manner why they are not eligible. Several expressed the feeling that treatment of clients is selective. One participant indicated he no longer receives needed services "*because of my T cell count*" (he did not understand the implications of this T cell count on eligibility).
- It was also clear that several participants who have received HIV services long term are members of a community that know each other and what level of income and resources others have. The belief is that agencies do not always do a fair job in enforcing eligibility rules and being fair in distribution of services. They are aware of what services others receive and have the perception that agencies unfairly provide services to favorites who they believe get more than their fair share.

- Participants expressed frustration with the implications of periodic availability of funds (at agency level). The belief is that it is a matter of chance that the point at which an individual needs a given service coincides with the time an agency has funding. "*Funds run out when you need help the most. They said I was eligible for rent assistance for 3 months but when the doctor finally scheduled the surgery they did not have funds to help me*".
- Participants discussed the fact that a consequence aging and of living with HIV/AIDS long term is the complications of co-morbidities. All participants reported having multiple medical issues in addition to AIDS. Several indicated that medical care for other conditions was lacking. One participant indicated that he is diabetic and that his insurance won't cover the testing strips.
- Aged participants also pointed to ironies of HIV care. Only when your HIV status has progressed to AIDS and your health has deteriorated are you eligible for disability assistance. (Participants are referencing financial support, not access to HIV medical care).
- When asked what recommendations the group had for assisting the aged population, participants said: "*Walk a mile in our shoes*"; *Let the community speak to get the message out to the media*"; and "*Advocate for us with the right people who have the power*". "*Don't neglect us – it's hard when you get old*"

Homeless Focus Group

The homeless focus group consisted of five participants who were either homeless at the time of the session or who reported being homeless in the recent past. All were males ranging in age from 41 to 53. Current living arrangements ranged from living in a friends garden, to living in shelters. Most reported moving from place to place where friends or relatives would let them sleep on their couch a day or two at a time. The housing situation for all participants involved long term instability.

Without question no focus group exemplified the cumulative effect multiple socio-economic issues has upon adherence to medical care. While all five were selected for the homeless focus group, all five could also have been in the substance abuse/mental health group. Being homeless is only one of several significant challenges they face.

The fundamental outcome of this focus group is the realization that homelessness is a complex issue that cannot be resolved simply by more funding for housing. All five participants related their personal experiences with staying in shelters, residing in low income housing units and "rough" neighborhoods characterized by crime and drugs. All five said emphatically that they would rather sleep in a camp in the woods than stay in a shelter. Essentially, they felt safer and more at peace on the street than they do in a shelter or temporary housing facility.

- All five reported a criminal background that is a major barrier to passing a background check to get into either government sponsored or private apartment rental. Three acknowledged previous unpaid rent and/or utility bills that likewise prevent approval for future housing.

- Participants spoke of the cumulative stigma and mental anguish that comes from being identified as homeless and HIV positive. Three of the five were Black and felt that racial prejudice only added to the problems of being homeless.
- All five spoke of being lonely, feeling ostracized, rejected and "*just worthless in most people's eyes*". The group suggested the feeling of being at peace when camping alone is a way of escaping from the way others treat them.
- Varied opinions were expressed regarding shelters and organizations providing food and homeless serviced. "*I can't stand shelters. People are always stealing your stuff or trying to force you to have sex and take drugs*". Participants suggested shelters are a bad environment because "*when you get a bunch of homeless guys together bad things happen. It doesn't take long for someone to start talking about getting a drink and having sex*". However one participant indicated shelters provide a sense of community. "*No one is judging your there. You can talk to people*".
- Three of the five reported that homelessness is the reason they became infected. "*You don't understand – having a bed for the night in someone's place is not the same as having a home. They invite you to stay with them for a reason*". "*You will agree to do a lot of things when you are hungry and cold*". "*After a time you just don't care*" (all participants nodded in agreement at that statement). Participants also suggested than low self-esteem and homeless stereotypes contribute to the "don't care" attitude.
- All five participants described a background that includes residing in a low income neighborhood permeated by crime, drugs and prostitution. All five made it clear that homelessness is a choice they have made in order to escape low income neighborhoods.
- All participants reported receiving medical care on a very sporadic basis. One participant is now on renal dialysis three times a week and thus now receives consistent medical care for HIV. However, even that participant indicated it was a challenge to remember to take his medication at the right time. "*You have to understand that it is an effort just to survive*".
- Participants also spoke of transportation as a barrier. They are clearly confused about what agencies have told them regarding their eligibility for bus passes.

Substance abuse and Mental Health Focus Group

These two topics were merged by the Needs Assessment Committee. This was an extremely difficult group to recruit. Nevertheless this was the largest focus group with seven participants owing to the opportunity to leverage a mental health support group meeting. The merit of combining the two topics was validated by the fact that all seven reported problems with substance abuse in addition to the need for mental health care. In fact, the two issues were found to be very much interrelated for the focus group participants. Three participants were women and four were men. All have lived with HIV/AIDS long term. Ages ranged from late thirties to late fifties.

This was also the most difficult group to engage in open discussion regarding the topic. Several participants had the propensity to dominate the conversation while others were withdrawn. Ultimately some of the input from the more withdrawn participants provided the best insight into issues. Facilitating this focus group was delicate at certain points owing to the fact that some participants' mental condition necessitated moving on from a topic when discussion resulted in agitation or otherwise became unproductive from a needs assessment standpoint.

- As with every focus group lack of resources and the struggle to provide for basic living needs was a point of discussion. However, what was different in the comments of this group was the criminal background participants reported. The common theme is that illegal drugs are expensive and the lifestyle led to crime and repeated incarceration. While the focus group was not directed at incarceration, a fair amount of the discussion related to incarceration experiences. Two consistent points came from incarceration experience. First, unprotected sex is a frequent experience without regard to HIV status. Second, HIV medical care while incarcerated is inconsistent.
- One participant indicated he became HIV positive while incarcerated. Others reported unprotected sex and rape. "*No one talks about their status and no one cares*".
- The remaining five participants indicate they acquired HIV/AIDS as a result of drug use. One indicated she turned to prostitution to pay for drugs and acquired HIV as a result. "*When you need to get high you do what you have to*. *Nothing else matters*".
- Several issues reported by participants were common to other focus groups. Feelings of loneliness, desperation and hopelessness were frequently mentioned. Participants made it clear that drugs provide an escape from those negative feelings and thus the lure to repeatedly use drugs is compelling. "*All that stuff they tell you in the support group sounds right, but when you want to stop the pain you can't help yourself. You know that even when they are telling you all that stuff*".
- One participant indicated that while he feels a responsibility to not expose others to HIV, he also fears rejection if he reveals his status. Consequently he indicates he has had unprotected sex on occasion with the realization that he is risking his partner. Another participant replied "*You are not the only one. We all do that sometimes*." The group suggested this is a much a fear of rejection and loneliness as it is sex drive.
- Perhaps the most compelling insight came from discussions about behavior and attitudes. When asked about receiving prevention education one participant said "*You don't get it. Sex is incredible when you are high and it is better bareback. You are never going to stop the spread of HIV because people don't want to use protection when they are high*". (A particular drug was referenced which is taken every few minutes to maintain the experience). There was general consensus by the group that people just don't care when high.

- Several participants reported being bi-polar and indicated that the side effects from the medications limit their ability to function. Two participants reported that medication causes mental confusion and that they either forget to take HIV medications or take them at incorrect intervals. Based upon statements made several participants appear to be receiving medical case management to assist with their care. However they also recognized that they are experiencing mental confusion and memory loss which makes adherence to medical care challenging regardless of support they may be receiving. "*A lot of times I just don't remember and I get upset if I think about it, so I try not to*".
- Several participants noted the importance of support groups and counseling to their mental health and recovery. "*I am very grateful for the help I receive. I would be lost without it*".

African American Focus Group

There was overwhelming interest among consumers in participating in this focus group as a result of the gift cards. The group consisted of six participants, three women and three men. (Two other participants missed the session because Cap Metro was late). Ages ranged from late forties to early sixties. All have been living with HIV/AIDS long term and all are in care. Note: This session was facilitated by Joseph Collins, a minister and former Planning Council member.

- Several participants indicated that one of the most significant problems they face on a daily basis is the physical consequences of living long term with HIV and the side effects of antiretroviral medications. The group mentioned three primary problems that all found a challenge: Joint pain, weight gain and depression. Depression was cited as a consequence of living with pain long term. "HIV affects every area of your life". "Stress leads to other issues".
- All three women indicated weight gain as a serious side effect. They noted that in turn being overweight brought on other medical consequences. The group agreed that the medical problems are a major reason for the stress they live with.
- Several participants indicated that depression is the most disabling medical issue they face. They acknowledged "self-medicating" with illegal drugs because their primary either does not treat their depression or the medication they receive is ineffective. "*Sometimes you just can't take it anymore and need to escape even for a while*". Participants said self-medication meant turning to drugs, alcohol, sex, food or sleep (sleeping more than normal). Others discussed relying on prayer (religious convictions) or staying occupied with a positive activity.
- One participant expressed dismay that the self-medication discussion "*sounded bad*" and wanted to make it clear that stress and depression are devastating and never ending problems that they (society) does not understand and that "*pushes to do something to help ourselves*".
- One participant noted that crack is an upper that reduces depression and that it is the one thing that helps. However he went on to say that the cost of drugs leaves your more depressed and desperate because "*you spend your rent and food money on crack*".

- The group agreed that HIV is "*harder on a woman than a man*" because African American women traditionally hold the family together. One woman said "*the way Black society is we are used to the man being gone*".
- In response to the question regarding what HIV services are not available, one woman stated "*why is there no straight man support group*". She felt there was too much emphasis on MSM support. Another woman expressed the need for HIV negative partners to be part of a support group.
- When discussing socio-economic conditions several participants mentioned what they saw as a self-defeating financial situation: "*The more money I make the more rent I owe*" (housing program where costs is based upon income). The consensus was that they can't get ahead by working harder, "*so you don't try anymore*". One participant noted that when he gets a cost of living increase in his Social Security, his SNAP (Food Stamps) goes down proportionately. "*Do they think that is a COLA*?)"
- Participants expressed frustration with housing rules that prohibit pets. Several felt pets are a comfort that could help with the isolation and loneliness they feel.
- Housing rules were a subject brought up by several participants. They noted that a criminal background keeps them from receiving services and that there is no way to escape the dilemma "*especially for those of us who are trying to overcome our past*". This same sentiment was expressed by others with regard to SNAP (Food Stamp) eligibility. The group was of the strong opinion that bureaucrats making rules don't understand the consequences of rules relative to outcomes.
- One participant noted that "*having to sell yourself to survive*" is the worst part of the "*no win cycle you are caught in*". "*It makes you want to go back to drugs*".
- In response to the question regarding what is not working relative to HIV services, one participant noted that she wants to work but "*as you get older they won't hire you*".
- One participant indicates he needs a hip replacement so he can return to work. His doctor wants to explore non-surgical options first which the participant is led to believe is due to funding. However his doctor/clinic is seemingly guarded in communicate details regarding approval for surgery. The situation is frustrating as he wants to gain full mobility and return to work.
- Several participants mentioned the eligibility process for Social Security as being a system that is in serious need of revision. They noted that being denied the first time and having to use a lawyer for the appeal "is kind of a game they play". Participants felt that it is unfair to be denied the benefits you are entitled to and that it should not have to be commonplace to require use of a lawyer.
- Several participants felt that specific doctors with the Ryan White OAMC provider have poor communication skills "*they treat you like meat and don't listen to you*".

- Participants spoke at length about the impact of funding cycles on delivery of services. Some participants feel that "*case managers are not being fair because they are worried more about spending a lump of money by a date so they don't lose the money*" (than they are about helping us consistently).
- In response to a lead-in question regarding primary barriers to care for African Americans, substance abuse was the consensus number one issue. One participant noted that that not having the support to avoid drugs "when life depresses you" is a key issue.
- The group universally stated that better access to faith based support and spiritual counseling would be of tremendous value. "*Spiritual support is more powerful that mental health support*". One service that the group believed churches are uniquely qualified to provide is giving hope through inclusiveness.
- In response to the impact of stigma on African Americans living with HIV/AIDS, the damage of personal scars was quite apparent. Several participants spoke of losing a personal relationship with a partner or family member once they reveal their HIV status. The group noted that racial prejudice is a problem they encounter, but that being ostracized by their own family is the thing that is much more devastating.
- Participants spoke at length about the ignorance they encounter regarding HIV and specifically the fear people have of contracting HIV as a result of being near them. One participant said she feels dirty when she visits her daughter and grandchildren because he daughter avoids physical contact and do things like using bleach on the shower and toilet and throwing away bedding she slept on. She indicated the most painful thing about visiting her daughter is that she is not allowed to kiss her granddaughter. "*It hurts and then drugs are my escape*".
- Another participant indicated her family "*constantly throws my HIV status in my face"*. Her four year old granddaughter told her that "*my mom says you are going to die*". Another participant said it "hurts that someone won't shake hands with you". He noted that friends avoid you once they know. Conversely, he said that "keeping a secret weighs on you."
- As with every focus group, frustration with Metro Access also came up. "*They don't understand that you have good and bad days*". (A reference to the challenge of scheduling a ride for a medical appointment and then being unable to keep the appointment due to feeling ill on the scheduled day).

Hispanic Focus Group

The final focus group was conducted to examine the needs of Hispanic/Latino PLWHA. This was the least successful focus group for several reasons. First, it was quite difficult to recruit people for this group. Ultimately the focus group consisted of only two people, one male and one female. One participant stated "we are kind of private by nature" in response to the question of why it was difficult to recruit participants. Second was the issue of language. The two participants indicated they "speak a little Spanish" but would not feel comfortable participating in a focus group conducted exclusively in

Spanish. Attempts to recruit participants for a session to be conducted in Spanish were unsuccessful despite the availability of a Planning Council member to facilitate the session. Ultimately it became apparent that there are sufficient differences in culture and experiences for those PLWHA who speak only Spanish to necessitate a separate focus group.

- Participants related the same experiences and challenges discussed by other groups. Stigma, loneliness and fear of rejection dominated the discussion. One participant has kept her status completely secret from everyone but a small circle of friends. She has no intention of telling her family. The other participant is open (if not defiant) about his status and sexual orientation but acknowledges he is completely cut off from his family and has not heard or seen any family member in over 15 years. "They could not accept me when they found out. You pay a price and move on".
- One participant suggested that a "macho image" within the culture is a major factor in the risk posed to Hispanic women. The facilitator was unable to explore this point further due to the reluctance of the participant due to personal experience.
- Both participants have left the Catholic Church. Neither feels the church is accepting of them nor supportive of their needs. Both expressed the opinion that the issue of stigma, prevention and education are held back by cultural influences including the position and absence of leadership by the church.
- One participant acknowledged having unprotected sex with a partner who was unaware of his status. He acknowledged that his need for sex and fear of rejection were more important to him at that moment than his sense of responsibility. "*When I think about it I am ashamed and regret it, but I know it happens more often than you know*". He explained the need for intimacy is more than sexual drive. "*I feel so alone. I just want to be with someone*".
- Both participants are employed and one has insurance. Coverage is described as inadequate. "*It is not enough. I don't know what I would do without your program*".
- Participants spoke about the lack of communication they have with their doctor regarding their care. They suggested doctors exhibit an attitude that "*you wouldn't understand if I told you*" and act like explaining things is a nuisance. One participant noted that most of what he is told comes from the nurse who informs him what the doctor wants to do in treatment and changes in medication. "*Why the middle man? If I have a question the nurse says she will see what the doctor says. They never do*".
- One participant asked why Hispanics were not deemed a priority group and why more resources were not directed to their needs.

The Affordable Care Act

The Committee considered ACA as a candidate for a focus group. While ACA was ultimately not selected as a priority topic, the focus group facilitator asked the group about their knowledge of ACA as a final "bonus" question. Based upon participant responses:

- Not a single participant had a clear understanding of ACA. The most common response was "*is that Obamacare*?"
- Not a single participant reported being provided the opportunity for enrollment or otherwise being approached by one of the organizations providing enrollment.
- Participants were not entirely oblivious to "Obamacare" but most of what they indicated they have heard relates to the partisan political fight over the law and the negative aspects of implementation. No one was aware of how ACA could personally benefit them or specifically that they could not obtain insurance that was previously unattainable in light of their preexisting HIV status. One participant said "*they said I don't need it – I have Ryan White*".
- It was clear case managers or other provider staff has discussed ACA with them. However, based upon comments it appears the discussion often focused upon ACA as a federal income tax penalty threat. Several said they had been helped to establish their exemption from the mandate.

Given the methodology used to explore this issue it would not be appropriate to describe participant input as needs assessment findings. Nevertheless the responses from participants are reason for concern and clearly suggest the need for a more comprehensive analysis. One conclusion is inescapable: The Ryan White Program within the Austin TGA has not done an effective job in informing consumers about ACA nor leveraging ACA as a resource consistent with the payer of last resort policy.

Recommendations for Future Needs Assessment

This needs assessment survey occurred in the midst of initial transition to ACA. Future surveys will need to explore issues beyond the effectiveness of initial enrollment. The ongoing challenge for consumers with ACA sponsored insurance will be maintaining their insurance (keeping up with premiums, covering co-payments and deductibles etc.) and the effectiveness of Part A Health Insurance service delivery. The next needs assessment will need to incorporate questions dealing with those challenges.

Recommendations

- The Needs Assessment findings demonstrate that consumers are well aware of the erratic nature of availability of some services as a consequence of the funding process. While the goal of most service categories is to deliver services uniformly over the full 12 month grant cycle that often does not happen. Consumers are confirming the resulting start and stop of service delivery has a negative impact upon Ryan White Program goals (especially those related to continuity of care). The problem is the cumulative result of an inefficient bureaucracy related to budgeting and contracting policies and procedures. The net effect of the bureaucracy is that Ryan White budgets are often in place late and by the time the funds are actually available to a service provider to begin delivering service the grant year is already well underway. The process is compounded by the fact that some funds cannot be expended and thus carried over or reallocated with the expectation of being spent in an unrealistically short period. While little can be done to resolve the fundamental inefficiency of the process short of changes to the law, it is recommended that every effort be made to ensure the problem is minimized as the process does impact consumers.

- The Needs Assessment findings confirm that transportation remains a significant challenge for many consumers and one of the top service needs where significant number of consumers report unmet need. The dominant issue with transportation is rooted in complaints surrounding Metro Access and not funding or administration of transportation as a Ryan White service. Advocating with Capitol Metro on behalf of consumers continues to be a potential key to addressing consumer issues in this area. A specific comment made by consumers during this needs assessment was an expression of hope that someone advocate on their behalf.

- What is generally lost in the discussion of transportation is the needs and challenges faced by rural consumers. Those consumers not served by CARTS have very limited options for traveling to receive medical care and to obtain prescriptions. It is recommended that the following actions be taken to assist rural consumers:

    - Review HRUA transportation policies and procedures with specific focus on options available to rural consumers. Given the current cost of fuel, the value of gas cards may be inadequate to enable those consumers who have access to a vehicle to travel by car.

    - Obtaining prescriptions by mail is now commonplace. Enabling rural consumers to obtain prescriptions by mail would address a major challenge faced by these consumers. Advocating for mail delivery of HIV medications would seem to be a logical objective.

- It is not coincidental that there is an inverse relationship between economic status and overall health. The findings show that consumers with higher incomes and stable housing tended to report their health and adherence as good or very good at a notably higher rate than consumers with lower incomes and unstable housing. Obviously this finding is neither a revelation nor a previously unknown barrier to care. But the focus group findings emphasize a fact often lost in

the assessment of need at an individual service level: *Advancing the fundamental goals of the Ryan White Program cannot be accomplished by focusing on funding and service delivery of an individual program service*. The point was made previously in this report that a homeless consumer's challenges are generally not strictly a consequence of a lack of housing. Core needs are interrelated and resolution is complex. The core needs of consumers must be addressed as a package. Since Ryan White funding is limited it is not feasible to increase funding simultaneously to all core needs. Thus the solution may be found in ensuring that service funding is accomplished with a maximum focus on Ryan White not as an individual program but rather as a piece of the overall resource safety net for the HIV community. One point made by consumers is that they recognize that agencies and services are often siloes not working collectively to maximize funds and resources. Meaningful collaboration and sharing of funding information is a key to more effective use of funds. Developing a comprehensive community wide resource inventory is recommended.

- It is recommended that a targeted needs assessment be completed by early 2015 focused on HIV positive persons who are out of care. The current needs assessment was unsuccessful in recruiting this population for either the survey or focus group participation. Gaining additional insight into those who are out of care is essential in order to determine how to best get this population into care and linked to services. A residual supply of gift cards remains available as an incentive for an out-of-care focus group.

Appendix

Written Survey Questions

1. What is your zip code? _____________

2. What is your race/ethnicity? (*Select all that apply*)

☐ Latino/Hispanic
☐ African American/Black
☐ Caucasian/White
☐ Asian/Pacific Islander
☐ Native American
☐ Multi-Racial
☐ Other

3. What is your current relationship status?

☐ Single
☐ Partner/significant other
☐ Married
☐ Divorced/separated
☐ Widowed

4. What language do you feel most comfortable speaking?

☐ English
☐ Spanish
☐ Other (specify) _____________________________

5. Are you a United States Citizen?

☐ Yes ☐ No

If ***no***, are you a documented immigrant?

☐ Yes ☐ No ☐ Prefer not to answer

6. What is your age? ________________

7. Do you have? (*Check all you have*)

☐ Phone ☐ Text messaging ☐ Internet access

8. Do you use tobacco? ☐ Yes ☐ No

9. What is the highest level of education you completed?

☐ 8th grade or less
☐ High school or GED
☐ Vocational training
☐ Some college
☐ College degree

10. Has a doctor ever diagnosed you with AIDS (a T-cell count less than 200)?

☐ Yes

☐ No
☐ Working full time
☐ Working part-time
☐ Self-employed
☐ Working off and on
☐ Not Working
  If you are ***not*** working, why not?
  ☐ Student
  ☐ Looking for work
  ☐ Disabled
  ☐ Retired
☐ Don't know

11. What year did you find out you were HIV infected? _______________

12. What is your gender?
☐ Male ☐ Female ☐ Transgender

13. What is your sexual orientation?
☐ Heterosexual ☐ Gay/Lesbian ☐ Bisexual
☐ Other/Unsure/Prefer Not to Say

14. What best describes your work situation in the last 6 months?
☐ Working full time
☐ Working part-time
☐ Self-employed
☐ Working off and on
☐ Not Working
  If you are ***not*** working, why not?
  ☐ Student
  ☐ Looking for work
  ☐ Disabled
  ☐ Retired

15. What was your total income last month?
☐ Less than $500 ☐ $1,501- $2,000
☐ $501 - $1,000 ☐ More than $2,000
☐ $1,001 - $1,500

16. How many people in your household are only supported by your income? (*Including yourself*)

How many household members are under 18? _____

17. Did you receive any of the following in the last month? (Answer for yourself and not the household)
☐ SSI (Supplemental Security Income)
☐ Disability (SSDI)
☐ Unemployment

☐ Food Stamps (SNAP)
☐ Other benefits (Specify):_______________________
18. What kind of health insurance do you have? (This could be your insurance or someone else's if you are on their plan) *(Select all that apply)*

☐ No insurance
☐ MAP
☐ Insurance through my employer
☐ COBRA (continuation from last employer)
☐ Private insurance
19. Does your health insurance cover your HIV care?
☐ Yes ☐ No ☐ Some ☐ I don't know
20. Were you in jail or prison in the past 12 months?
22. Did your receive HIV medications while in jail/prison?
☐ Yes ☐ No
21. If yes, did the jail/prison medical staff know you were HIV positive?
☐ Yes ☐ No
☐ N/A: I wasn't prescribed medication at that time
23. As part of your release from jail/prison, which of the following did you receive? (*Select all that apply*)

	From jail staff	Other organizations
☐ **Information about finding housing**	☐	☐
☐ Referral to medical care	☐	☐
☐ Referral to case management	☐	☐
☐ HIV medication to take with you	☐	☐

☐ Other (specify) ___________________________
☐ None of the above
24. In the past 6 months did you have trouble getting housing?
☐ Yes ☐ No
25. If you answered yes above, what kept you from getting housing? (Select all that apply)
☐ I didn't have money for the deposit
☐ I could not find affordable housing
☐ I had no transportation to search for housing
☐ I have bad credit
☐ I have a criminal record
☐ I was put on a waiting list
☐ I did not qualify for housing assistance
☐ I have a physical/mental disability
☐ I have substance abuse issues
☐ Other (specify) _________________________

26. Mark the columns that tell us where you live NOW and where you lived 6 months ago

Apartment/house that I rent	☐	☐
Apartment/house that I own	☐	☐
Parent's/relatives apartment/house	☐	☐
Someone else's apartment/house	☐	☐
Boarding house/group home	☐	☐
Supportive/assisted living facility	☐	☐
Half-way house	☐	☐
Psychiatric facility	☐	☐
Substance abuse treatment facility	☐	☐
Nursing home/ physical rehab	☐	☐
Homeless (on street)	☐	☐
Homeless shelter	☐	☐
Domestic violence shelter	☐	☐
Public housing (including Section 8)	☐	☐
Hospice	☐	☐
Jail/prison	☐	☐
Hotel/motel	☐	☐

Other (specify) ___________________________________

27. Think about your living situation now: Do any of the following stop you from taking care of your HIV/AIDS? (Select all that apply)

☐ I don't have a safe and private room
☐ I don't have a place to store my medications
☐ I don't have a telephone where I can be called
☐ I don't have enough food to eat
☐ I don't have money to pay rent
☐ I don't have heating/air conditioning
☐ I don't want anyone to know I am HIV+
☐ I don't feel safe
☐ Other (specify)_________________________________
☐ None of the above

28. During the last 6 months, have you received counseling or treatment for mental health or emotional issues?

☐ Yes ☐ No

29. During the last 6 months, have you been prescribed medicine for your mental health?

☐ **Yes** ☐ **No**

☐ I couldn't afford the medicine
☐ I did not know where to get them
☐ I couldn't get transportation
☐ Other ________________________

30. During the last 6 months have alcohol or drugs affected you in any of the following ways? (*Select all that apply*)

☐ I had trouble keeping medical appointments
☐ I had trouble following my doctor's instructions
☐ I had trouble taking medications as prescribed
☐ I have tried to stop taking drugs or using alcohol
☐ I feel guilty about my drug/alcohol use
☐ I have abused drugs or alcohol in the past year

31. In general, how would you describe your overall health?

☐ Poor
☐ Fair
☐ Good
☐ Very good

31. In general, how would you describe your overall health?

☐ Poor
☐ Fair
☐ Good
☐ Very good

32. Did you receive HIV medical care during the last 6 months?

☐ Yes, I received all the medical care I needed
☐ I needed more medical care than I received
☐ I did not receive medical care

33. If you did not seek or receive HIV medical care in the last 6 months, why not?

☐ I did not know where to go
☐ I could not get an appointment
☐ I could not find transportation
☐ I could not afford it
☐ I could not get child care
☐ I had other things on my mind/other priorities
☐ I did not want anyone to know I was HIV+
☐ I did not feel sick
☐ Other (specify) ______________________________

34. Where do you regularly receive HIV medical care? (*Select all that apply*)

☐ **HIV clinic for HIV+ clients (*e.g. David Powell*)**
☐ Emergency room/hospital
☐ Community clinic
☐ Private doctor
☐ Private clinic (*e.g., Blackstock, Red River, AIDC*)
☐ VA clinic/hospital
☐ N/A; I do not receive HIV related medical care

35. Are you taking HIV medications prescribed by your doctor?

☐ **Yes** ☐ **No**

36. How many doses of medication have you missed in the last 3 days?

☐ **None**
☐ 1
☐ 2
☐ 3
☐ More than 3

37. If you are not currently taking prescribed HIV medications, why not?

☐ I am not currently prescribed HIV medication
☐ I don't know where to get the prescription filled
☐ I had difficulty getting a refill
☐ I can't afford them
☐ I can't afford the co-pay
☐ I feel healthy
☐ They make me feel sick
☐ I'm on a "drug holiday" directed by myself
☐ I'm on a "drug holiday" directed by my doctor
☐ I am worried someone will find out I have HIV
☐ I have trouble remembering to take them

38. Did you receive HIV dental care in the last year?

☐ Yes, I received all the dental care I needed
☐ I needed more dental care than I received
☐ I did not receive dental care

39. If you did not seek or receive HIV dental care in the last 12 months, why not?

☐ I did not know where to go
☐ I could not get an appointment
☐ I could not find transportation
☐ I could not afford it
☐ I could not get child care
☐ I had other things on my mind/other priorities
☐ I did not want anyone to know I was HIV+
☐ I did not feel sick
☐ I did not need dental care

40. Do you have other chronic medical conditions in addition to HIV (e.g., diabetes, cancer**)**

☐ Yes
☐ No

If yes, are you receiving medical care for these conditions?

☐ Yes
☐ No

Section 2: Assessment of Need **Medical Care**	Did you know about this?		Did you need this service in the last year?		On a scale of 1 to 5 how important is this service to you? (5 is most important)	Did you ask for this service?		Did you receive this service?	
a. HIV medical care	Y	N	Y	N	1 2 3 4 5	Y	N	Y	N
b. Free or reduced cost drug assistance	Y	N	Y	N	1 2 3 4 5	Y	N	Y	N
c. Dental care	Y	N	Y	N	1 2 3 4 5	Y	N	Y	N
d. Assistance with health insurance premium co-pay	Y	N	Y	N	1 2 3 4 5	Y	N	Y	N
e. Mental Health Care	Y	N	Y	N	1 2 3 4 5	Y	N	Y	N
f. End of life (hospice) services	Y	N	Y	N	1 2 3 4 5	Y	N	Y	N
g. Nutritionist	Y	N	Y	N	1 2 3 4 5	Y	N	Y	N

41. If you did not get case management services you needed, why not? (Mark all that apply)

☐ **Yes, I received all the case management services I needed**

☐ I needed more case management services than I received

☐ I did not receive any kind of case management

Case Management Case manager services:	Did you know about this service?		Did you need this service?		On a scale of 1 to 5 how important is this service? (5 is most important)	Did you ask for this service?		Did you receive this service?	
a. Helping you get to an appointment	Y	N	Y	N	1 2 3 4 5	Y	N	Y	N
b. Reminding you to take your medications	Y	N	Y	N	1 2 3 4 5	Y	N	Y	N
c. Providing you with short term help with a single issue?	Y	N	Y	N	1 2 3 4 5	Y	N	Y	N

42. How do you usually get to the HIV services you need?

☐ Walk or ride my bike
☐ Bus
☐ My own car
☐ My friend or relative gives me a ride
☐ Taxi
☐ Van service (STS or CARTS)
☐ Case manager takes me
☐ Other
(Specify):____

43. Who pays for your transportation for medical care?

☐ I pay (include buying gas)
☐ Friend or family member
☐ HIV agency
☐ Non-HIV agency
☐ Other (Specify):

Substance Abuse Counseling/Treatment	Did you know about this service?		Did you need this service?		On a scale of 1 to 5 how important is this service? (5 is most important)	Did you ask for this service?		Did you receive this service?	
a. Outpatient substance abuse counseling	Y	N	Y	N	1 2 3 4 5	Y	N	Y	N
b. Residential substance abuse treatment	Y	N	Y	N	1 2 3 4 5	Y	N	Y	N
Supportive Services									
a. Medical transportation (bus, taxi)	Y	N	Y	N	1 2 3 4 5	Y	N	Y	N
b. Child care	Y	N	Y	N	1 2 3 4 5	Y	N	Y	N
c. Food bank	Y	N	Y	N	1 2 3 4 5	Y	N	Y	N
d. Legal services	Y	N	Y	N	1 2 3 4 5	Y	N	Y	N
e. Translation service	Y	N	Y	N	1 2 3 4 5	Y	N	Y	N
f. Person who takes care of you at home	Y	N	Y	N	1 2 3 4 5	Y	N	Y	N
g. Housing services	Y	N	Y	N	1 2 3 4 5	Y	N	Y	N

Lessons Learned and Recommendations for Future Needs Assessments

The following list of issues was identified as a result of experience administering the written Needs Assessment survey:

1. The format for the grid questions was challenging for perhaps 15% of consumers. Almost everyone understood how to complete the grid once they were assisted with the first set of questions.
2. Consumers tended to "trail off" in responding to the grid questions (not every column completed). This was most apparent when they answered "no" to the first question (did you know about the service) since they obviously could not have ask for or received a service that they did not even know about. However, a few consumers made comments like "I wish I had known about that service" which makes it clear that need is separate from awareness. This "trail off" issue was also apparent with the two column questions like "now and 6 months ago"
3. Rating scale - Consumers tended to rate the importance of service at the end of the scale (5 of 1) rather than as a true measure. Also, consumers who had an unmet service need tended to rate that service higher than services which are being met. (People take for granted the relative importance of a need that is being satisfied).
4. The "Other" option was infrequently used and many who checked that option did not specify what the other reason was.
5. Literacy – A few consumers do not read in any language. Additionally a few had challenges in comprehending the survey due to dementia or limited IQ. The reading level was well above the 5th grade target due to inclusion of "industry" words for which consumers are not always familiar: *anonymous, incarceration, outpatient, substance abuse, hospice, nutritionist, chronic, supportive service* were all words that one or more consumers asked for help in defining. Also many acronyms are known only by the people who receive that service or activity (e.g., COBRA, MAP)
6. Language – Having the survey available in Spanish does not serve all Spanish speaking consumers because it is not a given that because one speaks Spanish and one also reads Spanish.
7. Survey Fatigue – The survey took most people 20 to 25 minutes to complete. Several people complained that the survey was too long. It was apparent that people rushed at the end and/or lost focus in an effort to finish. Unfortunately the most essential questions were at the end of the survey. (That said, most people took the survey seriously and did a thorough job completing).
8. The question "*did you ask for this service*" was confusing for some consumers who have received a given service long term because they did not need to ask for the service. For example, consumers receiving medical care for a long time simply had ongoing appointments scheduled without needing to ask for the service to be provided.
9. The question "*did you know about the service*" is relative rather than a black and white answer. Several people indicated that they had a vague idea that a given service was available but lacked sufficient information to know where to go for that service or if they would be eligible.

10. The mental health questions did not measure the true need for that service. Asking if someone received mental health service is quite different from measuring if people needed that service or if they recognized that they need mental health service.
11. The income question should have incorporated the federal poverty line into the scale.
12. Question 7 "Do you have phone…" should have gone the next step and asked additional questions that explore the type of phone service and what they use the service for. Many consumers have "Cricket" phones with very limited call capability and who incur fees for text messages. Knowing if people would be receptive to receiving HIV messages is important. Likewise, with the internet service question, the critical follow up questions is what the use the internet for (e.g., social networking).
13. Question "c" under the case management grid "…*short term help with a single issue*" confused a lot of consumers and was clearly the most frequent reason consumers ask for assistance.

On-line Survey

1. The limitations of Survey Monkey made it difficult to present the questions in s similar format to the look and feel of the written survey. There was no template that provided the equivalent structure to the grid questions.
2. Inability to issue a gift card while remaining anonymous.

Issues with Survey Administration

1. While leveraging the Food Bank schedule at ASA to solicit survey participants enabled us to reach a large number of consumers, the profile of the average food bank service client is not entirely reflective of the overall HIV community. The data shows many demographic elements over represented (African Americans, heterosexuals, women, older age demographic, low income). A strategy must be found for reaching additional groups and not relying upon the assistance of service providers is essential to future success. The approach that worked best was to schedule sessions through providers to reach consumers without relying upon the provider to issue/administer the survey. Sessions were conducted at David Powell, Project Transitions and Roosevelt Gardens that were very effective. This was done with scheduling and announcement via flyer. However, ultimately simply being on site at the right time proved to be the most essential component of success. Piggy-backing on support group meetings was likewise effective.
2. The most fundamental limitation to soliciting surveys at provider sites is that the vast majority of people at those locations are in care. Sampling those out of care, newly diagnosed or those in private care was a challenge. Writing letters to key private providers and clinics was largely unproductive. A key issue was the inability to provide a gift card incentive to those consumers.
3. Despite best efforts, a few consumers appear to have taken the survey more than once. Consumers were asked if they had taken it previously, and they had to sign a statement attesting that they had not previously received a gift card. However, the opportunity for low income consumers to receive a gift was a powerful incentive to take the survey a second time.
4. The gift card receipt log was at odds with the goal of administering the survey anonymously. The log was designed to capture 10 gift card recipients per sheet. This meant that the name and personal information could potentially be seen by those who signed subsequently. Using individual receipt sheets would be more confidential but administratively burdensome.