2016 Orlando Service Area HIV Needs Assessment

A collaboration of:
Orlando EMA HIV Health Services Ryan White Planning Council
Central Florida AIDS Planning (CFAP) Consortium
Orange County Government, Ryan White Grant Administration
People Living with HIV/AIDS in the Orlando Service Area and Ryan White HIV/AIDS Program Consumers

Disclaimer:
The 2016 Orlando Service HIV/AIDS Needs Assessment summarizes primary data collected from May to September 2016 from 695 self-selected, self-identified HIV infected individuals using either a self-administered written survey or online via Survey Monkey. The majority of respondents resided in the tri-county area of Orange Osceola and Lake Counties at the time of data collection. Though quality control measures were applied, limitations to the raw data and data analysis exist, and other data sources should be used to provide context for and to better understand the results. Data collected through this process represent the most current *primary* data source on people living with HIV/AIDS in the Orlando Service Area. Census, surveillance, and other data presented here reflect the most current data available at the time of the report.

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EXECUTIVE SUMMARY

The 2016 Orlando Service Area HIV Needs Assessment presents data on the HIV service needs, barriers, and other factors influencing access to HIV care for people living with HIV (PLWH) in the five Counties of Brevard, Lake, Orange, Osceola and Seminole as determined through a consumer survey. The overall goal of a needs assessment is to ensure the consumer point-of-view is infused into the data-driven decision-making activities of local HIV planning. Data is used to help set priorities for the allocation of HIV services funds, in the development of the comprehensive HIV plan, and in the design of annual service implementation plans. In 2016, 695 consumers participated in the Needs Assessment survey, and the results were statistically weighted to better represent the demographic composition of all PLWH in the Houston Area today. The last Needs Assessment was conducted in 2013.

HIV Service Needs in the Orlando Service Area

According to the 2016 Needs Assessment, all funded HIV services in the Orlando Service Area are needed by consumers. The top five most needed services are:

1. Medications
2. Primary Care
3. Case Management
4. Oral Health, and
5. Health Insurance

Accessibility of HIV Services in the Orlando Service Area

In addition to revealing the most needed HIV services in the Orlando Service Area, the 2016 Needs Assessment provides information about access to those services, which helps planners better understand where barriers to services may exist. In 2016, at least half of the consumers who said they needed each HIV service *also* said that they were able to get the services. There were some services, however, that were less accessible than others: oral health, health insurance, housing, and food services were the four *least* accessible services according to the 2016 Needs Assessment.

Barriers to HIV Services in the Orlando Service Area

To further understand barriers to HIV services, the 2016 Needs Assessment also gathered information about the types of difficulties consumers experience when services are not easily accessible. Overall, few barriers to services were reported in 2016. When they were reported, however, the most common are:

1. Not knowing where to go for the service
2. Not knowing how to get the service
3. Lack of transportation, and,
4. Believing they were not eligible for the service

This data is used to better understand the HIV care needs and patterns of PLWH in the Orlando Service Area, to identify any new or emerging areas of need, and to ultimately improve the system of HIV services so that it best meets the needs of PLWH.

The 2016 Orlando Service Area HIV/AIDS Needs Assessment is a collaboration between the Ryan White Part A Planning Council and the Ryan White Part B Consortium. A total of __ individuals assisted in the planning and implementation of the needs assessment, of which __% were PLWHA.
For more information about the 2016 Needs Assessment, contact the Office of Support at (407) 836-8107 or visit www.ocfl.net/ryanwhite.

INTRODUCTION

What is an HIV/AIDS needs assessment?

An HIV/AIDS needs assessment is a process of collecting information about the needs of people living with HIV (PLWH) in a specific geographic area. The process involves gathering data *from multiple sources* on the number of HIV cases, the number of PLWH who are not in care, the needs and service barriers of PLWH, and current resources available to meet those needs. This information is then analyzed to identify what services are needed, what barriers to services exist, and what service gaps remain.

Special emphasis is also placed on gathering information about the need for services funded by the Ryan White HIV program and on the socio-economic and behavioral conditions experienced by PLWH that may influence their need for and access to services both today and in the future. In the Orlando Service Area, primary data collected directly from PLWH in the form of a *consumer survey* is the principal source of information for the HIV needs assessment process. Consumer surveys are administered every three years to a representative sample of PLWH residing in the Orlando Service Area.

How are HIV/AIDS needs assessment data used?

Needs assessment data is integral to the information base for HIV services planning, and they are used in almost every decision-making process of the Planning Council and the Consortium, including setting priorities for the allocation of funds, developing the comprehensive plan, and crafting the annual implementation plan. Needs assessment data is also used for a variety of *non*-Council purposes, such as in funding applications, evaluation and monitoring, and the improvement of services by individual providers.

In the Orlando Service Area, HIV needs assessment data is used for the following purposes:

- Ensuring the consumer point-of-view is infused into all of the data-driven decision-making activities of the Orlando HIV Health Services Planning Council and the CFAP Consortium.
- Revising local service definitions for HIV care, treatment, and support services in order to best meet the needs of PLWH in the Orlando Service Area.
- Setting priorities for the allocation of Ryan White Part A and B funds.
- Establishing goals for and then monitoring the impact of the Orlando Service Integrated HIV Prevention and Care Plan (Comprehensive Plan) for improving the HIV prevention and care system.
- Determining if there is a need to target services by analyzing the needs of particular groups of PLWH.
- Determining the need for special studies of service gaps or subpopulations that may be otherwise underrepresented in data sources.
- By the Planning Council, other Planning Bodies, specific Ryan White HIV Program Parts, providers, or community partners to assess needs for services.

Needs assessment data is specifically mandated for use during the Planning Council's How to Best Meet the Need, Priority & Allocations, and Comprehensive HIV Planning processes. Because consumer surveys are administered every three years, their results are used in Planning Council activities for a three year period. Other data sources produced during interim years of the cycle, such as epidemiologic data and estimates of unmet need, out-of-care analyses and provider capacity and capability are used to provide additional context for and to better understand consumer survey results.

METHODOLOGY

Needs Assessment Planning

Planning the 2016 Orlando Service Area HIV needs assessment was a collaborative process between HIV prevention and care stakeholders, the Orlando Service Area Planning Bodies for HIV prevention and care, all Ryan White HIV/AIDS Program Parts, and individual providers and consumers of HIV services. To guide the overall process and to provide specific subject matter expertise, the Planning Committee of the Planning Council took the lead:

- The Planning Committee of the Planning and the Comprehensive Planning Committee provided overall direction to the needs assessment process and approved all final work products.
- The Workgroup developed the consumer survey sampling plan, which aimed at producing a representative sample of surveys.
- The Workgroup decided to use the same survey that was utilized in 2013 and to utilize Survey Monkey as the data collection tool.
- Planning Council Support was charged with the analysis to determine how the survey data should be analyzed and reported in order to serve as an effective tool for HIV planning.

In total, 25 individuals and staff participated in the planning process, of which at least 33% were persons living with HIV (PLWH).

Consumer Sampling Plan

The 2016 Orlando Service Area HIV needs assessment sample size was determined based on current total HIV prevalence for the Orlando Service Area (2014). Respondent composition goals were proportional to demographic and geographic representation in total prevalence. Funded-agency representation was proportional to total client share for the same time period (2014). Efforts were also taken to attract out-of-care consumers and members of special populations. Survey Monkey tallies of select respondent characteristics were conducted during survey administration to assess real-time progress toward attainment of sampling goals.

Consumer Survey

Data for the 2016 Orlando Service Area HIV/AIDS needs assessment were collected using a 45-item online survey of open-ended, multiple choice, and scaled questions addressing five topics (in order):

- Demographics
- HIV Medical Care
- Ryan White Services
- Jail/Prison Release Services
- Housing

Topics and questions were determined by the Workgroup by adopting the 2013 needs assessment survey. A cover sheet explained the purpose of the survey, risks and benefits, planned data uses, and consent.

Data Collection

The Survey was translated into Spanish and Creole and flyers with the links to the consumer survey for the 2016 Orlando Service Area HIV needs assessment along with paper copies of the surveys in the three languages (English, Spanish, Creole) were distributed to HIV Program providers, HIV Prevention providers, housing facilities, support groups, and specific community locations and organizations serving special populations. Staff contacts at each location were responsible for promotion and participant recruitment. Out-of-care consumers were recruited through flyers, word of mouth, and staff promotion.

Inclusion criteria were an HIV or AIDS diagnosis and residency in counties in the Orlando Service Area. Participants were self-selected and self-identified according to these criteria. Participation was voluntary, anonymous, and respondents were advised of these conditions verbally and in writing. Most surveys were completed in 15 to 20 minutes. Surveys were reviewed by Planning Council Support and tracked via Survey Monkey. A total of 695 consumer surveys were collected from May to October 2016.

Data Management

The majority of the surveys were completed via paper copies and data entered by Planning Council Support staff. Skip-logic questions were entered based on first-order responses; and affirmative responses only were entered for "check-all" questions. Surveys that could not be accurately entered by staff were eliminated (n=10). Data were periodically reviewed for quality assurance. Missing or invalid survey entries are excluded from analysis per variable; therefore, denominators will vary across results. Also, proportions may not sum to 100% for every variable due to missing or "check-all" responses. All data management and analysis was performed by Survey Monkey.

Limitations

Data produced by the 2016 needs assessment is unique because they reflect the first-hand perspectives of PLWH in the Orlando Service Area. However, there are limitations to the generalizability, reliability, and accuracy of the results that should be considered during their interpretation and use. These limitations are summarized below:

- *Convenience sampling*. A representative sample of PLWH in the Orlando Service Area proportional to geographic, demographic, transmission risk, and other characteristics were used. Despite such efforts, respondents were not randomly selected, and the resulting sample is not proportional to current HIV prevalence. To mitigate this bias, data were statistically weighted for primary race/ethnicity, and age group using current HIV prevalence for the Area. The majority of respondents were Ryan White HIV Program clients at the time of data collection, therefore, it not possible to determine if results reflect non-Ryan White systems.
- *Reporting bias*. Survey participants were self-selected and self-identified, and the answers they provided to survey questions were self-reported. Because the survey tool was anonymous, data could not be corroborated with medical or other records. Consequently, results should not be used as empirical evidence of reported outcomes. Other data sources should be used if confirmation of results is needed.
- *Instrumentation*. Full data accuracy cannot be assured due to variability in comprehension and completeness of surveys by individual respondents. Though real-time quality assurance reviews were performed of each survey by staff, there were missing data as well as indications of misinterpretation of survey questions. It is possible that literacy and language barriers contributed to this limitation as well. In addition, some surveys for consumers under age 18 were completed on their behalf by their primary caregiver.
- *Data management*. The use of multiple staff to enter survey data could have produced transcription and transposition errors in the dataset.

Data presented here represent the most current repository of *primary* data on PLWH in the Orlando Service Area. With these caveats in mind, the results can be used to describe the experiences of PLWH in the Orlando Service Area and to draw conclusions on how to best meet the HIV service needs of this population.

BACKGROUND

The Orlando Service Area

The Orlando Service Area consists of five counties in East Orlando Service: Brevard, Lake, Orange, Osceola and Seminole. The service area includes the four counties that comprises the Orlando EMA (Lake, Orange, Osceola and Seminole) three of which overlaps with the Part B Consortium or Area 7 (Orange, Osceola and Seminole). The fifth county of the Service Area, Brevard County, completes the four counties that comprise Area 7. Lake County, an EMA County, is one of 15 counties of Area 3/13. Together the five counties represent 14.8% of the total population of Florida. Orange County is home to 42.8% of the population of the Orlando Service Area with a population density of 1,268 persons per square mile. Brevard County has 19.2% of the Orlando Service Area population; Seminole County at 15.1%; Lake County at 10.7%; and Osceola County at 10.3%. Seminole County is the most densely populated at 1,367 persons per square mile. Population density ranges from 202.4 to 535.0 persons per square mile for Osceola, Lake and Brevard counties.

Population estimates from the Florida Department of Health, Office of Health Statistics estimated the total population of the Orlando Service Area at 2,884,534 persons, with 71.0% of the population identifying as White; 18.6% Black, and 29.4% Hispanic. By age, 15.9 percent are 0-12 years; 16.6% are 13-24 years; 26.4% are 25-44 years and 41.2% of the population is 45+ years of age. The general population is younger when compared to the PLWHA population where 60.0% are at least 45 years or older.

Population growth among the five counties in the Orlando Service Area was greatest in Osceola, at 11.3% from 2010 to 2014. Brevard County's population is older when compared to other counties in the service area. By gender, females represented a slightly larger percentage of the population when compared to their male counterparts, but still well within the 1:1 ratio.

Osceola County had the highest percentage of those living in poverty (2014) in the Orlando Service Area at 19.3%. Orange County, with poverty at 18.2% was higher than the poverty rates in Brevard County at 14.5%, Lake County at 13.8% and Seminole County at 11.8%.

According to the American Community Survey (2010-2014), Osceola County had the highest rate of uninsured adults at 23.3%, while Lake County adults were the lowest at 15.7%. Uninsured among adults in Brevard County, at 16.0% was lower that the percentages in Orange, at 21.6% and Seminole, at 16.6%.

HIV/AIDS in the Orlando Service Area

As of 2014, a total of 12,659 persons were living with HIV/AIDS in the Orlando Service Area. PLWHA are predominately Black males, ages 45+ years with a transmission exposure of MSM. The Black population is disproportionately represented as they account for 39% of PLWHA but only comprise 18.6% of the general population. The White and Hispanic populations are underrepresented as they account for 71.6% and 29.4% of the general population, respectively, but 35.0% and 24.0% of the PLWHA population. Among the PLWHA population, 66% are below the age of 45 years, with 16% between 13-24 years.

Figure 1: Number and Percent of HIV, AIDS, and PLWHA in the Orlando Service Area (as of 12/31/2014)

Indicator	HIV Incidence		AIDS Incidence		PLWHA	
	Number	Percent	Number	Percent	Number	Percent
Total	**845**	**100%**	**381**	**100%**	**12,659**	**100%**
White, Non-Hispanic	280	33%	107	28%	4,405	35%
Black, Non-Hispanic	279	33%	173	45%	4,925	39%

Hispanic	259	31%	90	24%	3,056	24%
Other	27	3%	11	3%	273	2%
Male	667	79%	267	70%	9,174	72%
Female	192	23%	114	30%	3,485	28%
0-12 yrs.	4	0%	0	0%	24	0%
13-24 yrs.	138	16%	33	9%	527	4%
25-44 yrs.	419	50%	185	49%	4,504	36%
45+yrs.	284	34%	163	43%	7,604	60%
MSM	537	64%	196	51%	6,781	54%
IDU	47	6%	37	10%	1,373	11%
MSM/IDU	26	3%	15	4%	464	4%
Hetero	224	27%	133	35%	3,804	30%
Other	9	1%	0	0%	215	2%

Source: eHARS

According to the CDC, individuals with sexually transmitted diseases and TB are at a higher risk of HIV infection than that of the general population who are disease-free. The table below contains the number of individuals in the Orlando Service Area who had been diagnosed with an STD in 2014.

Figure 2: Persons at Higher Risk for HIV Infection

	Syphilis	Gonorrhea	Chlamydia	TB	Hepatitis A	Hepatitis B	Hepatitis C
Total	**231**	**2,503**	**10,917**	**84**	**5**	**16**	**2,246**
White, Non-Hispanic	81	404	1,912	14	3	12	430
Black, Non-Hispanic	69	1,097	3,095	26	1	1	87
Hispanic	58	230	1,345	22	1	2	62
Other	23	772	4,565	22	0	1	1,667
Male	223	1,426	2,922	57	1	12	1,350
Female	8	1,076	7,979	27	4	4	891
0-12 yrs.	0	0	0	1	0	0	6
13-24 yrs.	56	1,369	7,064	6	1	0	150
25-59 yrs.	173	1,119	3,831	57	5	13	1,552
60+yrs.	2	15	22	20	0	3	538

Source: Florida Department of Health, Bureau of Communicable Disease, HIV/AIDS Section

The clients in the Ryan White system of care tend to have lower employment rates, live in poverty, have unstable housing, and higher than average rates of poverty. The socioeconomic data that was reported by the RSR is found in the table below. It should be noted that Insurance Status was unknown/not reported for 1,283 clients.

Figure 3: Ryan White Clients by Health Insurance Status and Poverty

Socioeconomic Indicator	Number	Percent
Medicaid	106	5.4%
Medicare	23	1.2%
Marketplace Exchanges	181	9.3%
Uninsured	527	27.0%
138% FPL	232	12.6%
400% FPL	644	34.9%

Source: RSR Clinical Summary Report FY 2014

The number of PLWHA grew from 10,548 in 2010 to 12,659 in 2014, which represented an 18.5% increase of those living with HIV infection. Among population groups, Blacks represented 18.6% of the Orlando Service Area population. However, they represented 33.0% of the new HIV cases, 45.0% AIDS cases, and 38.9% of PLWHA in the Orlando Service Area. Hispanics represented 27% of the general population and comprised 29% of the new HIV cases and 26% of new AIDS cases. The most significant increases were among new AIDS and HIV cases in the Hispanic population when comparing eHARS data from 2012 to 2014. They are as follows: among Hispanic MSM new AIDS cases increased 52% and new HIV cases 106.2%; HIV cases among Hispanic male IDU increased 141.7%; HIV case among Hispanic male youth (13-24 years) increased 45%; HIV cases among Hispanic female youth increase from 1 case in 2012, to 5 cases in 2014 (400%); and new AIDS cases among Hispanic Women of Childbearing Age (WCBA) were up 85.7% while new HIV cases for this population increased 181.8%.

HIV Care Continuum in the Orlando Service Area

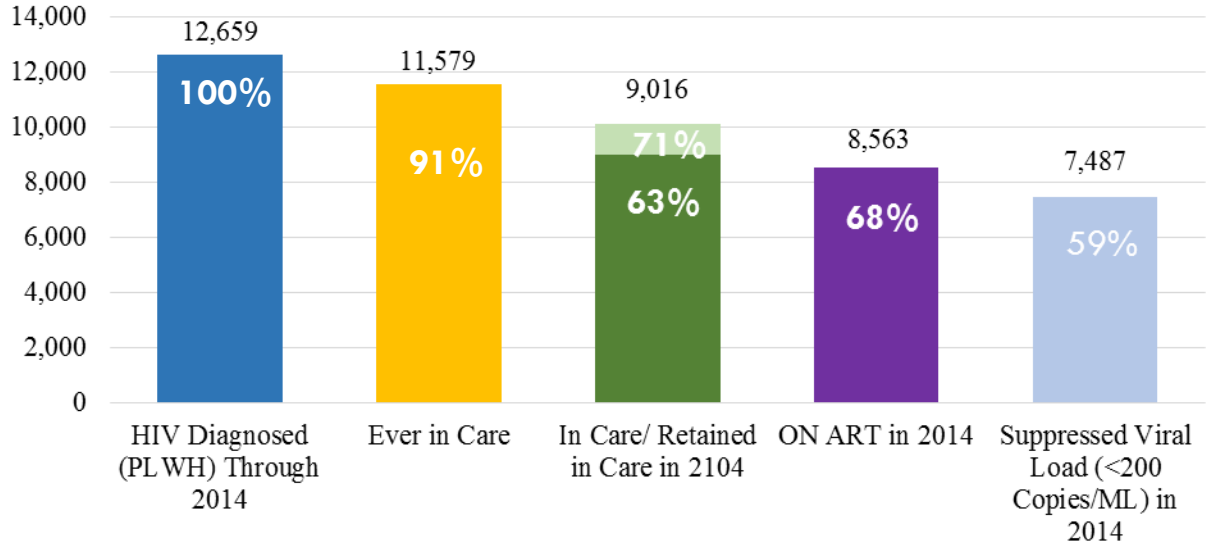
The HIV Care Continuum is a model that is used by federal, state, and local agencies to identify issues and opportunities related to improving the delivery of services to PLWH across the entire HIV Continuum of Care. The HIV Care Continuum has five main "steps" or stages including: HIV diagnosis, linkage to care, retention in care, antiretroviral use, and viral suppression. The State of Florida has developed a diagnosis-based model to identify issues and opportunities related to improving the delivery of services to high-risk, uninfected individuals. Since the Orlando Service Area's HIV Continuum of Care chart is developed by the Florida Department of Health, it uses a diagnosis-based model.

The diagnosis-based model of the HIV Care Continuum allows the service area to display each step of the continuum as a percentage of the number of PLWH who were only diagnosed. The diagnoses-based continuum directs steps that can be taken to get individuals with HIV into care and virally suppressed (<200 copies/ml).

The HIV Care Continuum depicted below illustrates the HIV epidemic for the Orlando Service Area.

Please note that in order to be considered "Retained in Care," an individual must have gone to two medical visits at least three months apart during 2014.

Figure 4: 2014 HIV Care Continuum of the Orlando Service Area



- 82% of those diagnosed with HIV in 2014 had documented HIV-related care within 3 months of diagnosis
- 83% of PLWHA in care had a suppressed viral load in 2014

An individual does not need to be "Retained in Care" in order to be prescribed ART, thereby showing a higher number of people prescribed ART than those considered to be "Retained in Care." Definitions for numerators and denominators are as follows:

I. HIV Diagnosed: Number of reported cases of HIV Infection regardless of AIDS

II. Ever in Care: PLWHA with at least 1 documented viral load (VL) or CD4 lab, medical visit or prescription since HIV diagnosis.

Linkage to Care: Numerator is the number of clients who have received at least one medical visit during 2014; Denominator is the total number of reported HIV cases

III. Retained in Care: Numerator is the number of clients who have received two or more visits three months apart during 2014; Denominator is total number of reported HIV cases

IV. Antiretroviral Use: Numerator is the number of clients with access to prescribed HIV medications according the PHS treatment guidelines; Denominator is the total number of reported HIV cases for 2014.

V. Viral Load Suppression: Numerator is clients with viral load <200; Denominator is total reported HIV cases for 2014.

DEMOGRAPHICS

PARTICIPANT COMPOSITION

A summary of the geographic, demographic, socio-economic, and other composition characteristics of individuals who participated in the 2016 needs assessment provides both a "snapshot" of who is living with HIV in the Orlando Service Area today as well as context for other needs assessment results.

Overall, 60.86% of needs assessment participants were male, 37.01 were female and only 1.81 identified as Transgender (male to female). 48.32% were Black or African American, 37.92% White or Caucasian and 28.72 % were Hispanic. 61.15% identified as Straight, 31.76% as gay and 6.42% as bi-sexual. In terms of residence, 60% of the respondents were residing in Orange County, 13.76% in Brevard County, 13.21 in Lake County, 8.36% in Osceola County and 1.58% in Seminole County at the time of data collection. Over half (66.82%) was between the ages of 45 and 64 and 22.94% were between the ages 25 and 44 with an average age of 52.

The average household income of participants was $8,088 per year, with the majority living at 100% of federal poverty (FPL). Other socio-economic characteristics of participants include: 51.07% were not working and of these 24.74% were disabled, 3and 17.53% were due to health reasons but not disabled. 84.82% of respondents were in medical care at the time of data collection with 15.08% not in care and 71.58% had no health insurance.

OVERALL SERVICE NEEDS AND BARRIERS

The Ryan White Program provides a spectrum of HIV-related services to persons living with HIV (PLWH) who may not have sufficient resources for managing HIV disease. At the local level, determinations of which HIV services to provide are made by the Planning Council and the Consortium. In addition, housing services for PLWH are provided through the federal Housing Opportunities for People with AIDS (HOPWA) program. The primary purpose of an HIV needs assessment is to gather information about the need for and barriers to services funded by the Ryan White Program locally as well as other federal programs like HOPWA.

Overall Ranking of Funded Services, by Need

In 2016, 16 HIV core medical and support services were funded through the Ryan White Part A Program and through the Part B Program, and housing services were provided through the local HOPWA program. Participants of the 2016 needs assessment were asked to indicate which of these funded services they needed and got in the past 12 months.

All funded services received a ranking of need by needs assessment participants. At 81.83%, medication was the most needed funded service in the Orlando Service Area, followed by medical care at 79.51%, case management at 77.64%, oral health care at 54.94% and health insurance at 45.20%. When compared to the last needs assessment conducted in 2013, the top five needed services remained the same for core services, for support services treatment adherence and health education and risk reduction ranked high among needed support services in both 2016 and 2013.

Overall Ranking of Barriers Experienced by Consumers

A list of 17 commonly experienced barriers to services was presented to needs assessment participants from which to select the specific condition or issue that made the service they needed *difficult* to access. Results show that all funded services were reported to have barriers. Overall, the barrier experienced most often by PLWH (when barriers were reported) was lack of knowledge of where to go for the service (45.98% of all reported barriers), followed by not being able to pay for services (15%) and lack of transportation (11.72%).

Other Identified Needs

In addition to the HIV services listed above, there are other services allowable for funding by the Ryan White Program in local communities if there is a demonstrated need. Several of these other services have been funded by the Ryan White Program in the Orlando Service Area in the past. The 2016 needs assessment queried the need for these other services that are not currently funded by Ryan White in order to gauge any new or emerging service needs in the community. In addition, some of these services are currently funded through other HIV-specific non-Ryan White sources, namely housing-related services provided by the Housing Opportunities with People with AIDS (HOPWA) program, as indicated.

Eleven other/non-Ryan White funded HIV-related services were assessed in the consumer survey. Participants could also write-in other types of services that they needed. Of the 11 preset options provided, health education and risk reduction was selected most often as a need (30.23%) with food bank a close second at 25.58% of respondents with an additional 12.65% needing it but could not get. Housing-related services were cited second and third. It should be noted that services that were written-in most often as a need (and that are not currently funded by Ryan White) were (*in order*): employment assistance and job training, vision hardware/glasses, and support groups.