

**Prepared by** 

Nadia E. Barreto-Najarro Department of Community Services 810 Datura Street West Palm Beach, FL 33401 (561) 355-4785 Fax (561) 844-3310 nbarreto@pbcgov.org

Funded through the Ryan White HIV/AIDS Treatment Modernization Act of 2009 Department of Community Services Palm Beach County, Florida

# TABLE OF CONTENTS

- I. Introduction / Page 2
- II. Executive Summary / Page 3
- III. Epidemiology / Page 6
- IV. Methodology / Page 13
- V. Key Findings / Page 16
  - A. PLWHA and Provider Survey Findings / Page 16
    - 1. Characteristics of PLWHA Survey Respondents / Page 16
    - 2. PLWHA who are currently In Care / Page 23
    - 3. PLWHA who are Now In Care, but Have Been Out of Care Within the Past Five Years / *Page 30*
    - 4. PLWHA who are Out of Care / Page 35
    - 5. Comparison of PLWHA who are In Care with PLWHA who are Out of Care / *Page 46*
    - 6. Prioritization of Service Categories / Page 50
    - 7. Service Utilization, Gaps, and Barriers / Page 53
    - 8. Findings from Provider Surveys / Page 55
  - B. Trends in Service Utilization, Gaps, and Barriers (2000-2013) / Page 59
  - C. Highlights Regarding Populations of Special Concern / Page 67
    - 1. African-American Heterosexuals / Page 68
    - 2. Men who Have Sex with Men (MSM) / Page 83
    - 3. Haitian Men and Women / Page 98
    - 4. Hispanic Men and Women / Page 113
    - 5. In Care Individuals Recently Incarcerated in the Past 12 Months / Page 127
    - 6. Individuals Aged 50 and Over/ Page 138

# Appendices / Page 152

- A. PLWHA 2013 Survey
- B. Focus Group Script 2013
- C. Provider Survey 2013
- D. Ryan White Service Category Definitions 2013

# I. INTRODUCTION

The Palm Beach County HIV CARE Council conducts a Comprehensive Needs Assessment every three years.

The Comprehensive Needs Assessment 2013-2016 is a collaboration amongst community agencies and volunteers. With the data from this process, the Palm Beach County EMA looks forward to becoming aware of service category utilization, barriers to care, and gaps in HIV services.

There is a commitment to reviewing the data and using this information for the benefit of PLWHA in Palm Beach County, identifying needs and service priorities for the Ryan White Program.

# II. E X E C U T I V E S U M M A RY

# **Overview and Purpose**

Every three years the Ryan White Part A Planning Council conducts a Comprehensive Needs Assessment. The findings in the Comprehensive Needs Assessment 2013-2016 are to be used by the planning council to help identify the needs and service priorities of PLWHA residing in Palm Beach County.

Information was gathered from respondents who were in primary medical care, as well as respondents who were out of primary medical care. In this study, the definition of "in care" or "in primary care" is the definition adopted by "Health Resources and Services Administration (HRSA) for being "in primary medical care" if the patient has been in...

"...receipt of one of the following HIV-related primary medical care services within the past 12 months:

- HIV/AIDS medical care
- Lab work for CD4 count
- Lab work for viral load count

This definition is an "operational" or working definition of being "in care" and uses information likely to be available in most states and EMAs.

# Epidemiology

The mid-year population estimate of Palm Beach County in 2011 was 1,327,309. Of these, 3,066 were people living with HIV (not AIDS) and 4,669 were people living with AIDS. Within the past two years, 2010 and 2011, the number of new AIDS cases reported in Palm Beach County was 495.

An examination of demographic characteristics of PLWHA in the county and PLWHA served by the Ryan White Program suggest that no populations are underserved. Moreover, analyzing HIV and AIDS data trends from 2000-2011 suggest the total number of new HIV cases and new AIDS cases in Palm Beach continue to decrease. Also decreasing from 2000 to 2011 is the number of age adjusted HIV/AIDS deaths in Palm Beach County.

Geographic distribution of the total number of HIV/AIDS cases and total number of HIV/AIDS alive & out of care in 2011 illustrate the highest number of PLWHA along the eastern and southwestern areas of the Palm Beach County map.

# Methodology

The Comprehensive Needs Assessment 2013-2016 utilized three data collection strategies including surveys of PLWHA, focus groups of PLWHA, and surveys of HIV service providers. The PLWHA survey and focus group script were similar to those which were used in the 2000, 2003, 2007 and 2010 Comprehensive Needs Assessments.

Throughout the surveying process, sampling was monitored to ensure that the demographic and social characteristics of survey respondents represented the diversity of the PLWHA population in Palm Beach County. Using this stratified sampling methodology resulted in a survey sample similar to the profile of PLWHA in the Palm Beach County EMA. Likewise, survey respondents were recruited from all areas of the county and from populations of special concern to ensure representation of the geographic diversity of PLWHA in the county and the voices of selected populations of special concern.

# Key Findings Highlights Regarding PLWHA and Provider Survey Finding

A total of 366 survey respondents participated in the Comprehensive Needs Assessment 2013-2016. Of these, 211 indicated they were currently in primary medical care. When asked where they received their HIV/AIDS medical care, 197 of the 211 indicated a response. Of the 197 in care respondent who indicated one source, 54.8% said Public Clinic/Health Department and 36.6% said Doctor's Office.

Out of the total 211 respondents that indicated they were currently in care, 33 responded that during the previous five years there had been a period of at least 12 months where they had not gone to the doctor. When asked what prevented them from receiving HIV/AIDS medical care, the three most frequently identified reasons were "I did not have medical insurance," I could not afford care," and "I was using drugs or alcohol" (33.3%).

155 out of 366 survey respondents indicated they were out of care. When asked about the reasons for not being in care, the three most frequently mentioned reasons include; I did not feel sick (57.4%, 89), I was depressed (38.7%, 60), and I did not want people to know that I have HIV (37.4%, 58).

Eleven providers in Palm Beach County completed a 22-item on-line survey in regards to addressing disparities, improving services, mitigating barriers, and improving or expanding HIV service delivery. When providers were asked, "what is the single most important change you would suggest to improve services for individuals of families infected with HIV?" The responses included themes in increasing service capacity and availability, promoting client empowerment, and improving systematic approaches to change.

# **Highlights Regarding Trends in Service Utilization, Gaps, and Barriers** (2000-2013)

Data analyses for each year's needs assessment were conducted to identify trends from 2000 through 2013. Examination of service category utilization, gaps, and barriers has varied slightly in the five needs assessments throughout the 13 years. Utilization has remained highly utilized (by more than 50% of respondents) from 2000 through 2013 in laboratory diagnostic testing, primary medical care, and case management services. Gaps in care that generally remained somewhat consistent over time are in the service categories of case management and transportation. Barriers to services have remained low and fairly consistent except for a few notable exceptions in 2013, health insurance food bank, and transportation.

# **Highlights Regarding Populations of Special Concern**

In addition to focusing on PLWHA who are in care and those who are out of care, this Needs Assessment focused on populations of special concern. Six PLWHA populations of African-American heterosexuals, Men who Have Sex with Men (MSM), Haitian men and women, Latin/Hispanic men and women, individuals who have been recently incarcerated (in the past 12 months), and individuals aged 50 and over were examined through survey and focus group responses.

### African-American Heterosexual Survey Respondents

Out of the total 366 needs assessment survey respondents, 194 respondents indicated they were African-American heterosexuals. 122 (62.9%) indicated they were in HIV/AIDS medical care and 72 (37.1%) were out of care. When asked in a focus group, "what has helped to get in care and stay in care?" PLWHA representation from this population indicated funding and insurance.

### MSM Survey Respondents

12.3% (45) of all survey respondents identified themselves as MSM. Only one individual of this population identified as Transgender (male to female). When asked in a focus group about the quality of HIV services in Palm Beach County, representation from this population indicated services have been adequate and they have been able to access the services they need.

### Haitian Men and Women Survey Respondents

28 (7.6%) of all survey respondents indicated they were Haitian and 23 (82.1%) indicated they were in care. When asked in a focus group, "what will it take to persuade individuals to go back to the doctor for HIV/AIDS medical care?" individuals from this population indicated counseling, moral support, and knowing where to go.

# Hispanic Men and Women Survey Respondents

Out of the total 366 needs assessment survey respondents, 60 (16.4%) indicated they were Hispanic. 15 (25.0%) reported Puerto Rico as their country of origin, and 14 (23.3%) said the US. When asked in a focus group, "In the past 3 years, have services improved, decline, or remain the same?" members of this population indicated services have improved.

# Recently Incarcerated (in the past 12 months) Survey Respondents

17 (8.1% of all in care respondents) indicated they were incarcerated in the past 12 months. 11 (64.7%) said they received HIV/AIDS related medical care while in jail/prison. When asked in a focus group for additional comments in regards to HIV/AIDS services in Palm Beach County, individuals from this population indicated group sessions and sharing of information is a benefit to PLWHA.

# Age 50+ Survey Respondents

127 (34.7% of all respondents) indicated they were age 50 and over. 105 (82.7%) said they are straight (heterosexual). When asked in a focus group for reasons individuals of this population are not going to the doctor for HIV/AIDS medical care, responses indicated shame and lack of privacy.

# III. EPIDEMIOLOGY

The data sources for this section are Florida Department of Health, HIV/AIDS & Hepatitis Program (2012), *AIDS Incidence, AIDS Prevalence, and HIV (Not AIDS) Prevalence.* 

# Palm Beach County Demographics

The 2011 mid-year population estimate for Palm Beach County was 1,327,309. Of these, 48% were male and 52% female. The county is racially and ethnically diverse. In 2011, 60% of the population was White non-Hispanic, 17% was Black non-Hispanic, 19% was Hispanic, and 4% was other races/ethnicities. A large proportion of the county's population is senior retirees. The 2011 age distribution in years was as follows: 0-12, 14%; 13-19, 8%; 20-24, 6%; 25-29, 6%; 30-39, 11%; 40-49, 13%; 50-59, 13%; 60+, 28%. (Florida Department of Health, Bureau of HIV/AIDS Surveillance Section (2012). *Epidemiological Profile, Palm Beach County*.)

### People Living with HIV (HIV [Not AIDS]) Prevalence)

As of December 31, 2011, the number of people living with HIV (not AIDS) (PLWH) in Palm Beach County was 3,066. This translates to an HIV prevalence rate of 231 per 100,000 (100,000 X 3,066/1,327,309). 61% of these people were non-Hispanic Blacks, 25% were non-Hispanic Whites, and 13% were Hispanics. Over one-half (59%) were males. 98% were adults age 20+. A greater proportion (50%) was in the older adult age group (age 45+ years) than the younger adult age group (age 20-44; 48%). Among adults and adolescents, the most frequent exposure category was heterosexual (59%), followed by men having sex with men (MSM; 32%). Among the 20 pediatric cases (age 0-12), all were exposed due to a mother with/at risk for HIV infection.

### People Living with AIDS (AIDS Prevalence)

As of December 31, 2011, the number of people living with AIDS (PLWA) in Palm Beach County was 4,669, representing an AIDS prevalence rate of 352 per 100,000 (100,000 X 4,669/1,327,309). Approximately two-thirds (64%) of these people were non-Hispanic Blacks, 22% were non-Hispanic Whites, and 12% were Hispanics. About two-thirds (63%) were males, and 99% were adults age 20+. Similar to the HIV (not AIDS) adult prevalence, a greater proportion of the people living with AIDS were older adults aged 45+ (67%) than younger adults age 20-44 (32%). The exposure categories are similar to those of people living with HIV. Among adults and adolescents, the most frequent exposure category was heterosexual (58%), followed by MSM (29%). All of the 6 pediatric cases (age 0-12) were exposed due to a mother with/at risk for HIV infection.

# New AIDS Cases Reported Within the Past Two Years (AIDS Incidence)

The number of new AIDS cases reported in Palm Beach County in 2010 and 2011 was 495. 64% of these were non-Hispanic Blacks, 18% were non-Hispanic Whites, and 15% were Hispanics. 65% were males. Almost all (98%) of these cases were adults age 20+. 53% were age 20-44 and 46% were age 45+. Among adults and adolescents, the most frequent exposure category was heterosexual (66%), followed by MSM (27%). There were no pediatric cases (age 0-12) exposed due to a mother with/at risk for HIV infection.

### **Disproportionate Impact on Certain Populations**

HIV/AIDS has a significant disproportionate impact on Palm Beach County's minority communities, homeless, and formerly-incarcerated individuals, as indicated in the following table:

	PLWHA Subpopulations in Palm Beach County through 2011					
	(A) Number of PLWHA (N=7,735)	(B) Percent of All PLWHA (A/7,735)	(C) Number in Total County Population (N=1,327,309)	(D) Percent of Total County Population (C/1,327,309)	(E) HIV/AIDS Prevalence Rate per 100,000 (100,000XA/C)	
Black (non- Haitian)	3,390 <sup>1</sup>	44%	168,568 <sup>2</sup>	13%	2,011	
Hispanic	1004 <sup>4</sup>	13%	257,189 <sup>5</sup>	19%	390	
MSM	2,373 <sup>4</sup>	31%	37,624 <sup>3</sup>	3%	6,367	
IDU	$687^4$	9%	14,718 <sup>4</sup>	1%	4,668	
Haitian Born	1,431 <sup>4</sup>	19%	56,295 <sup>5</sup>	4%	2,542	
Homeless	31 <sup>6</sup>	0.4%	3,228 <sup>9</sup>	0.3%	960	
Formerly Incarcerated	447	0.6%	1,332 <sup>10</sup>	0.1%	3,303	

Based on the data in the above table, the HIV/AIDS prevalence rate in the general population of Palm Beach County is 583 per 100,000 population (100,000 X 7,735/1,327,309). The prevalence rates in the above table indicate that:

- Among non-Haitian Blacks, the HIV/AIDS prevalence rate is more than 3 times higher than among the general population.
- Among men who have sex with men (MSM), the HIV/AIDS prevalence rate is more than 10 times higher than among the general population.
- Among intravenous drug users (IDU), the HIV/AIDS prevalence rate is more than 8 times higher than among the general population.
- Among Haitian-born persons, the HIV/AIDS prevalence rate is more than 4 times higher than among the general population.
- Among homeless persons, the HIV/AIDS prevalence rate is 1.6 times higher than among the general population.
- Among formerly incarcerated individuals, the HIV/AIDS prevalence rate is almost 6 times higher than among the general population.

<sup>&</sup>lt;sup>1</sup> Florida Department of Health, Bureau of HIV/AIDS Surveillance Section (2012). Section 2 – Table 1b: Background Data Used for the Calculations of AIDS Prevalence, and HIV (not AIDS) Prevalence.

<sup>&</sup>lt;sup>2</sup> Florida Department of Health, Bureau of HIV/AIDS Surveillance Section (2012). *Epidemiological Profile, Palm Beach County*.

<sup>&</sup>lt;sup>3</sup>Estimate based on prevalence of 7.5% MSM among males age 18+ in Florida, Lieb, S., et al., (2009). Estimating Populations of Men Who Have Sex with Men in the Southern United States. *Journal of Urban Health*, November 13, 2009; Population data from U.S. Census (2010). *American Community Survey, 2010, Palm Beach County.* 

<sup>&</sup>lt;sup>4</sup> Estimate based on prevalence of 1.4% IDU among persons age 18+ in South Florida, Lieb, S., et al., (2004). An HIV Prevalence-based Model for Estimating Urban Risk Populations of Injection Drug Users and Men Who Have Sex with Men. *Journal of Urban Health*, *81 (3)*; Population data from U.S. Census (2010). *American Community Survey*, 2010, Palm Beach County.

<sup>&</sup>lt;sup>5</sup> U.S. Census (2010). American Community Survey, 2010, Palm Beach County.

<sup>&</sup>lt;sup>6</sup> Palm Beach County Continuum of Care (2011). 2011 Point in Time Count.

<sup>&</sup>lt;sup>7</sup> Florida Department of Health, Bureau of HIV/AIDS Surveillance Section (2012). *Co-Morbidities/Other Factors/Surrogate Markers*.

### Populations Underrepresented in the Ryan White Program

Underrepresented populations may be identified by comparing demographic characteristics of the PLWHA population in the county with the characteristics of PLWHA served by the Ryan White Program-funded system in the county.

Comparison of all PLWHA with PLWHA Served, Palm Beach County, 2011				
	PLWHA <sup>8</sup>	PLWHA Served <sup>9</sup>		
RACE/ETHNICITY				
White	23%	18%		
Black	62%	62%		
Hispanic	13%	15%		
Asian/Pacific Islander	0%	0%		
American Indian	0%	0%		
Other/Unknown/Multiracial	1%	4%		
GENDER				
Male	62%	57%		
Female	38%	43%		
AGE (years)				
0-12	0%	0%		
13-44	40%	37%		
45+	60%	63%		

Analyses of demographic characteristics of PLWHA in the county and PLWHA served by the Ryan White Program show that the populations differ by more than 5 percentage points, suggesting that no populations are underserved.

### HIV and AIDS Data Trends

The total number of HIV cases in Palm Beach County continues to decrease. The data in the table below summarizes the decrease in the number of new cases from a high of 770 in 2000 to 348 in 2011 as well as a decrease in the rate, from 67.7 to 26.2 per 100,000 population. (Florida Department of Health, CHARTS Community Health Assessment Resource Tool Set).

Palm Beach County HIV Data				
	New	Rate per	Total	
Year	Cases	100,000	Population	
2000	770	67.7	1,137,532	
2001	725	62.3	1,163,115	
2002	789	66.2	1,191,948	
2003	693	56.6	1,223,687	
2004	598	47.6	1,255,696	
2005	532	41.6	1,278,804	
2006	463	35.8	1,294,795	
2007	486	37.3	1,304,214	
2008	556	42.5	1,308,741	
2009	362	27.6	1,313,848	
2010	311	23.6	1,320,309	
2011	348	26.2	1,327,313	

<sup>&</sup>lt;sup>8</sup> Florida Department of Health, Bureau of HIV/AIDS Surveillance Section (2012). Section 2 – Table 1b: Background Data Used for the Calculations of AIDS Prevalence, and HIV (not AIDS) Prevalence.

<sup>&</sup>lt;sup>9</sup> Palm Beach County Department of Community Services (2012). 2011 RSR Report.

Because it may take many years for people infected with HIV to develop AIDS, AIDS data tend to represent HIV transmission that may have occurred many years ago. The Bureau of HIV/AIDS suggests that individual and population disparities in the development of AIDS may include the following factors:

- late diagnosis of HIV •
- access to/acceptance of care
- delayed prevention messages •
- stigma •
- prevalence of STDs in the community
- prevalence of injection drug use
- complex matrix of factors related to socioeconomic status •

Although the total number of AIDS cases in Palm Beach County continues to increase, the number and rates of new AIDS cases has decreased over time. The data in the following table show that the number of new cases and rate per 100,000 population decreased between 2000 to 2011, from 499, 43.9 per 100,000 to 237, 17.9 per 100,000 (Florida Department of Health, CHARTS Community Health Assessment Resource Tool Set).

Palı	Palm Beach County AIDS Data			
	New	Rate per	Total	
Year	Cases	100,000	Population	
2000	499	43.9	1,137,532	
2001	450	38.7	1,163,115	
2002	506	42.5	1,191,948	
2003	428	35	1,223,687	
2004	417	33.2	1,255,696	
2005	343	26.8	1,278,804	
2006	359	27.7	1,294,795	
2007	274	21	1,304,214	
2008	320	24.5	1,308,741	
2009	287	21.8	1,313,848	
2010	239	18.1	1,320,309	
2011	237	17.9	1,327,313	

As with new HIV and new AIDS cases, the number of age adjusted HIV/AIDS deaths has dramatically decreased since 2000, dropping from 165 deaths in 2000 to 65 deaths in 2011 with a concomitant decrease in rates per 100,000 population from 15.3 to 5.0. The data in the table below show that while there has been a decrease in rates among all races, grave disparities still exist between racial categories. For example, the death rate among Blacks decreased from 75.4 in 2000 to 23.8 in 2011 but this rate is still higher than the rate for Whites (Florida Department of Health, CHARTS Community Health Assessment Resource Tool Set).

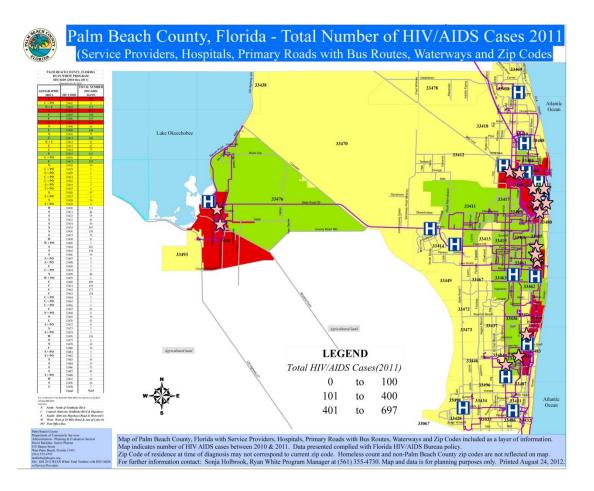
2000-2011						
Year	Number of	All	White	Black	Hispanic*	
	Deaths	Races/Ethnicities				
		Rate per 100,000	Rate per	Rate per	Rate per	
			100,000	100,000	100,000	
2000	165	15.3	5.7	75.4	-	
2001	147	13.3	3.7	73.8	-	
2002	157	13.8	4	71.5	-	
2003	156	13.3	4.3	66.2	-	
2004	175	14.8	4.9	69.7	8.7	
2005	149	12.3	3.8	49.9	7.1	
2006	162	12.8	3.5	63.2	4.6	
2007	118	9.7	3.3	40.9	1.8	
2008	118	9.3	3.2	38.7	3.6	
2009	103	8	2.4	35.8	2	
2010	64	4.8	1.6	21.5	1.2	
2011	65	5	1.7	23.8	1.9	

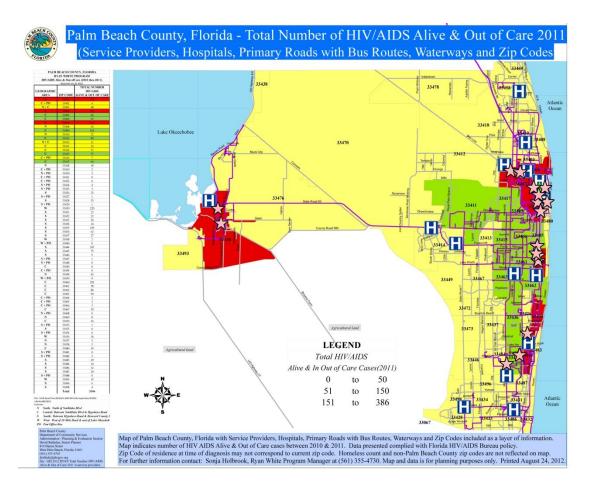
### Palm Beach County EMA Total Deaths and Age Adjusted HIV/AIDS Death Rates

\*The availability of official Hispanic population data from the Office of Economic and Demographic Research began in 2004.

### **Geographic Distribution**

The following two maps, prepared by the Palm Beach County Community Services Department (using data provided by the Palm Beach County Health Department), illustrate the geographic distribution of total number of HIV/AIDS cases and total number of HIV/AIDS alive & out of care for 2011. As shown on these two maps, the ZIP codes along the eastern corridor and the southwestern area of the county have the highest number of PLWHA, the highest number of PLWHA who are not in care, and the highest number of HIV related service providers.





# IV. M E T H O D O L O G Y

The Comprehensive Needs Assessment 2013-2016 utilized three data collection strategies including surveys of PLWHA, focus groups of PLWHA, and surveys of HIV service providers. The PLWHA survey and focus group script were similar to those which were used in the 2000, 2003, 2007, and 2010 Comprehensive Needs Assessments. With the guidance and approval of the Planning Committee, additional components were added regarding utilization of medical care and case management. Service categories specified in the survey were correlated to those used by the planning council and HRSA to facilitate clear and concise data analysis. In addition, questions were added to capture data regarding PLWHA who are out of care.

# PLWHA Survey

A 79-item survey was developed and implemented to collect information from PLWHA regarding service priorities and needs. Demographic data elements included gender, sexual orientation, race, ethnicity, age, and geographic area of residence. The data collector determined if the respondent was in or out of primary medical care by asking the following questions:

"Have you received one of the following HIV-related primary medical care services within the past 12 months?

HIV/AIDS medical care Lab work for CD4 T-cell count Lab work for a viral load test

Respondents identified as "out of care" were asked five additional questions relating to being out of primary medical care. Respondents identified as being "in care" were asked additional questions regarding access to and availability of services. In addition, the respondents in care were asked if during the past five years there had been a period of at least 12 months when they were not receiving HIV-related primary medical care (no HIV/AIDS medical care, no lab work for CD4 T-cell count or no lab work for a viral load test).

Trained data collectors administered three hundred sixty-six (366) surveys to PLWHA in locations including but not limited to bus stops, homeless shelters, soup kitchens, clinics, and high-risk neighborhoods. Surveys were also promoted and distributed at community forums and other appropriate venues. After completing the survey, each respondent received a \$10.00 gift card.

Surveys were collected during May and June 2013. The Data Collection Team met weekly with the planner to discuss data collection issues and review aggregate demographic information from the collected surveys. Data were entered into the survey posted on Survey Monkey, and then exported from Survey Monkey into an Excel database for further analysis.

# **Provider Survey**

Provider surveys were completed by the following organizations:

- 1. Compass, Inc.
- 2. Florida Health Palm Beach County
- 3. FoundCare/CAP, Inc.
- 4. Gratitude House, Inc.

- 5. Health Care District of Palm Beach County
- 6. Health Council of Southeast Florida
- 7. Legal Aid Society of Palm Beach County, Inc.
- 8. Minority Development & Empowerment, Inc.
- 9. The Childrens Place at Homesafe, Inc.
- 10. Triple O Medical Services
- 11. VA Medical Center

### PLWHA Focus Groups

Focus groups were conducted with populations of special concern:

- African-American Heterosexuals
- Men who Have Sex With Men (MSM)
- Haitian Men and Women
- Latin/Hispanic Men and Women
- Recently Incarcerated in Past 12 Months
- 50+ Age Group

Focus group participants were recruited by focus group facilitators who were representatives of or persons who work closely with the population of special concern.

At the beginning of each focus group, the definition of being "in primary medical care" was reviewed, as were the HIV services that would be discussed during the focus group. Focus group participants maintained anonymity and agreed to maintain confidentiality. At the end of each focus group session, each participant was given a \$25 Wal-Mart gift card.

### Data Analyses

All analyses were performed using Excel and Survey Monkey. Frequencies and percentages were calculated on all scale items and cross-tabs were computed between selected variables to explore relationships between survey items. Tables were created to summarize and illustrate survey responses. As needed, data were analyzed by sub-populations including gender, race, ethnicity, geographic region and sexual orientation as well as populations of special concern.

### **Training Data Collectors**

An in-depth training session was conducted by the health planner for the survey data collectors and the focus group facilitators. The training included strategies to locate PLWHA who are out of care. Data collectors and focus group facilitators signed a confidentiality agreement, and were given identification cards. The identification cards contained contact information regarding the health planner. A sample of the identification card is displayed below.

Palm Beach County CARE Council DATA COLLECTION TEAM MEMBER Name of Data Collector May/June 2013 Questions?	Photo of Data Collector
Contact: Nadia Barreto-Najarro, Health Planner	
Cell 561-531-9670 Work 561-355-4785	

# A. PLWHA AND PROVIDER SURVEY FINDINGS

# 1. CHARACTERISTICS OF PLWHA SURVEY RESPONDENTS

Throughout the surveying process, sampling was monitored to ensure that the demographic characteristics of survey respondents represented the diversity of the PLWHA population in Palm Beach County. As shown in the following table, using this stratified sampling methodology resulted in a survey sample similar to the demographic profile of PLWHA in the Palm Beach County EMA. HIV/AIDS Case Prevalence data cited in this section were provided by the Florida Department of Health HIV/AIDS & Hepatitis Program.

As shown in the following table, of the 366 survey respondents, 52.5% (192) were male compared to 61.60% (4,801) of the PLWHA in the area. Females were 47.5% (174) of survey respondents while only 38.40% (2,988) of the PLWHA in the area are female.

Gender	Prevalen	HIV/AIDS Case Prevalence Through 2011*		vey ndents
	number percent		number	percent
Male	4,801	61.6%	192	52.5%
Female	2,988	38.4%	174	47.5%
Total	7,789 100.0%		366	100.0%
*Source: Florida Department of Health, HIV/AIDS & Hepatitis Program(as of 5/16/2012)				

### Comparison of HIV/AIDS Case Prevalence in Palm Beach County with Survey Respondents by Gender

Overall, Black not Hispanic survey respondents were somewhat overrepresented at 66.4% (243) compared to Black not Hispanic PLWHA in the county (62.9%, 4,898). In contrast White not Hispanic were somewhat underrepresented as 16.1% (59) of the survey respondents were Hispanic while 23.4% (1,819) of PLWHA in Palm Beach County are White not Hispanic.

#### Comparison of HIV/AIDS Case Prevalence in Palm Beach County with Survey Respondents by Race and Ethnicity

Race/Ethnicity	Preva	DS Case alence h 2011*	Survey Respondents		
	number percent		number	percent	
Black Not Hispanic	4,898	62.9%	243	66.4%	
White Not Hispanic	1,819	23.4%	59	16.1%	
Hispanic	961	12.3%	48	13.1%	
Other/Unknown	111	1.4%	16	4.4%	
Total	7,789 100.0%		366	100.0%	
*Source: Florida Department of Health, HIV/AIDS & Hepatitis Program(as of 5/16/12)					

As summarized in the following table, the distribution of respondents by age range was similar to the distribution of PLWHA in the EMA. Age ranges 45-49, 50-59, and over 60 were somewhat underrepresented and ages below 24, 25-29, and 40-44 were somewhat overrepresented compared to PLWHA in the county.

### Comparison of HIV/AIDS Case Prevalence in Palm Beach County with Survey Respondents by Age Range

Age	HIV/AIDS Case Prevalence Through 2011*		Survey Respondents	
	number	percent	number	percent
Below 24	336	4.3%	21	5.7%
25-29	326	4.2%	27	7.4%
30-39	1,314	16.9%	62	16.9%
40-44	1,094	14.0%	64	17.5%
45-49	1,430	18.4%	65	17.8%
50-59	2,181	28.0%	100	27.3%
60+	1,108	14.2%	27	7.4%
Unknown	n/a	n/a	n/a	n/a
Total	7,789	100.0%	366 100.0%	
*Source: Florida Department of Health, HIV/AIDS & Hepatitis Program (current age on 12/31/2011)				

The survey sample was also similar to several special populations tracked by the Florida Department of Health, HIV/AIDS & Hepatitis Program. These special populations include heterosexuals, men who have sex with men (MSM), Haitian born persons, Hispanic, and 50+ age group.

The risk category "Heterosexual/Other" was somewhat overrepresented with 69.9% (256) of survey respondents compared to 58.3% (4,542) of the HIV/AIDS case prevalence. MSM were underrepresented with 12.3% (45) of the survey sample compared to 30.0% (2,334) of PLWHA in the county. Haitian Born was slightly overrepresented with 7.7% (28) of the respondents compared to 7.2% (561) of PLWHA in the county. Hispanic persons were underrepresented with 16.4% (60) of respondents compared with 18.1% (1,416) of PLWHA case prevalence in Palm Beach County. The 50+ age group was also underrepresented with 34.7% (127) compared with 42.2% (3,289) PLWHA in Palm Beach County.

Special Population	HIV/AIDS Case Prevalence Through 2011* (N=7,789) number percent		Survey Respondents (N=366)	
			number	percent
Heterosexual/Other	4,542	58.3%	256	69.9%
MSM	2,334	30.0%	45	12.3%
Haitian Born	561 7.2%		28	7.7%
Hispanic	1,416	18.1%	60	16.4%
50+ age group**	3,289	42.2%	127	34.7%
*Source: Florida Department of Health, HIV/AIDS & Hepatitis Program (as of 05/16/12) **(Current age on 12/31/2011)				

### Comparison of HIV/AIDS Case Prevalence in Palm Beach County with Survey Respondents by Special Population

Surveys were administered throughout the four main geographic areas of the county to ensure a broad and representative sample - especially in the western area of the county which has a disproportionately high rate of cases. As shown in the following table, the survey sample was approximately proportional to the number of PLWHA in the central and northern areas of the county.

Geographic Location	HIV/AIDS Cases Alive through 2011 EXCL DOC (N=7,635) number Percent		Survey Respondents (N=366)		
			number	percent	
Central County	4289	56.2%	213	58.2%	
North County	422	5.5%	23	6.3%	
South County	2188	28.7%	76	20.8%	
West County	736	9.6%	53	14.5%	
No response	n/a n/a		1	0.2%	
Note: DOH case data excludes ZIP Codes with fewer than 3 cases.					
Source: Florida Department of Health, HIV/A	IDS & Hepa	titis Program			

# Comparison of HIV/AIDS Case Prevalence in Palm Beach County with

### Survey Respondents by Geographic Area

Respondents were asked where they were living when they first tested positive for HIV. Of all respondents, 236 (64.5%) indicated they first tested positive in the same county they live in now (68, 18.6% in another county in Florida). Respondents who said they were living in another state accounted for 14.8% (54) and 8 (2.2%) were living outside the United States. The table below summarizes frequencies and includes the percentages of all respondents and of those who responded to this question.

Residence at Time of Testing Positive					
Survey Question 18A. Where were you living when you first tested positive for HIV? (check one only)					
Survey Respondents					
Residence at Time of Diagnosis	number	percent of all respondents			
		(N=366)			
In the same county I live in now	236	64.5%			
In another county in Florida	68	18.6%			
In another state	54	14.8%			
Outside of the United States	8	2.2%			
Total	366	100.0%			

### Desidence at Time of Testing Desitive

As summarized in the following table, most of the PLWHA in the EMA are in care as are the survey respondents (56.8% of PLWHA in EMA and 57.7% of survey respondents).

PLWHA in Palm Beach County EMA					
PLWHA	Palm Bea	spondents			
PLVVHA	number	percent	Number	percent	
In care	4,392	56.8%	211	57.7%	
Out of Care	3,343	43.2%	155	42.3%	
Total	7,735	100.0%	366	100.0%	

# Comparison of In Care and Out of Care Survey Respondents with

# \*Florida Department of Health, HIV/AIDS & Hepatitis Program

# Socioeconomic Characteristics of Survey Respondents

As summarized in the following tables, 40.4% (148) of respondents indicated a category that was less than a high school graduation level of education as follows:

- Less than high school graduation 88, 24%
- Eighth grade or less 46, 12.6% •

No formal schooling 14, 3.8% ٠

High school or GED was the highest level of education reported by 25.4% (93) respondents.

Survey Question 10A. What is the highest level of education that you have completed? (check only one)				
Level of Education	· · · ·	All Respondents (N=366)		
	number	percent		
High school graduation	93	25.4%		
Less than high school graduation	88	24.0%		
Some college	49	13.4%		
Eighth grade or less	46	12.6%		
College graduate	36	9.8%		
GED (high school equivalency)	27	7.4%		
No formal schooling	14	3.8%		
Technical/trade school	13	3.6%		
Total	366	100.0%		

### Level of Education Completed

When asked to indicate their work situation in the past year, 14.8% (54) indicated they were working a full-time job and 11.7% (43) said they were working off and on. "Not Working", the most frequently reported situation, was reported by 59.8% (219) of all respondents.

Survey Question 12A. What best describes your work situation in the past 12 months? (check one only)				
Employment Status	All Respondents (N=366)			
	number	percent		
Working full-time job	54	14.8%		
Working part-time job	38	10.4%		
Self employed	12	3.3%		
Working off and on	43	11.7%		
Not working	219	59.8%		
Total	366	100.0%		

### **Employment Situation in the Past Year**

Of the 259 respondents who cited a reason for not working, more than half (46.3%, 120) cited health reasons (37.8%, 98 on disability and 8.5%, 22 NOT on disability). More than a third (33.6%, 87) said they had been looking for a job.

Survey Question 13A. Why were you unable to work during the past 12 months? (check one only)				
Reason for Not Working	Respondents (N=366)			
	number	percent		
This does not apply to me. I worked during the past 12 months.	107	29.2%		
Student	5	1.4%		
Looking for a job/unable to find employment	87	23.8%		
Attending job training	1	0.3%		
For health reasons, on disability	98	26.8%		
Retired	1	0.3%		
For health reasons, NOT on disability	22	6.0%		
Other	45	12.3%		
Total	366	100%		

Respondents were asked the following two questions in order to determine their federal poverty level, (Question 14A) "In 2012, how many family members (including yourself) lived in your household?" and (Question 15A) "In 2012, what was the total annual family household income before taxes?"

Nearly three-fourths (77.3%, 283) of the respondents indicated they are living at or below 100% of the federal poverty level. Another 11.2% (41) were living at a rate between 101% and 150% poverty. See the table below for a summary of all responses.

Federal Poverty	All Resp (N=3		Percent of those who answered
Level	number	percent	this question (N=358)
Below 100%	283	77.3%	79.0%
101% - 150%	41	11.2%	11.5%
151% - 200%	7	1.9%	2.0%
201% - 250%	8	2.2%	2.2%
251% - 300%	3	0.8%	0.8%
Over 300%	16	4.4%	4.5%
No response	8	2.2%	n/a
Total	366	100.0%	100.0%

# Respondents by Federal Poverty Level

The next section is divided into four parts as follows:

- Findings regarding PLWHA Survey Respondents Who Are Currently In Care
- Findings regarding PLWHA Survey Respondents Who Are Now In Care, But Have Been Out of Care within the Past Five Years
- Findings regarding PLWHA Survey Respondents Who Are Out of Care
- Findings regarding a Comparison of PLWHA Survey Respondents Who Are Out of Care with PLWHA Survey Respondents Who Are In Care

PLWHA are considered to be "in care" if they have received ...

"...one of the following HIV-related primary medical care services within the past 12 months:

- HIV/AIDS medical care
- Lab work for CD4 count
- Lab work for viral load count

PLWHA who do not meet these criteria are considered to be "out of care".

# 2. PLWHA WHO ARE CURRENTLY IN PRIMARY MEDICAL CARE

Survey respondents were identified as being "in primary medical care" if they met the criteria established by Health Resources and Services Administration (HRSA) as follows:

"...in receipt of one of the following HIV-related primary medical care services within the past 12 months:

- HIV/AIDS medical care
- Lab work for CD4 count
- Lab work for viral load count

As summarized in the following table, 56.8% (4,392) of the PLWHA in the county are in care compared to 57.7% (211) of the survey respondents.

### Comparison of In Care and Out of Care Survey Respondents with PLWHA in Palm Beach County EMA

PLWHA	Palm Bea	ch EMA*	Survey Respondent	
FLVVNA	number	percent	Number	percent
In care	4,392	56.8%	211	57.7%
Out of Care	3,343	43.2%	155	42.3%
Total	7,735	100.0%	366	100.0%
*Florida Department of Health, HIV/AIDS & Hepatitis Program				

Survey respondents who were identified as being in care were asked to describe their frequency of utilization and prioritization of the twenty-six service categories in the continuum of care. In addition, in accordance with HRSA guidelines they were asked about their history and experience being in care, as well as out of care.

Of all 366 respondents, 57.7% (211) were identified as being in primary medical care and 155 (43.2%).

### In or Out of Care

Survey Question 11B. Did you get HIV/AIDS medical care OR a CD4 T-cell count OR a viral load lab test during the past 12 months?

In or Out of Care	Respondents (N=366) number percer	
In Care	211	57.7%
Out of Care	155	43.2%
Total	366	100.0%

# Access to Health Care

Most of the respondents who are in care indicated that they receive their medical care at either the health department (54.8%, 108 out of 197) or a doctor's office (36.6%, 72 out of 197).

Survey Question 32A. Where did you regularly receive your HIV/AIDS medical care during the past 12 months? (check one only)					
Medical Care Provider	Provider (N=211)		In Care Respondents Who Answered a Provider for this Question (N=197)		
	number	percent	number	percent	
This does not apply to me. I did not receive HIV/AIDS-related medical care in the past 12 months	2	0.9%	n/a	n/a	
Walk-In Emergency Clinic	1	0.5%	1	0.5%	
Doctor's Office	72	34.1%	72	36.6%	
Hospital Emergency Room	1	0.5%	1	0.5%	
Veteran's Administration	2	0.9%	2	1.0%	
Public Clinic/Health Department	108	51.2%	108	54.8%	
HIV Specialty Clinic	8	3.8%	8	4.1%	
Other	5	2.4%	5	2.5%	
Respondents with more than one response	12	5.7%	n/a	n/a	

### **Medical Care Provider**

When in-care respondents were asked, "In which county did you get your HIV/AIDS-related medical care in the past 12 months?" nearly all (200, 95.6% of the 209 who responded) mentioned Palm Beach County, 4 mentioned Broward, one said both "Palm Beach and Indian River Counties," and another said "Palm Beach and Broward Counties."

Survey Question 33A. In which county did you get your HIV related medical care in the past 12 months?					
County	In Care Respondents (N=211)		Respond Answe	Care ents Who red this n (N=209)	
	number	percent	number	percent	
Broward	4	1.8%	4	1.9%	
Boyd	1	0.5%	1	0.5%	
Haiti	1	0.5%	1	0.5%	
Jamaica	1	0.5%	1	0.5%	
Palm Beach	200	94.8%	200	95.6%	
Broward and Palm Beach County	1	0.5%	1	0.5%	
Indian River County and Palm Beach County	1	0.5%	1	0.5%	
No Response	2	0.9%	n/a	n/a	
Total	211	100	209	100	

As shown in the following table, 25 (11.8%) of all in-care respondents reported being been hospitalized for an HIV/AIDS related condition during the past 12 months.

Survey Questions 35A. Have you been hospitalized for an HIV/AIDS related condition during the past 12 months?				
Hospital Utilization in the last 12 months? In Care Respondents (N=211) number percent				
No	186	88.2%		

All 211 respondents who are in care were asked to identify barriers to getting the services they needed during the past 12 months. The 71 (33.6%) who responded they had barriers to getting services most frequently mentioned the following:

- Transportation problems (31.0%, 22)
- Didn't know where to get services (26.8%, 19)
- I was depressed (26.8%, 19)

The following table summarizes all responses to this question.

Barriers Trying to Get Needed Services		In Care Respondents (N=211)		spondents wered this n (N=71)
	number	percent	number	percent
This does not apply to me. I did get the services I needed during the past 12 months.	140	66.4%	n/a	n/a
I did not know where to get services	19	9.0%	19	26.8%
I could not get an appointment	12	5.7%	12	16.9%
I could not get transportation	22	10.4%	22	31.0%
I could not get childcare	2	0.9%	2	2.8%
I could not pay for services	13	6.2%	13	18.3%
I did not want people to know that I have HIV	4	1.9%	4	5.6%
I could not get time off work	10	4.7%	10	14.1%
I was depressed	19	9.0%	19	26.8%
I had a bad experience with the staff	14	6.6%	14	19.7%
Services were not in my language	6	2.8%	6	8.5%
I did not qualify for services	12	5.7%	12	16.9%
Other (please specify)	17	8.1%	17	24.0%
Wait List (2) Limited services Sometimes I am not eligible due to my immigration status I have TPS Appointments take too long Lack of communication Did not like timeline I did not go back because I was asked for to many documents Waiting time to long at health department The nurse is trying to get my meds and doctor's appointments in order Migrated to USA I'm not eligible for Medicaid Nurse stopped coming to check my blood sugar because Medicaid does not approve it				

More than half (53.5%, 38) of in care respondents who cited barriers trying to get needed services said they had encountered more than one problem. The table below summarizes the number and percentage of respondents by the number of barriers cited.

Number of Barriers	In Care Respondent who Answered this Question (N=71)			
	number	percent		
One	33	46.5%		
Two to Four	32	45.0%		
More than Four	6 8.5			
Total	71 100.0%			

All 211 respondents who are in care were asked to identify problems they have had trying to get needed services. The 97 (46%) who responded that they had problems trying to access needed services most frequently mentioned the following:

- Transportation problems (32.0%, 31)
- Wait list (32.0%, 31)
- Didn't know how to apply (30.9%, 30)
- Eligibility process to difficult (30.9%, 30)

Survey Question 66A. Have you had any of the following problems while trying to get needed services? (check any or all that apply)				
Problems While Trying to Get Needed Services	In Care Respondents (N=211)		In Care Respondents Who Indicated One or More Problems (N=97)	
	number	percent	number	percent
Did not have any problems trying to get needed services	113	53.6%	n/a	n/a
Turned down/not eligible	26	12.3%	26	26.8%
Didn't know <u>where</u> to apply	26	12.3%	26	26.8%
Didn't know <u>how</u> to apply	30	14.2%	30	30.9%
Transportation problems	31	14.7%	31	32.0%
On wait list	31	14.7%	31	32.0%
Eligibility process to difficult	30	14.2%	30	30.9%
Other	28	13.3%	28	28.9%

More than half (62.9%, 61) of in care respondents who cited problems while trying to get needed services said they had encountered more than one problem. The table below summarizes the number and percentage of respondents by the number of problems cited.

While Trying to Get Needed Services			
Number of Problems	In Care Respondents who Answered this Question (N=97)		
	number	percent	
One	36	37.1%	
Two to Four	60	61.9%	
More than Four	1	1.0%	
Total	97	100.0%	

Number of Problems

A little over a quarter (26.5%, 56) of in care respondents reported they lack permanent housing. 37 (17.5%) said because they did not have enough money for deposit, and 33 (15.6%) said that they did not qualify for housing assistance.

# 3. PLWHA WHO ARE NOW IN CARE, BUT HAVE BEEN OUT OF CARE WITHIN THE PAST FIVE YEARS

The 211 respondents who are currently in care were asked if there had been a period during the last 5 years where they had not gone to the doctor for at least 12 months. Of the 211 respondents in care, 15.6% (33) responded in the affirmative. The table to the right summarizes all responses to this question.

#### Out of Care within the Past 5 Years

Survey Question 26A. During the past five years has there been a period of at least 12 months when you did not go to the doctor for HIV/AIDS medical care?

Out of Care within the Past 5 Years?	In Care Respondents (N=211)	
	number	percent
Yes	33	15.6%
No	177	83.9%
No Response	1	0.5%
Total	211	100.0%

The following table lists all the reasons respondents cited for being out of care. Note that respondents were told to "check any or all that apply." The three most frequently mentioned reasons are as follows:

- I did not have medical insurance (33.3%, 11).
- I could not afford care (33.3%, 11).
- I was using alcohol or drugs (33.3%, 11).

Survey Question 29A. What prevented you from getting HIV/AIDS medical care during this time? (check any or all that apply)			
Reasons for preventing HIV/AIDS Medical Care		In Care Respondents Who Had Been Out of Care and Returned to Care (N=33)	
		percent	
I did not have medical insurance.	11	33.3%	
I could not afford care.	11	33.3%	
I had heard bad things about the medications and their side effects.	6	18.2%	
I knew where to go but I did not want to go there.	2	6.1%	
I was afraid of being identified as HIV-positive.	5	15.2%	
I was using drugs or alcohol.	11	33.3%	
I found it difficult to apply for insurance.	8	24.2%	
Other (please specify)	9	27.3%	
No transportation			
Homeless			
Family Problems Life issues, son passed away, got killed			
Just because I started working so I missed my appointment			
I couldn't miss school Could not get off from work			
Long waiting period at the clinic			

#### **Out of Care Reasons**

The table to the right summarizes the number of reasons respondents identified for having been out of HIV/AIDS medical care. Close to half (42.4%, 14) cited only one reason, while more than half (57.6, 19%) cited two or more reasons, suggesting that PLWHA who are out of care may need to overcome multiple problems in order to get into and stay in care.

### Number of Reasons for Having Been Out of Care

Number of Reasons	In Care Respondents Who Had Been Out of Care and Returned to Care (N=33) number percen	
	number	percent
1	14	42.4%
1 2 to 4		•
	14	42.4%

The thirty-three in care respondents who had been out of care for at least 12 months within the past five years were asked what services did they need but not get while they were out of care. The three most frequently identified services were transportation (51.5%, 17), food (51.5%, 17), and housing (48.5%, 16). The table to the right displays all responses to this question.

#### Services Needed When Out of Care

Survey Question 30A. While you were out of HIV/AIDS medical care, what services did you need and not get? (check any or all that apply)

Services Needed When Out of Care	In Care Respondents Who Were Out of Care (N=33)	
	number	percent
Food	17	51.5%
Financial assistance	15	45.5%
Housing	16	48.5%
Transportation	17	51.5%
Case management	15	45.5%
Substance abuse treatment	12	36.4%
Treatment Adherence	7	21.2%
Mental health services	8	24.2%
None/No response	2	6.1%
Other (specify)	6	18.2%
None (2)		
Homeless		
Medicines		
Better hrs		
Support-		
services		

The table below displays the number of services that the respondents identified. More than three-fourths (78.8%, 26) said they needed, but could not get more than one service while they were out of care.

Number of Services You Needed But Couldn't Get	In Care Respondents Who Were Out of Care and Returned to Care (N=33)	
	number	percent
1	5	15.1%
2 to 4	19	57.6%
More than 4	7	21.2%
None/No Response	2	6.1%
Total	33	100.0%

Respondents who are currently in care but had been out of care for at least 12 months over the past five years, were asked to identify the reasons for returning to HIV/AIDS medical care. The most frequently identified reasons were:

- I was able to deal with other problems in my life that kept me out of care. (51.5%, 17).
- I got sick and knew I needed care (48.5%, 16).
- I was ready to deal with my illness (33.3%, 11).

The following table summarizes all the responses to this question.

### **Reasons for Returning to Care**

Survey Question 31A. What are the reasons that you would go back to HIV/AIDS medical care? (check any or all that apply)			
Reasons for Returning to Care		In Care Respondents Who Had Been Out of Care and Returned to Care (N=33)	
		Percent	
I got sick and knew I needed care.	16	48.5%	
I was ready to deal with my illness.	11	33.3%	
I got a referral to get into care.	5	15.2%	
An outreach worker found me and helped me get into care.	9	27.3%	
I was able to deal with other problems in my life that kept me out of care.	17	51.5%	
Other, for example:	3	9.1%	
Insurance issues I am aware that I need to keep up with medical care I got insurance			

More than half (54.5%, 18) identified more than one reason that they returned to care. The data in the table to the right suggest that PLWHA returning to care is a complex process. The table below contains all of the responses.

Returning to Care			
Number of Reasons	In Care Respondents Who Had Been Out of Care and Returned to Care (N=33)		
	number	percent	
1	15	45.5%	
2 to 4	17	51.5%	
5 to 8	1	3.0%	
Total	33	100.0%	

# Number of Reasons for Returning to Care

# 4. PLWHA WHO ARE OUT OF CARE

Per HRSA's definition, PLWHA have not received primary medical care and are "out of care" if they have not had at least one of the following during the last 12 months:

- HIV/AIDS medical care
- Lab work for CD4 count
- Lab work for viral load count

As summarized in the following table, 43.2% of PLWHA in Palm Beach County are out of care compared 42.3% of survey respondents.

	Palm Bea	ch EMA Survey Respondent		spondents
PLWHA	number	percent	number	percent
In care	4,392	56.8%	211	57.7%
Out of Care	3,343	43.2%	155	42.3%
Total	7,735	100.0%	366	100.0%

# Comparison of In Care and Out of Care Survey Respondents with PLWHA in Palm Beach County EMA in 2011 as of 12/31/11

The following table summarizes some of the demographic and risk exposure categories and geographic region of the 155 respondents who were not in care.

Who are Out of Primary Medical Care (N=155)				
Race/Ethnicity	number	percent		
Black	107	69.03%		
White	42	27.10%		
Mixed/More than One Race	5	3.23%		
Other	1	0.64%		
Ethnicity	number	percent		
Hispanic/Latino/a	24	15.48%		
Not Hispanic/Latino/a	126	81.29%		
Haitian	5	3.23%		
Gender	number	percent		
Male	77	49.68%		
Female	78	50.32%		
Transgender	0	0.00%		
Age	number	percent		
Under 18	0	0.00%		
18-24	12	7.74%		
25-29	19	12.26%		
30-39	28	18.06%		
40-44	32	20.65%		
45-49	27	17.42%		
50-59	30	19.35%		
60-69	7	4.52%		
70.				
70+	0	0.00%		
70+ Special Populations	0 number	0.00% percent		
Special Populations	number	percent		
Special Populations Black heterosexual	number 72	<b>percent</b> 46.45%		
Special Populations Black heterosexual MSM	<b>number</b> 72 23	<b>percent</b> 46.45% 14.84%		
Special Populations Black heterosexual MSM Haitians	number           72           23           5	percent           46.45%           14.84%           3.23%		
Special Populations Black heterosexual MSM Haitians Hispanics	number 72 23 5 24	percent           46.45%           14.84%           3.23%           15.48%		
Special Populations Black heterosexual MSM Haitians Hispanics Recently Incarcerated	number           72           23           5           24           0	percent           46.45%           14.84%           3.23%           15.48%           0.00%		
Special Populations Black heterosexual MSM Haitians Hispanics Recently Incarcerated 50+ Age Group	number           72           23           5           24           0           37	percent           46.45%           14.84%           3.23%           15.48%           0.00%           23.87%		
Special PopulationsBlack heterosexualMSMHaitiansHispanicsRecently Incarcerated50+ Age GroupGeographic Region	number           72           23           5           24           0           37           number	percent         46.45%         14.84%         3.23%         15.48%         0.00%         23.87%         percent		
Special PopulationsBlack heterosexualMSMHaitiansHispanicsRecently Incarcerated50+ Age GroupGeographic RegionEast County	number           72           23           5           24           0           37           number           83	percent         46.45%         14.84%         3.23%         15.48%         0.00%         23.87%         percent         53.55%		

#### Characteristics of Respondents

# Who are Out of Primary Medical Care (N=155)

Respondents were asked what best describes their situation regarding being out of care. Of the 155 respondents who were out of care, (72.9%, 113) reported that they had been receiving care for HIV but had stopped more than 12 months ago. 12.3% (19) respondents had <u>not</u> been recently diagnosed but had never been in medical care, and 11.6% (18) respondents had recently been diagnosed with HIV and have not entered medical care.

Question 21A. What best describes your situation? (check only one)					
Out of Care Situation	Out of Care Respondents (N=155)				
	number	Percent			
I have recently been diagnosed with HIV, and have not entered medical care.	18	11.6%			
I have <u>not</u> been recently diagnosed but have never been in medical care.	19	12.3%			
I had been receiving medical care for HIV, but I stopped more than 12 months ago.	113	72.9%			
Other (specify)	5	3.2%			
Drug user (2) When I found out that I had HIV I just gave up on everything The medicine made me sick so I stopped after I was diagnosed Just so tired of all these meds and doctors appointments					
Total	155	100.0%			

#### **Out of Care Situation**

When asked about the reasons for not being in care, the five most frequently mentioned reasons were:

- I did not feel sick. (57.4%, 89)
- I was depressed. (38.7%, 60)
- I did not want people to know that I have HIV. (37.4%, 58)
- I was not ready to deal with having HIV. (36.8%, 57)
- I could not get transportation. (24.5%, 38)

The following table summarizes all responses to this question.

Survey Question 22A. If you did not get HIV/AIDS medical care during the past 12 months, please indicate the reason/s why? (check any or all that apply)			
Reasons for Not Getting Medical Care	Out o Respor (N=:	ndents	
	number	percent	
This does not apply to me. I got HIV/AIDS related medical care in the past 12 months.	0	0.0%	
I did not know where to go.	12	7.7%	
I could not get an appointment.	17	11.0%	
I could not get transportation.	38	24.5%	
I could not get childcare.	8	5.2%	
I could not pay for services.	22	14.2%	
I did not want people to know that I have HIV.	58	37.4%	
I was not ready to deal with having HIV.	57	36.8%	
I did not feel sick.	89	57.4%	
I could not get time off work.	7	4.5%	
I was depressed.	60	38.7%	
I had a bad experience with the medical staff.	20	12.9%	
Other (specify)	30	19.4%	
Drug User (4)			
Ready to give up			
Can't stop using drugs			
No private place to go			
When I got out of jail they gave me Pravastatin			
Everybody knows your business at the clinic.			
No interest in life anymore.			
People I knew at health center			
Appointments not available when I could go			
Scared to go get help			
I get so angry sometimes with my husband			
I am very hurt			
My family is ashamed of me			
Newly diagnosed			
I am happy I talked to this nice lady today. I am going to start back doing the right thing			
Lazy			
Could not get Medicaid, denied medical services			
I hate to go to the clinic			
My money too important			
I believe I'm okay			

# **Reasons for Not Getting Medical Care**

I feel I don't have it	
Right now it's too late	
I did not feel sick other than fatigue and nausea so made no	
relationship to HIV	
13 years positive, I was in the hospital when I found out	
l don't care	
Child's mother on drugs	
HIV isn't going anywhere,	
in a few years everybody is going to have it	

As summarized in the following table, 80.6%, (125) identified more than one reason for being out of care.

Medical Care				
Number of Reasons	Out of Care Respondents (N=155)			
	number	percent		
1	30	19.4%		
2	42	27.1%		
3	47	30.3%		
4	21	13.5%		
5	11	7.1%		
6	4	2.6%		
Total	155	100.0%		

#### Number of Reasons for Not Getting Medical Care

When service providers were asked, "What are the most common reasons that people living with HIV/AIDS are not in primary medical care?" their responses were similar as summarized in the following table:

#### **Reasons for Not Getting Medical Care**

Survey Question 22A. If you did not get HIV/AIDS medical care during the past 12 months, please indicate the reason/s why? (check any or all that apply)

Provider Survey Question 18. What are the most common reasons that people living with HIV/AIDS are not in primary medical care? (check all that apply)

Reasons for Not Getting Medical Care	Respo	Out of Care Respondents (N=155)		Provider Respondents (N=11)	
	number	percent	number	percent	
This does not apply to me. I got HIV/AIDS related medical care in the past 12 months.	0	0.0%	0	0.0%	
I did not know where to go.	12	7.7%	3	27.3%	
I could not get an appointment.	12	11.0%	2	18.2%	
I could not get transportation.	38	24.5%	5	45.5%	
I could not get childcare.	8	5.2%	3	27.3%	
I could not pay for services.	22	14.2%	3	27.3%	
I did not want people to know that I have HIV.	58	37.4%	6	54.5%	
I was not ready to deal with having HIV.	57	36.8%	6	54.5%	
I did not feel sick.	89	57.4%	5	45.5%	
I could not get time off work.	7	4.5%	5	45.5%	
I was depressed.	60	38.7%	4	36.4%	
I had a bad experience with the medical staff.	20	12.9%	3	27.3%	
Other (specify)	30	19.4%	2	18.2%	
Drug user (5)	1		1	1	
Ready to give up					
No private place to go					
When I got out of jail they gave me Pravastatin					
Everybody knows your business at the clinic					
No interest in life anymore					
People I knew at health center					
Appointments not available when I could go					
Scared to go get help					
I get so angry sometimes with my husband					
I am very hurt					
My family is ashamed of me					
Newly diagnosed I am happy I talked to this nice lady today, I am going to start back doing the right thing Lazy					
Could not get Medicaid, denied medical services					

I hate to go to the clinic

My money too important

I believe I'm okay				
I feel I don't have it				
Right now it's too late				
I did not feel sick other than fatigue and nausea so	made no			
relationship to HIV				
13 years positive, I was in the hospital when I foun	d out			
I don't care				
Child's mother on drugs				
HIV isn't going anywhere, in a few years everybody	/ is going to	o have it		
Per Providers:				
Ryan White eligibility process is burdensome				
Thank goodness all veterans are eligible for HIV pr	imary care	services		
No Response	0	0.00%	1	9.1%

Provider respondents and out of care respondents identified the same reasons for being out of care but provider respondents cited several of these reasons at higher rates. For example, while 37.4% of out of care respondents cited "I did not want people to know that I have HIV", 54.5% of providers cited that reason. The following table summarizes a comparison of some of the reasons cited by more frequently by providers than out of care respondents.

#### **Reasons for Not Getting Medical Care**

Reasons	Out of Care Respondents Re (N=155)		Respo	Provider Respondents (N=11)	
	number	percent	number	percent	
I did not want people to know that I have HIV.	58	37.4%	6	54.5%	
I was not ready to deal with having HIV.	57	36.8%	6	54.5%	
I could not get transportation.	38	24.5%	5	45.5%	

When respondents who are not in HIV/AIDS medical care were asked what services would help them get into care, the three most frequently chosen responses were substance abuse treatment (58.1%), housing (57.4%), and transportation (53.4%). The table below summarizes all responses to this question.

HIV/AIDS medical care? (check any or all that apply)			
Services Needed	Out of Care Respondents (N=155)		
	number	percent	
Financial assistance	76	49.0%	
Food	67	43.2%	
Housing	89	57.4%	
Case management	46	29.7%	
Transportation	83	53.4%	
Substance abuse treatment	90	58.1%	
Mental health services	46	29.7%	
Treatment Adherence	33	21.3%	
Other (e.g. more caring people, privacy, insurance)	26	16.8%	

Services Needed to Get Into Primary Medical Care

Survey Question 24A. What services would help you to get

The following table summarizes the number of supportive services needed by respondents who are out of care in order to get into care. For example, 14.8% (23) said they needed only one service. Of all out of care respondents, 85.2% (132) said they needed more than one.

# Number of Services Needed to Get Into Medical Care

Number of Services Needed	Out of Care Respondents (N=155)		
	number	percent	
1	23	14.8%	
2	27	17.4%	
3	32	20.7%	
4	24	15.5%	
5	24	15.5%	
6	14	9.0%	
7	8	5.2%	
8	0	0.0%	
9	3	1.9%	
Total	155	100.0%	

Providers were asked the same question regarding services that PLWHA need to get into primary medical care. In general, provider respondents and out of care respondents identified the same scope of services needed, but provider respondents cited these services more frequently.

For example, 63.6% of provider respondents indicated that PLWHA need case management services to get into care, while only 29.7% of out of care respondents did. Likewise, 54.5% of providers indicated that PLWHA need mental health services, compared to 29.7% of out of care respondents who cited this service as necessary to get into care.

In the table below, the three most frequently mentioned responses are highlighted.

#### Services Needed to Get Into Primary Medical Care

Survey Question 24A. What services would help you to get HIV/AIDS medical care? (check any or all that apply)

Provider Question 19. What services, other than medical care and medication, do people living with HIV/AIDs need to get into primary medical care? (check all that apply)

Services Needed	Respo	Out of Care Respondents (N=155)		Provider Respondents (N=11)	
	number	percent	number	percent	
Financial assistance	76	49.0%	3	27.3%	
Food	67	43.2%	4	36.4%	
Housing	89	57.4%	5	45.5%	
Case management	46	29.7%	7	63.6%	
Transportation	83	53.4%	6	54.5%	
Substance abuse treatment	90	58.1%	5	45.5%	
Mental health services	46	29.7%	6	54.5%	
Treatment Adherence	33	21.3%	3	27.3%	
Other (e.g. more caring people, privacy, insurance)	3	4.3%	1	9.1%	
No response	0	0.0%	1	9.1%	

Respondents who are out of care were asked what would be some reasons they would go to the doctor for HIV/AIDS medical care. The most frequently cited reasons were:

- When I get sick and know I need care. 77.4% (120)
- When I am ready to deal with my illness. 43.2% (67)
- I get transportation to go to a doctor or clinic. 30.3% (47)

The following table summarizes all responses to this question.

Survey Question 25A. What would be some of the reasons why you would go to the doctor for HIV/AIDS medical care? (check any or all that apply)							
Reasons	Out of Care Respondents (N=155)						
	number	percent					
I get sick and know I need care.	120	77.4%					
I am ready to deal with my illness.	67	43.2%					
Someone else with HIV/AIDS reaches out to me.	44	28.4%					
I get transportation to go to a doctor or clinic.	47	30.3%					
Someone arranges to have my care paid for.	37	23.9%					
Other (explain)	13	8.4%					
A private place to go He want help Have some one walk me through it Too sick to do for myself Just found out status All the help available People like this lady staying in my life, who did this survey Help with money I will go when I am ready I guess if I am about to die Do not want to be judged and able to be self, prefer one-on-one No partiality Maybe if I am about to die							

#### **Reasons to Enter Primary Medical Care**

Most respondents who are not in care (63.9%, 99) cited more than one reason to enter care. The following table summarizes the number of reasons cited by all respondents who are out of care.

Number of Reasons Cited	Out o Responder	
	number	percent
1	56	36.1%
2	51	32.9%
3	28	18.1%
4	14	9.0%
5	6	3.9%
Total	155	100.0%

#### Number of Reasons to Get Into Medical Care

Providers were asked to identify the reasons that would prompt PLWHA to enter primary medical care. Providers and PLWHA alike most frequently cited the following two reasons:

- "Get sick and know I/they need care."
- "...ready to deal with my/their illness."

As with other survey items, providers and PLWHA identified the same scope of responses, but provider respondents cited these responses more frequently. In the table below, the most frequently cited reasons are highlighted.

#### **Reasons to Enter Primary Medical Care**

Survey Question 25A. What would be some reasons why you would go to the doctor for HIV/AIDS medical care? (check any or all that apply)

Provider Survey 20. What would be some reasons people living with HIV/AIDS would enter primary medical care? (check all that apply)

Reasons	Respo	f Care ndents 155)	-	vider ndents :11)					
	number	percent	number	Percent					
I get sick and know I need care.	120	77.4%	10	90.9%					
I am ready to deal with my illness.	67	43.2%	8	72.7%					
Someone else with HIV/AIDS reaches out to me.	44	28.4%	5	45.5%					
I get transportation to go to a doctor or clinic.	47	30.3%	5	45.5%					
Someone arranges to have my care paid for.	37	23.9%	5	45.5%					
Other (explain)	13	8.4%	1	9.1%					
A private place to go He want help Have some one walk me through it Too sick to do for myself Just found out status All the help available People like this lady staying in my life, who did this survey Help with money I will go when I am ready I guess if I am about to die Do not want to be judged and able to be self, prefer one-on-one No partiality Maybe if I am about to die <b>Per Provider:</b> Free HIV testing to identify patients sooner									
Skipped question	0	0.0%	1	9.1%					

# 5. COMPARISON OF PLWHA WHO ARE IN CARE WITH PLWHA WHO ARE OUT OF CARE

The data in this section highlight some of the socioeconomic differences between survey respondents who are in care and respondents who are out of care.

Overall, out of care respondents reported a lower level of educational achievement than in care respondents.

Survey Question 11A. What is the highest level of education that you have completed? (check only one)											
Level of Education	-	ondents 366)	Respo	Care ndents 211)	Out of Care Respondents (N=155)						
	number	percent	number	percent	number	Percent					
Less than high school graduation	88	24.0%	46	21.8%	42	27.1%					
High school graduation	93	25.4%	51	24.1%	42	27.1%					
Some college	49	13.4%	32	15.2%	17	11.0%					
Eighth grade or less	46	12.6%	20	9.5%	26	16.8%					
College graduate	36	9.8%	32	15.2%	4	2.5%					
GED (high school equivalency)	27	7.4%	14	6.6%	13	8.4%					
No formal schooling	14	3.8%	9	4.3%	5	3.2%					
Technical/trade school	13	3.6%	7	3.3%	6	3.9%					
Total	366	100.0%	211	100.0%	155	100.0%					

#### Comparison of Highest Level of Education Completed

A higher percentage of respondents who are out of care indicated that they were unemployed compared to those who are in care (67.1% out of care compared to 54.5% in care). Among respondents in both groups, "working part-time" was the third most frequently mentioned status (11.9% in care compared to 8.4% out of care).

Survey Question 12A. What best describes your work situation in the past year? (check one only)										
Employment Status	All Resp (N=3		In C Respoi (N=2	ndents	Out of Care Respondents (N=155)					
	number	percent	number	percent	number	percent				
Working full-time job	54	14.8%	41	19.4%	13	8.4%				
Working part-time job	38	10.4%	25	11.9%	13	8.4%				
Self employed	12	3.3%	8	3.8%	4	2.6%				
Working off and on	43	11.7%	22	10.4%	21	13.5%				
Not working	219	59.8%	115	54.5%	104	67.1%				
Total	366	100.0%	211	100.0%	155	100.0%				

#### Comparison of Work Situation in the Past Year

Г

Among those who cited a reason for not working, "looking for a job" was the most frequently mentioned reason among out of care respondents compared to 23.5% of in care respondents.

The reason most frequently cited by in care respondents was "for health reasons, on disability" (57.6%) while only 17.3% of out of care respondents mentioned this reason.

Nearly 10% of in care and out of care respondents mentioned "for health reasons, NOT on disability".

Survey Question 13A. Why were you unable to work during the past 12 months? (check one only)									
Reason for Not Working	Responde answer Question		who ans	espondents wered this n (N=132)	Out of Care Respondents who answered this Question (N=127)				
	number	percent	number	percent	number	Percent			
Student	5	1.9%	3	2.3%	2	1.6%			
Looking for a job	87	33.6%	31	23.5%	56	44.1%			
Attending job training	1	0.4%	1	0.7%	0	0.0%			
For health reasons, on disability	98	37.8%	76	57.6%	22	17.3%			
Retired	1	0.4%	1	0.7%	0	0.0%			
For health reasons, NOT on disability	22	8.5%	12	9.1%	10	7.9%			
*Other	45	17.4%	8	6.1%	37	29.1%			
Total	259	100.0%	132	100.0%	127	100.0%			
*Other includes reasons such as the fo	llowing:								
All Respondents	In Ca	re Responde	ents	Out of Care Respondents					
jail no legal paperwork homeless taking care of elderly father work not steady	out of cour no legal pa homeless taking care work not st	perwork of elderly fa	ather	Jail on drugs out of work just don't wa hours are lo	ng				
on drugs out of work just don't want to hours are long work the streets out of country				work the str	eets				

#### **Comparison of Reasons for Not Working**

Respondents' 2012 annual household size and income were compared to Federal Poverty Levels (FPL). As shown in the following table, a higher percentage of the out of care respondents were living at or below 100% of the FPL than the in care respondents, 80.6% and 74.9%, respectively.

Federal Poverty Level	(10-500)		In C Respoi (N=2	ndents	Out of Care Respondents (N=155)			
	number	percent	number	number percent		percent		
Below 100%	283	77.3%	158	74.9%	125	80.6%		
101% - 150%	41	11.2%	26	12.3%	15	9.7%		
151% - 200%	7	1.9%	4 7.9%		3	1.9%		
201% - 250%	8	2.2%	7	3.3%	1	0.6%		
251% - 300%	3	0.8%	1	0.5%	2	1.4%		
Over 300%	16	4.4%	15	7.1%	1	0.6%		
No response	8	2.2%	0	0.0%	8	5.2%		
Total	366	100.0%	211	100.0%	155	100.0%		

Comparison of In Care and Out of Care at Federal Poverty Level

# 6. PRIORITIZATION OF SERVICE CATEGORIES

Respondents who are in care were asked to identify the five service categories they considered to be most important to *them*.

The five most frequently selected service categories include the following:

- Primary Medical Care (60.2%, 127)
- Laboratory Diagnostic Testing (54.0%, 114)
- Medications (53.1%, 112)
- Case Management (47.4%, 100)
- Food Bank or Food Vouchers (37.9%, 80)

	C3							
Survey Question 36A. Which five services do you think are most important for people with HIV/AIDS?								
Service Category	Respo	Care ndents 211)						
	number	percent						
Primary Medical Care	127	60.2%						
Laboratory Diagnostic Testing	114	54.0%						
Medications	112	53.1%						
Case Management	100	47.4%						
Food Bank or Food Vouchers	80	37.9%						

The table on the following page summarizes all in care responses to this question as well as the responses of service providers.

# Five Most Important Services

Five Most Important Services Survey Question 36A. Which five services do you think are most important for people with HIV/AIDS?										
Provider Survey Question 21. If we have limited funding, what are the five (5) most important services?										
Service Category	Respo	Care ondents =211)	Provider Respondents (N=11)							
	#	# %		%						
Primary Medical Care	127	60.2%	5	45.5%						
Laboratory Diagnostic Testing	114	54.0%	4	36.4%						
Medical Specialist	42	19.9%	4	36.4%						
Nurse Care Coordination	10	4.7%	1	9.1%						
Case Management	100	47.4%	7	63.6%						
Medications	112	53.1%	5	45.5%						
Dental /Oral Health	38	18.0%	3	27.3%						
Health Insurance	22	10.4%	2	18.2%						
Mental Health Services	27	12.8%	1	9.1%						
Substance Abuse Residential	4	1.9%	0	0.0%						
Substance Abuse Outpatient	3	1.4%	0	0.0%						
Nutrition Counseling	9	4.3%	1	9.1%						
Early Intervention Services	21	10.0%	1	9.1%						
Home Health Care	4	1.9%	0	0.0%						
Hospice Services	1	0.5%	0	0.0%						
Food Bank or Food Vouchers	80	37.9%	1	9.1%						
Transportation	41	19.4%	2	18.2%						
Outreach	19	9.0%	3	27.3%						
Health Education/Risk Reduction	7	3.3%	0	0.0%						
Treatment Adherence	18	8.5%	0	0.0%						
Legal Support	19	9.0%	1	9.1%						
Rehabilitation	2	0.9%	1	9.1%						
<b>Emergency Financial Assistance</b>	15	7.1%	1	9.1%						
Linguistic Services	2	0.9%	0	0.0%						
Peer Mentoring	12	5.7%	1	9.1%						
Housing	60	28.4%	1	9.1%						
Support Groups	11	5.2%	1	9.1%						
Other (please specify)	2	0.9%	0	0.0%						
No Response	3	1.4%	1	9.1%						

#### **Five Most Important Services**

Notable differences between PLWHA and providers include the following:

- Providers cited Case Management as the most important service, while PLWHA ranked Primary Medical Care as the most important service.
- 54.0% of PLWHA cited Laboratory Diagnostic Testing as one of the five most important services compared to 36.4% of providers who mentioned this service category
- Providers mentioned Medical Specialist at almost twice the rate of PLWA (36.4% compared to 19.9%).
- Food was mentioned by 37.9% of PLWHA but by 9.1% of providers.

# 7. SERVICE UTILIZATION, GAPS, AND BARRIERS

Survey respondents in care were asked to describe their level of utilization of the twenty-seven service categories prioritized by the planning council. The 211 respondents in care described their utilization of each survey categories as one of the following:

- "I received this service" if they utilize the service
- "I needed this service but was unable to get it" to show possible gaps in services
- "I needed this service but was unaware if it was offered or how to access" to show barriers to service utilization
- "I did not need this service" if they do not utilize the service

#### Utilization: "I received this service"

The five most frequently utilized "I received this service" services:

Laboratory Diagnostic Testing 95.7%, 202 Primary Medical Care 92.9%, 196 Medications 90.0%, 190 Case Management 81.5%, 172 Oral/Dental Health 75.8%, 160

Gaps: "I needed this service but was unable to get it"

The five top ranked "I needed this service but was unable to get it" services: Housing 13.7%, 29 Food Bank or Food Vouchers 10.0%, 21 Transportation 9.5%, 20 Emergency Financial Assistance 8.5%, 18 Case Management 7.1%, 15

In the Out of Care section of this report, data from respondents who are out of care report several service gaps. When respondents who are not in HIV/AIDS medical care were asked what services would help them get into care, the three most frequently chosen responses were "substance abuse treatment" (58.1%) , "housing" (57.4%), and "transportation" (53.4%).

#### **Barriers**

The top five services in the "I needed this service but was unaware if it was offered or how to access" categories were:

- 1. Emergency Financial Assistance (17.1%)
- 2. Food Bank or Food Vouchers (15.2%)
- 3. Legal Support (13.3%)
- 4. Housing (10.0%)
- 5. Support Groups (9.5%)

The following table summarizes all responses regarding utilization, gaps, and barriers with the top five ranked services highlighted for emphasis.

Utilization Gaps Barriers												
	U	tilizati	on		Gap	S						
Service Categories		l received this service		servi	I needed this service but was unable to get it		I needed this service but was unaware if it was offered or how to access			I did I	l did not need th service	
	Rank	#	%	Rank	#	%	Rank	#	%	Rank	#	%
CORE SERVICES												
Outpatient Medical Care												
Primary Medical	2	196	92.9%		4	1.9%		1	0.5%		10	4.7%
Laboratory Diagnostic Testing	1	202	95.7%		4	1.9%		1	0.5%		4	1.9%
Medical Specialist		159	75.4%		5	2.4%		9	4.3%		38	18.0%
Nurse Care Coordination		72	34.1%		8	3.8%		10	4.7%		121	57.3%
Case Management	4	172	81.5%	5	15	7.1%		5	2.4%		19	9.0%
Medications	3	190	90.0%		5	2.4%		5	2.4%		11	5.2%
Dental/Oral Health	5	160	75.8%		12	5.7%		11	5.2%		28	13.3%
Health Insurance		83	39.3%		9	4.3%		12	5.7%		106	50.2%
Mental Health Services		84	39.8%		4	1.9%		11	5.2%		112	53.1%
Substance Abuse Treatment												
Substance Abuse Residential		34	16.1%		4	1.9%		7	3.3%		166	78.7%
Substance Abuse Outpatient		23	10.9%		3	1.4%		10	4.7%	5	175	82.9%
Nutrition Counseling		112	53.1%		7	3.3%		11	5.2%		81	38.4%
Early Intervention Services		57	27.0%		5	2.4%		10	4.7%		139	65.9%
Home Health Care		15	7.1%		3	1.4%		7	3.3%	3	185	87.7%
Hospice Services		3	1.4%		0	0.0%		1	0.5%	1	207	98.1%
	1	1	1			1			1	1		
Food Bank or Food Vouchers		113	53.6%	2	21	10.0%	2	32	15.2%		45	21.3%
Transportation		103	48.8%	3	20	9.5%		18	8.5%		70	33.2%
Outreach		32	15.2%		3	1.4%		10	4.7%		164	77.7%
Health Education/Risk Reduction		94	44.5%		4	1.9%		13	6.2%		100	47.4%
Treatment Adherence		98	46.4%		4	1.9%		10	4.7%		99	46.9%
Legal Support		69	32.7%		11	5.2%	3	28	13.3%		103	48.8%
Rehabilitation Services		22	10.4%		3	1.4%		14	6.6%		171	81.0%
Emergency Financial Assistance		61	28.9%	4	18	8.5%	1	36	17.1%		96	45.5%
Linguistics Services		19	9.0%		4	1.9%		12	5.7%	4	176	83.4%
Peer Mentoring		67	31.8%		7	3.3%		18	8.5%		119	56.4%
Housing		65	30.8%	1	29	13.7%	4	21	10.0%		96	45.5%
Support groups		79	37.4%		5	2.4%	5	20	9.5%		107	50.7%
Other (extended service hours, etc.)		0	0.0%		1	0.5%		6	2.8%	2	202	95.7%

# Service Utilization, Gaps, and Barriers

# 8. FINDINGS FROM PROVIDER SURVEYS

The eleven providers who completed a 22-item on-line survey represented a broad range of types of organizations and agencies that provide services to PLWHA in Palm Beach County as follows:

Type of Organization or Agency	number	percent
Community-based organization (not AIDS-specific)	2	18.2
Substance abuse treatment facility	1	9.1%
Public Health Department	1	9.1%
Other (please specify)	7	63.6%
Non Profit Organization, Non Direct Service Provider		
Community Health Center/ASO		
Therapeutic Group Home		
VA Medical Center - Out Pt. Clinic		
Infectious Disease Practice		
Pharmacy Services		
Legal Services		

#### **Provider Survey Respondents**

Provider Survey responses included information about providers' efforts to:

- Address racial, gender, and geographic disparities
- Improve services
- Mitigate barriers to delivering services to PLWHA
- Enhance efforts to collaborate and coordinate with other organizations
- Plan for expansion of service delivery

Most of the organizations that participated in the Provider Survey report that they are working to address racial, gender, and geographic disparities in health outcomes for PLWHA. Ryan White funded organizations comply with the Cultural Competency and Linguistic Standards of Care implemented in 2003.

The following is a list of the providers' responses to Provider Survey Question 13 "How is your organization working to address racial, gender, and geographic disparities health outcomes for PLWHA?"

- We have a prevention and outreach department that reaches out to various groups of people throughout the county and across racial and gender lines. We also have the following support groups: "Brothas Speak" for Black MSM, a group for HIV+ women, a group for HIV+ MSM of all races, and a group for HIV+ Latino men. Our constituents live throughout the county and we advertise our services through our website, our weekly e-mail blast which has over 3600 subscribers, our bi-weekly column in the South Florida Gay News (which has over 350 distribution points throughout Palm Beach, Broward, and Miami-Dade Counties), and our Facebook page (with over 2100 followers).
- Assist clients in receiving Health Care District and Medicaid, prevention programs that target at risk populations, teen clinic in Belle Glade, migrants, incarcerated.

- By providing a comprehensive program to address medical and support service needs of people living with HIV/AIDS. CAP/FoundCare is the largest organization devoted to serving people living with HIV/AIDS with a wide array of services in Palm Beach County.
- We do not discriminate against any population. We service 8-18 year old youth.
- All veterans are treated equally.
- Work with other organization with free HIV testing lectures.
- Provide information, education and outreach that targets population at risk of HIV or HIV positive. Work in collaboration with community businesses and faith base organizations.
- We currently serve all patients equally regardless of race, gender, and location
- Through culturally competent, linguistically diverse providers.

In analyzing providers' responses, several main categories or themes emerged. These categories or themes as well as more specific responses are listed in the following sections.

Providers responded to the question "What is the single most important change you would suggest to improve services for individuals or families infected with HIV?" as follows:

## Increase Service Capacity & Availability

- Housing
  - o Need more available low cost housing options
- Easier access to care
- Make access to case managers easier to patients

## Promote Client Empowerment

• A housing program that would include training for clients to empower them to take responsibility for their health. This would include GED programs, job interview training, and childcare. This would not be a free service, but based on what the client could pay, either in cash or service until they were gainfully employed.

## Improve Systematic Approach to Change

- Larger selection of providers
- Include more consumers in the decision making process
- Follow the treatment cascade, prevention, treatment, retention and adherence
- Diversify funding so clients can have more choice to where they can get assistance
- Better messaging about available services

When providers were asked to, "List three barriers that their organization has faced when providing care to people living with HIV/AIDS," they responded as follows:

# Systematic Issues

- Contracting process
  - Financial constraints: having to work within the strict guidelines of the funder
- Funding
  - Lack of funding for program rent, leading to loss of space to provide services
  - Lack of funding
  - Limited funding (rationing services)
- Eligibility
  - Non compliance from clients regarding eligibility documentation
  - Eligibility documentation: Income/Insurance
  - Too much paperwork

# Service Capacity & Availability

- Case Management
  - Access to case management
- Mental Health and Substance Abuse
  - Mental Health
  - Drug Rehab
- Housing
  - Homelessness
- Transportation
  - Lack of transportation for patients
  - Client transportation issues
- Dental
  - Dental care is not covered

# Psychological and Cultural Issues

- Treatment Adherence
  - Client adherence to scheduled medical appointments
- Literacy issues

Six providers specified the following ways in which the CARE Council could help their agencies better coordinate services with other providers in the area:

# Facilitate Outreach and Networking

- Organize at least once a year a health resource fair
- Have a quarterly provider symposium for managers and front-line staff
- Actively engage in the process to facilitate more collaboration so that providers can coordinate all of our efforts
- Pull in agencies that provide services that are needed and learn how to link our clients to non-HIV services

## Ensure a Seamless System of Care

- Providers should have one case manager to service three private doctor's offices
- List low cost dental care in communities

Three organizations are planning to provide additional services to PLWHA. The following are the responses describing the areas of expansion:

- We are continually looking to expand our peer navigation program to help move clients toward self-sufficiency and advocacy
- We would like to expand but need funding. We also like to provide fee for service like we did in the past
- We are not based on funding, but could expand based on need.

#### **Other Comments**

- With ACA, we don't see the need to expand medical/dental care at this time. We will have a better idea in Oct.
- Service planning is driven by funding availability; right now it appears that cuts are on the horizon, so we will focus on core services

# B. TRENDS IN SERVICE UTILIZATION, GAPS, AND BARRIERS (2000-2013)

Needs assessments were conducted in 2000, 2003, 2007, 2010, and 2013. The tables below contain service utilization, gaps, and barrier data from each study. In addition to data analyses for each year's needs assessment, analyses were conducted to identify trends from 2000 through 2013. Service categories used to analyze utilization, gaps, and barriers have varied slightly in the five needs assessments. Therefore, it was not possible to analyze trends for those categories that were not included in all needs assessments. For example Spiritual/Religious Counseling was a service that was included in earlier needs assessments, but was removed from the list of services used after the 2007 needs assessment. The list of service categories in the 2013 data collection instrument includes only the services in the current continuum of care that were prioritized by the CARE Council in 2013. In some cases, this has resulted in nonconsecutive rankings in the tables below.

#### Utilization: "I received this service"

Although rates of utilization have changed for the following services, they have *remained highly utilized* (by more than 50% of respondents) from 2000 through 2013. The following table lists the services from the highest to lowest rates of utilization in 2013.

Service categories that Kemain righty offized Since 2000														
	20	00	20	2003		2007		2010		2013				
Service Categories	(N=271)		(N=271)		(N=	400)	(N	=252)	(N=	=296)		(N=211)		
	rank	%	rank	%	rank	%	rank	%	rank	#	%			
Laboratory Diagnostic Testing	1	75%	2	72.0%	2	71.0%	3	75.7%	1	202	95.7%			
Primary Medical Care	3	59%	8	52.8%	4	56.3%	2	76.0%	2	196	92.9%			
Case Management	2	68%	1	73.5%	1	74.6%	6	57.8%	4	172	81.5%			
Oral/Dental Health	6	58%	5	61.5%	3	57.5%	5	59.5%	5	160	75.8%			
Medical Specialist	n/a	n/a	n/a	n/a	8	40.0%	4	61.1%	6	159	75.4%			

#### Service Categories that Remain Highly Utilized Since 2000

The following services *significantly increased in utilization* from 2000 through 2013. The following table lists the services from the highest to lowest rankings of utilization in 2013.

Service Categories that Significantly Increased in Utilization S	Since 2000
------------------------------------------------------------------	------------

	2	000	2	003	2007		20	10	2013			
Service Categories	(N=271)		(N=400)		(N=252)		(N=296)		(N=211)			
	rank	%	rank	%	rank	%	rank	%	rank	#	%	
Primary Medical Care	3	59.0%	8	52.8%	4	56.3%	2	76.0%	2	196	92.9%	
Medications*	8	53.0%	7	56.3%	17	31.0%	1	76.4%	3	190	90.0%	
Medical Specialist	n/a	n/a	n/a	n/a	8	40.1%	4	61.1%	6	159	75.4%	
Transportation	24	27.0%	15	44.8%	6	45.6%	7	40.2%	9	103	48.8%	
*No category "Medications" prio	r to 201	0; most o	closely i	resemble	d "Drug	g Reimbu	rsement'	' in 2007.				

The following services (listed from the highest to lowest rankings of utilization in 2013) *significantly decreased in utilization* from 2000 through 2013.

	2000		20	2003		2007		2010	2013		
Service Categories	(N=	(N=271)		.) (N=400)		(N=252)		=296)	(N=211)		
	rank	%	rank	%	rank	%	rank	%	rank	#	%
Outreach	n/a	n/a	n/a	n/a	11	36.1%	18	15.9%	22	32	15.2%
Rehabilitation*	n/a	n/a	n/a	n/a	n/a	n/a	19	11.1%	24	22	10.4%
Home Health Care	45	6%	42	5.5%	22	15.9%	22	8.1%	26	15	7.1%
Hospice	35	11.0%	41	5.8%	27	5.6%	23	4.7%	27	3	1.4%
*"Rehabilitation Services" were ac	lded to	the 2010	) surve	y.							

#### Service Categories that Significantly Decreased in Utilization Since 2000

The following table summarizes all utilization data from the current and past four needs assessments.

Utilization of Service Ca	-	000		003	-	007		010			
Service Categories	(N=	271)	(N=	400)	(N=	252)	(N=	=296)		(N=211	)
	rank	%	rank	%	rank	%	rank	%	rank	#	%
CORE SERVICES	1	1					I				
Outpatient Medical Care											
Primary Medical Care	3	59%	8	52.8%	4	56.3%	2	76.0%	2	196	92.9%
Laboratory Diagnostic Testing	1	75%	2	72.0%	2	71.0%	3	75.7%	1	202	95.7%
Medical Specialist	n/a	n/a	n/a	n/a	8	40.0%	4	61.1%	6	159	75.4%
Nurse Care Coordination	n/a	n/a	43	5.0%	24	13.1%	16	18.9%	15	72	34.1%
Case Management	2	68%	1	73.5%	1	74.6%	6	57.8%	4	172	81.5%
Medications*	8	53%	7	56.3%	17	31.0%	1	76.4%	3	190	90.0%
Dental/ Oral Health	6	58%	5	61.5%	3	57.5%	5	59.5%	5	160	75.8%
Health Insurance	23	27%	25	22.3%	14	34.9%	8	34.5%	13	83	39.3%
Mental Health Services	16	35%	23	27.0%	9	38.1%	13	29.7%	12	84	39.8%
Substance Abuse Treatment											
Substance Abuse Residential	n/a	n/a	24	22.8%	24	15.1%	19	11.1%	21	34	16.1%
Substance Abuse Outpatient	n/a	n/a	24	22.8%	23	15.1%	20	9.5%	23	23	10.9%
Nutrition Counseling	n/a	n/a	n/a	n/a	n/a	n/a	11	31.8%	8	112	53.1%
Early Intervention Services	27	23%	21	29.8%	5	51.6%	17	17.6%	20	57	27.0%
Home Health Care	45	6%	42	5.5%	22	15.9%	22	8.1%	26	15	7.1%
Hospice	35	11%	41	5.8%	27	5.6%	23	4.7%	27	3	1.4%
SUPPORT SERVICES											
Food Bank or Food Vouchers	11	43%	15	44.8%	10	37.7%	9	33.4%	7	113	53.6%
Transportation	24	27%	15	44.8%	6	45.6%	7	40.2%	9	103	48.8%
Outreach	n/a	n/a	n/a	n/a	11	36.1%	18	15.9%	22	32	15.2%
Health Education/Risk Reduction**	n/a	n/a	n/a	n/a	n/a	n/a	10	32.4%	11	94	44.5%
Treatment Adherence	n/a	n/a	n/a	n/a	12	35.7%	10	32.4%	10	98	46.4%
Legal Support	17	33%	20	34.3%	12	34.9%	14	27.7%	16	69	32.7%
Rehabilitation**	n/a	n/a	n/a	n/a	n/a	n/a	19	11.1%	24	22	10.4%
Emergency Financial Assistance	25	25%	18	36.5%	13	57.5%	15	20.3%	19	61	28.9%
Linguistics Services	40	10%	29	17.3%	26	12.3%	21	8.8%	25	19	9.0%
Peer Mentoring**	n/a	n/a	n/a	n/a	n/a	n/a	n/a	n/a	17	67	31.8%
Housing**	n/a	n/a	n/a	n/a	n/a	n/a	n/a	n/a	18	65	30.8%
Support groups	n/a	n/a	n/a	n/a	n/a	n/a	12	30.1%	14	79	37.4%
*The category "Medications" was cal	led "Dru	ıg Reiml	oursem	ent" or "l	Drug/M	edicine"	or "Dru	g Prescrip	tion Pro	gram"	in

#### Utilization of Service Categories Across the 2000, 2003, 2007, 2010, and 2013 Needs Assessments

\*The category "Medications" was called "Drug Reimbursement" or "Drug/Medicine" or "Drug Prescription Program" in previous Needs Assessments.

\*\* Only HRSA service categories and "Support groups" were used in the 2010 survey. Therefore, the categories "HIV Prevention" and "Vocational Rehabilitation" were not used (as in previous years) and "Health Education/Risk Reduction" and "Rehabilitation Services" were added to the 2010 survey. Peer Mentoring and Housing were in the 2013 survey.

# Service Gaps: "I needed this service but was unable to get it"

This section includes data from the 2000, 2003, 2007, 2010, and 2013 needs assessments regarding services which respondents indicated they "needed this service but was unable to get". The table below lists the service gaps that *remained somewhat consistent* from 2000 through 2013.

Across the	2000, 2	Across the 2000, 2003, 2007, 2010 and 2013 Needs Assessments											
		2000		2003		2007		2010		13			
Service Categories	(N=271)		(N=400)		(N=252)		(N=296)		(N=211)				
	rank	%	rank	%	rank	%	rank	%	rank	%			
CORE SERVICES													
Primary Medical Care	21	6.0%	26	9.5%	25	6.3%	13	3.7%	12	1.9%			
Laboratory Diagnostic Testing	24	2.0%	31	7.8%	22	9.1%	12	4.1%	12	1.9%			
Case Management	19	9.0%	24	10.0%	21	10.7%	7	7.4%	5	7.1%			
SUPPORT SERVICES													
Transportation	10	21.0%	17	13.5%	9	21.4%	3	14.2%	3	9.5%			
Health Education/Risk Reduction*	n/a	n/a	n/a	n/a	n/a	n/a	11	4.7%	12	1.9%			
Linguistics Services	23	4.0%	33	6.8%	19	11.5%	9	6.4%	12	1.9%			
*Only HRSA service categories and "Sup	port gro	oups" we	re used	in the 20	10 surv	ey. Ther	efore, t	he catego	ory "HIV				
Prevention" was not used (as in previou	s years)	and "Hea	alth Edu	ucation/R	isk Red	uction" w	as add	ed to the	2010 surv	/ey.			

#### Service Gaps that Remained Somewhat Consistent Across the 2000, 2003, 2007, 2010 and 2013 Needs Assessments

The following table displays the service categories for which gaps significantly decreased from 2000 through 2013.

	20	2000		03	20	07	2010		20	13
Service Categories		271)		400)		(N=252)		(N=296)		211)
	rank	%	rank	%	rank	%	rank	%	rank	%
	Talik	70	Tank	70	Tank	70	Tank	70	тапк	70
CORE SERVICES										
Medications*	17	11.0%	20	11.5%	5	26.6%	15	3.0%	11	2.4%
Oral/Dental Health	12	19.0%	9	20.0%	7	23.8%	6	8.4%	6	5.7%
Health Insurance	9	22.0%	7	23.8%	8	21.4%	4	11.1%	8	4.3%
Substance Abuse Residential	n/a	n/a	28	9.0%	24	7.1%	13	3.7%	12	1.9%
Substance Abuse Outpatient	n/a	n/a	28	9.0%	23	8.1%	13	3.7%	13	1.4%
Early Intervention Services	18	10.0%	18	12.8%	11	19.0%	13	3.7%	11	2.4%
Home Health Care	23	4.0%	29	8.8%	12	16.3%	13	3.7%	13	1.4%
Hospice	23	4.0%	21	11.8%	18	12.3%	15	3.0%	15	0.0%
SUPPORT SERVICES										
Outreach	n/a	n/a	n/a	n/a	14	14.7%	15	3.0%	13	1.4%
Treatment Adherence	n/a	n/a	n/a	n/a	14	14.3%	14	3.4%	12	1.9%
Rehabilitation **	n/a	n/a	n/a	n/a	n/a	n/a	5	8.1%	13	1.4%
*The category "Medications" was called previous Needs Assessments.	"Drug R	eimburse	ement" (	or "Drug,	/Medicir	ne" or "D	rug Pres	scription	Program	" in

Service Gaps that Somewhat Decreased Across the 2000, 2003, 2007, 2010 and 2013 Needs Assessments

\*\*Only HRSA service categories and "Support groups" were used in the 2010 survey. Therefore, the category "Vocational Rehabilitation" was not used and the data were not included (as they were in previous years) and "Rehabilitation Services" was added to the 2010 survey.

The table below displays all service gap data across the past five needs assessments.

Gaps in Service Catego		000		003		007		010		3	
Service Categories	(N=	271)	(N=	400)	(N=	:252)	(N=	296)	(	N=21	.1)
	rank	%	rank	%	rank	%	rank	%	rank	#	%
CORE SERVICES											
Outpatient Medical Care											
Primary Medical Care	21	6.0%	26	9.5%	25	6.3%	13	3.7%	12	4	1.9%
Laboratory Diagnostic Testing	24	2.0%	31	7.8%	22	9.1%	12	4.1%	12	4	1.9%
Medical Specialist	n/a	n/a	n/a	n/a	19	11.1%	10	5.4%	11	5	2.4%
Nurse Care Coordination	n/a	n/a	25	9.8%	18	12.3%	16	2.0%	9	8	3.8%
Case Management	19	9.0%	24	10.0%	21	10.7%	7	7.4%	5	15	7.1%
Medications*	17	11.0%	20	11.5%	5	26.6%	15	3.0%	11	5	2.4%
Dental/ Oral Health	12	19.0%	9	20.0%	7	23.8%	6	8.4%	6	12	5.7%
Health Insurance	9	22.0%	7	23.8%	8	21.4%	4	11.1%	8	9	4.3%
Mental Health Services	19	9.0%	23	10.8%	15	13.9%	8	7.1%	12	4	1.9%
Substance Abuse Treatment											
Substance Abuse Residential	n/a	n/a	28	9.0%	24	7.1%	13	3.7%	12	4	1.9%
Substance Abuse Outpatient	n/a	n/a	28	9.0%	23	8.1%	13	3.7%	13	3	1.4%
Nutrition Counseling	n/a	n/a	n/a	n/a	n/a	n/a	8	7.1%	10	7	3.3%
Early Intervention Services	18	10.0%	18	12.8%	11	19.0%	13	3.7%	11	5	2.4%
Home Health Care	23	4.0%	29	8.8%	12	16.3%	13	3.7%	13	3	1.4%
Hospice	23	4.0%	21	11.8%	18	12.3%	15	3.0%	15	0	0.0%
SUPPORT SERVICES											
Food Bank or Food Vouchers	12	19.0%	3	27.0%	3	32.1%	1	26.4%	2	21	10.0%
Transportation	10	21.0%	17	13.5%	9	21.4%	3	14.2%	3	20	9.5%
Outreach	n/a	n/a	n/a	n/a	14	14.7%	15	3.0%	13	3	1.4%
Health Education/Risk Reduction**	n/a	n/a	n/a	n/a	n/a	n/a%	11	4.7%	12	4	1.9%
Treatment Adherence	n/a	n/a	n/a	n/a	14	14.3%	14	3.4%	12	4	1.9%
Legal Services/Permanency	11	20.0%	19	23.3%	17	13.1%	5	8.1%	7	11	5.2%
Rehabilitation**	n/a	n/a	n/a	n/a	n/a	n/a	5	8.1%	13	3	1.4%
Emergency Financial Assistance	2	34.0%	5	26.3%	2	32.5%	2	21.3%	4	18	8.5%
Linguistics Services	23	4.0%	33	6.8%	19	11.5%	9	6.4%	12	4	1.9%
Peer Mentoring**	n/a	n/a	n/a	n/a	n/a	n/a	n/a	n/a	10	7	3.3%
Housing**	n/a	n/a	n/a	n/a	n/a	n/a	n/a	n/a	1	29	13.7%
Support groups	n/a	n/a	n/a	n/a	n/a	n/a	7	7.4%	11	5	2.4%
Other	n/a	n/a	n/a	n/a	n/a	n/a	n/a	n/a	14	1	0.5%
*The category "Medications" was called	"Drug Re	eimburser	ment" or	"Drug/M	edicine"	or "Drug P	rescript	ion Progra	am" in p	revio	s

#### Gaps in Service Categories Across the 2000, 2003, 2007, 2010, and 2013 Needs Assessments

Needs Assessments. \*\*Only HRSA service categories and "Support groups" were used in the 2010 survey. Therefore, the categories "HIV Prevention" and "Vocational Rehabilitation" were not used and the data were not included (as in previous years) and "Health Education/Risk

Reduction" and "Rehabilitation" were added to the 2010 survey. Peer Mentoring and Housing services were in the 2013 survey.

# Barriers to Services: "Can Get, But Won't Use" (2000, 2003, and 2007), "Needed But Didn't Know About Service" (2010), and "Needed this service but was unaware if it was offered or how to access" (2013)

With a few notable exceptions in 2013 (health insurance, food bank, and transportation) the rates of respondents indicating barriers to particular services have *remained low and fairly consistent*. The following table summarizes data from the past five needs assessments with services having the highest rates of barriers highlighted for emphasis.

#### Barriers to Service Categories Across the 2000, 2003, 2007, 2010 and 2013 Needs Assessments (in 2000, 2003, and 2007, "Can Get, But Won't Use", in 2010, "Needed But Didn't Know About Service," in 2013 "Needed this service but was unaware if it was offered or how to access")

	20	00	20	03	20	07	2	010			
Service Categories	(N=	271)	(N=4	400)	(N=	252)	(N=	296)		(N=211)	
	rank	%	rank	%	rank	%	rank	%	rank	#	%
CORE SERVICES									·		
Outpatient Medical Care											
Primary Medical Care	13	1.0%	18	1.0%	9	2.8%	13	3.7%	16	1	0.5%
Laboratory Diagnostic Testing	12	2.0%	19	0.8%	10	2.4%	12	4.1%	16	1	0.5%
Medical Specialist	n/a	n/a	n/a	n/a	2	6.7%	10	5.4%	12	9	4.3%
Nurse Care Coordination	n/a	n/a	11	2.8%	5	4.8%	16	2.0%	11	10	4.7%
Case Management	9	3.0%	15	1.8%	9	2.8%	7	7.4%	15	5	2.4%
Medications*	8	4.0%	10	3.0%	9	2.8%	15	3.0%	15	5	2.4%
Dental/ Oral Health	4	6.0%	14	2.0%	9	2.8%	5	8.4%	10	11	5.2%
Health Insurance	9	3.0%	17	1.3%	6	4.0%	4	11.1%	9	12	5.7%
Mental Health Services	5	5.0%	13	2.3%	7	3.6%	8	7.1%	10	11	5.2%
Substance Abuse Treatment											
Substance Abuse Residential	1	7.0%	9	3.3%	3	6.0%	13	3.7%	13	7	3.3%
Substance Abuse Outpatient	1	7.0%	9	3.3%	5	4.8%	13	3.7%	11	10	4.7%
Nutrition Counseling	n/a	n/a	n/a	n/a	n/a	n/a	8	7.1%	10	11	5.2%
Early Intervention Services	3	6.0%	15	1.8%	8	3.2%	13	3.7%	11	10	4.7%
Home Health Care	6	4.0%	16	1.5%	10	2.4%	13	3.7%	13	7	3.3%
Hospice	10	3.0%	14	2.0%	7	3.6%	15	3.0%	15	1	0.5%
SUPPORT SERVICES									·		
Food Bank or Food Vouchers	8	4.0%	16	1.5%	9	2.8%	1	26.4%	2	32	15.2%
Transportation	13	1.0%	20	1.0%	12	1.6%	3	14.2%	6	18	8.5%
Outreach	n/a	n/a	n/a	n/a	5	4.8%	15	3.0%	11	10	4.7%
Health Education/Risk Reduction**	n/a	n/a	n/a	n/a	7	n/a	11	4.7%	8	13	6.2%
Treatment Adherence	n/a	n/a	n/a	n/a	11	2.0%	14	3.4%	11	10	4.7%
Legal Support	10	3.0%	15	1.8%	6	4.0%	6	8.1%	3	28	13.3%
Rehabilitation**	n/a	n/a	n/a	n/a	n/a	n/a	6	8.1%	7	14	6.6%
Emergency Financial Assistance	11	3.0%	17	1.3%	11	2.0%	2	21.3%	1	36	17.1%
Linguistics Services	12	2.0%	18	1.0%	5	4.8%	9	6.4%	9	12	5.7%
Peer Mentoring**	n/a	6	18	8.5%							
Housing**	n/a	4	21	10.0%							
Support groups	n/a	n/a	n/a	n/a	n/a	n/a	6	7.4%	5	20	9.5%
Other	n/a	14	6	2.8%							

\*The category "Medications" was called "Drug Reimbursement" in previous Needs Assessments.

\*\*Only HRSA service categories and "Support groups" were used in the 2010 survey. Therefore, the categories "HIV Prevention" and "Vocational Rehabilitation" were not used and data were not included (as in previous years) and "Health Education/Risk Reduction" and "Rehabilitation Services" were added to the 2010 survey. Peer Mentoring and Housing were in the 2013 survey.

# C. Highlights Regarding Populations of Special Concern

Previous Part A grant applications have included sections that focused on the following populations of special concern:

- 1. Men who Have Sex with Men (MSM)
- 2. Haitian Men and Women
- 3. African American Women
- 4. African American Men Recently Released from Incarceration
- 5. Latin/Hispanic Men and Women

This Needs Assessment focuses on similar populations of special concern as follows,

- 1. African American Heterosexuals
- 2. Men who Have Sex with Men (MSM)
- 3. Haitian Men and Women
- 4. Hispanic Men and Women
- 5. Individuals who have been recently incarcerated (in the past 12 months)
- 6. Individuals Aged 50 and over

For this Needs Assessment, focus groups were conducted with PLWHA from each of the six populations listed above. The following section highlights service delivery issues within all six of these populations of special concern. In addition, PLWHA survey data regarding the populations of special concern are compared with aggregated PLWHA survey data.

# **1 AFRICAN-AMERICAN HETEROSEXUAL**

## Unique Challenges

African-American heterosexuals face many barriers to care and experience many factors that complicate their care. Poverty, limited education, lack of health insurance, and lack of transportation continue to be significant problems for this population. Many African-American heterosexual PLWHA are not well informed about HIV/AIDS or do not feel the need for testing until well after they have been infected and become symptomatic. Additionally, there are high rates of reported stigma attached to HIV/AIDS. These factors create a culture of denial that results in late testing and diagnosis. Many African-American heterosexuals struggle with family rejection and the stigma of HIV, which affects adherence to medical regimens as well as their ability to disclose their HIV status to family, friends, or sexual partners. Further, some African-Americans subscribe to HIV/AIDS conspiracy beliefs, reflecting mistrust of the health care system.<sup>10</sup>

African-American women may feel disempowered in their relationships with men. African-American women who are of childbearing age are also at high risk for dropping out of care despite the high need for pre- and post-natal care, preventive care, screening, and other services, as well as HIV-related adherence counseling. Women may also prioritize their family's needs before their own health care needs. Finally, for women, additional factors such as partner domestic violence compound safety, security, and preventive health behaviors.<sup>11</sup>

# Service Gaps

The Comprehensive Needs Assessment 2013-2016 survey included 194 African-American heterosexual respondents. 63% reported they were in care. 20% had either no schooling or an education level of 8<sup>th</sup> grade or less, 63% were unemployed during the prior 12 months, and 87% were living at or below the poverty level.

## Out of Care African-American Heterosexuals

All out of care respondents were asked to describe their current situation regarding being out of care. The most frequently mentioned description by African-American heterosexuals was, "I had been receiving medical care for HIV, but I stopped more than 12 months ago" (78%)." The second most frequently described situation for African-American heterosexuals was "I have not been recently diagnosed but have never been in care" (11%). Respondents were asked to identify the reasons for being out of care. Among the African-American heterosexual out of care respondents, the most frequently cited reason in was, "I did not feel sick" (61%). When asked what services they needed to get into primary medical care, African-American heterosexual out of care respondents cited housing (53%), financial assistance (53%), substance abuse treatment (51%), treatment adherence services (50%), and food (40%).

## In Care African-American Heterosexuals

Among African-American heterosexual in care respondents, the most frequently reported service gaps ("I needed this service but was unable to get it") were food bank or food vouchers, housing, and emergency financial assistance (11% each); and legal support and case management (7%

 <sup>&</sup>lt;sup>10</sup> Miami-Dade HIV/AIDS Partnership (2009). *Comprehensive Plan for HIV/AIDS 2009-2011;* Florida Department of Health Bureau of HIV/AIDS (2006). *Silence is Death: The Crisis of HIV/AIDS in Florida's Black Communities*.
 <sup>11</sup> Ibid.

each). The most frequently cited barriers to services ("I needed this service but was unaware if it was offered or how to access it") were food bank or food vouchers and emergency financial assistance (16% each); and legal support, transportation, and support groups (11% each).

### African-American Heterosexuals Focus Group Findings

Focus group respondents reported that barriers to getting medical care were the high cost of medication, denial, fear, shame and stigma, not knowing where to go, waiting lists, and long waits in the clinic. Factors that would help PLWHA get into care were reported to be assurance of confidentiality, money, insurance, or having someone willing to pay for care. Respondents in care reported that funding, case management, and insurance helped them get into and stay in care. Respondents felt that over the past 3 years services have declined due to reduced funding. They felt that services have been inadequate in quantity and quality.

## Data Highlights Related to African-American Heterosexual Survey Respondents

- 72 (37.1%) are out of care and 122 (62.9%) are in care.
- 74 (38.1%) are male and 120 (61.9%) are female.
- 167 (86.1%) identified English and 25 (12.9%) identified Creole as their primary language.
- 38 (19.6%) had either no schooling or an education level of  $8^{th}$  grade or less.
- 123 (63.4%) had been unemployed during the past 12 months.
- 12 (6.2%) reported being a migrant or seasonal worker.
- 168 (86.6%) are at or below 100% of the federal poverty level.

Please see the following pages for additional data and analysis.

When out of care African-American heterosexuals were asked to describe their situation, 8.3% said they had been recently diagnosed and had not entered medical care, compared to 11.6% among all out of care respondents. The rate of African-American heterosexuals who had not been recently diagnosed but had never been in care was about the same rate as among all out of care respondents (11.1% and 12.3% respectively). Out of care African-American heterosexuals who had been receiving medical care for HIV but had stopped more than 12 months ago accounted for 77.8% of all out of care African-American heterosexual respondents. This category accounted for 72.9% of all out of care respondents.

The following table displays all responses to this survey question.

Survey Question 21A. What best describes your situation (check only one)										
Out of Care Situation	Respo	of Care ndents 155)	African-American heterosexuals Out of Care Respondents (N=72)							
	number	percent	number	percent						
I have recently been diagnosed with HIV, and have not entered medical care.	18	11.6%	6	8.3%						
I have <u>not</u> been recently diagnosed but have never been in medical care.	19	12.3%	8	11.1%						
I had been receiving medical care for HIV, but I stopped more than 12 months ago.	113	72.9%	56	77.8%						
Other (specify)	5	3.2%	*2	2.8%						
When I found out that I had HIV I just gave up on everything Heavy drug user The medicine made me sick so I stopped after I was diagnosed *Just so tired of all these meds and doctors appointments *Drug user										
Total	155	100.0%	72	100.0%						

**Out of Care Circumstances** 

When out of care African-American heterosexuals were asked to identify the reasons that they are not in HIV/AIDS medical care, the most frequently identified reason was the same as those most frequently mentioned by all out of care respondents, specifically, "I did not feel sick". Among out of care African-American heterosexuals, the second most frequently mentioned reason was "I did not want people to know that I have HIV" (38.9%) while this response given at a similar rate (37.4%) by all out of care respondents.

Other reasons most frequently cited by both groups include, "I could not get transportation", and "I was not ready to deal with having HIV".

The following table summarizes the responses by both groups to this question.

Survey Question 22A. If you did not get HIV/AIDS medical care during the past 12 months, please indicate the reason/s why? (check any or all that apply)							
Reasons for Not Getting Medical Care		of Care ndents	African-American heterosexuals Out of Care Respondents				
	(N=:	-	· ·	72)			
	number	percent	number	percent			
This does not apply to me. I got HIV/AIDS related medical care in the past 12 months.	0	0.0%	0	0.0%			
I did not know where to go.	12	7.7%	5	6.9%			
I could not get an appointment.	17	11.0%	5	6.9%			
I could not get transportation.	38	24.5%	16	22.2%			
I could not get childcare.	8	5.2%	1	1.4%			
I could not pay for services.	22	14.2%	8	11.1%			
I did not want people to know that I have HIV.	58	37.4%	28	38.9%			
I was not ready to deal with having HIV.	57	36.8%	27	37.5%			
I did not feel sick.	89	57.4%	44	61.1%			
I could not get time off work.	7	4.5%	4	5.6%			
I was depressed.	60	38.7%	24	33.3%			
I had a bad experience with the medical staff.	20	12.9%	8	11.1%			
Other (specify)	30	19.4%	*16	22.2%			
Ready to give up No interest in life anymore	1						
Scared to go get help							
I get angry sometimes with my husband							
I am very hurt							
Newly diagnosed		<b>.</b> .					
I am happy I talked to this nice lady today, I am goin	ng to start	back doing	; the right t	hing			
Lazy							
I hate to go to the clinic							

#### Reasons for Not Getting HIV/AIDS Related Medical Care

My money too important I feel I don't have it Right now it's too late 13 years positive, I was in the hospital when I found out Child's mother on drugs \*Drug user (4) \*I don't care \*HIV isn't going anywhere, in a few years everybody is going to have it \*Can't stop using drugs \*No private place to go \*When I got out of jail they gave me Pravastatin \*Everybody knows your business at the clinic \*People I knew at health center \*Appointments not available when I could go \*My family is ashamed of me \*Could not get Medicaid, denied medical services \*I believe I'm okay \*I did not feel sick other than fatigue and nausea so made no relationship to HIV

When out of care African-American heterosexual respondents were asked to identify the services that would help them get HIV/AIDS medical care, two selected services were the same as those selected by all out of care respondents. Compared to all out of care respondents, a higher percentage of African-American heterosexuals selected financial assistance, food, case management, mental health services, and treatment adherence.

The following table summarizes all responses to this survey question.

Survey Question 24A. What services would help you to get HIV/AIDS medical care? (check any or all that apply)								
Services	All Out of Care African-Ameri All Out of Care heterosexua Respondents Out of Care (N=155) Respondent (N=72)			sexuals f Care ndents				
	number	percent	number	percent				
Financial assistance	76	49.0%	37	51.4%				
Food	67	43.2%	38	52.8%				
Housing	89	57.4%	22	30.6%				
Case management	46	29.7%	38	52.8%				
Transportation	83	53.4%	29	40.3%				
Substance abuse treatment	90	58.1%	15	20.8%				
Mental health services	46	29.7%	22	30.6%				
Treatment Adherence	33	21.3%	36	50.0%				
Other (e.g. more caring people, privacy, insurance)	26	16.8%	9	12.5%				

#### Services Needed to Get Into Primary Medical Care

٦

When out of care African-American heterosexuals respondents were asked to identify reasons they would enter care, the most frequently mentioned factor was "I get sick and know I need care". Out of care African-American heterosexuals mentioned this reason as often as all out of care respondents (73.6% and 77.4%, respectively). Additionally, all out of care respondents as well as out of care African-American heterosexuals frequently identified "I am ready to deal with my illness."

The table below highlights the most frequently selected reasons identified by out of care African-American heterosexuals and all out of care respondents.

for HIV/AIDS medical care? <i>(check any or all that ap</i> Reasons	ply) Out o Respo (N=:	ndents	African-American heterosexuals Out of Care Respondents (N=72)			
	number	percent	number	percent		
I get sick and know I need care.	120	77.4%	53	73.6%		
I am ready to deal with my illness.	67	43.2%	24	33.3%		
Someone else with HIV/AIDS reaches out to me.	44	28.4%	28	38.9%		
I get transportation to go to a doctor or clinic.	47	30.3%	16	22.2%		
Someone arranges to have my care paid for.	37	23.9%	21	29.9%		
Other (explain)	13	8.4%	*7	9.7%		
Other (explain)138.4%*79.7%Too sick to do for myselfJust found out statusI guess if I am about to dieDo not want to be judged and able to be self. Prefer one-on-oneNo partialityMaybe if I am about to die*All the help available*People like this lady staying in my life, who did this survey*Help with money*I will go when I am ready*A private place to go*He want help*Have some one walk me through it						

# **Reasons to Enter Primary Medical Care**

When asked to rate the five most important services, in care African-American heterosexuals rated medications, case management, primary medical care, laboratory diagnostic testing, and food as the top five. This prioritization is similar to that of all in care respondents, but in different order. For example, 42.6% of in care African-American heterosexuals said food was one of the most important services, but only 37.9% of all in care respondents did so. Although 47.4% of all in care respondents said case management was one of the five most important services, only 41.8% of in care African-American heterosexuals agreed.

The following table highlights the most highly ranked service priorities among in care African-American heterosexuals and all in care respondents.

Survey Question 36A. Which five services do you think are most important for people with HIV/AIDS?							
Service Category	In C Respo (N=2	ndents	African-A heteros In C Respon (N=:	sexuals Care ndents			
	number	percent	number	percent			
Primary Medical Care	127	60.2%	68	55.7%			
Laboratory Diagnostic Testing	114	54.0%	66	54.1%			
Medications	112	53.1%	62	50.8%			
Case Management	100 47.4% 51 4						
Food Bank or Food Vouchers	80	37.9%	52	42.6%			

#### **Five Most Important Services**

The table on the next page summarizes all responses to this question.

### **Five Most Important Services**

Survey Question 36A. Which five services do you think are most important for people with HIV/AIDS?						
Service Category		Care ndents 211)	African-American heterosexuals In Care Respondents (N=122)			
	number perce					
Primary Medical Care	127	60.2%	68	55.7%		
Laboratory Diagnostic Testing	114	54.0%	66	54.1%		
Medical Specialist	42	19.9%	29	23.8%		
Nurse Care Coordination	10	4.7%	8	6.6%		
Case Management	100	47.4%	51	41.8%		
Medications	112	53.1%	62	50.8%		
Dental /Oral Health	38	18.0%	21	17.2%		
Health Insurance	22	10.4%	5	4.1%		
Mental Health Services	27	12.8%	12	9.8%		
Substance Abuse Residential	4	1.9%	3	2.5%		
Substance Abuse Outpatient	3	1.4%	3	2.5%		
Nutrition Counseling	9	4.3%	6	4.9%		
Early Intervention Services (HIV testing & counseling, medical evaluation)	21	10.0%	15	12.3%		
Home Health Care	4	1.9%	1	0.8%		
Hospice Services	1	0.5%	1	0.8%		
Food Bank or Food Vouchers	80	37.9%	52	42.6%		
Transportation	41	19.4%	23	18.9%		
Outreach	19	9.0%	9	7.4%		
Health Education/Risk Reduction	7	3.3%	6	4.9%		
Treatment Adherence	18	8.5%	14	11.5%		
Legal Support	19	9.0%	13	10.7%		
Rehabilitation	2	0.9%	1	0.8%		
Emergency Financial Assistance	15	7.1%	11	9.0%		
Linguistics Services	2	0.9%	2	1.6%		
Peer Mentoring	12	5.7%	5	4.1%		
Housing	60	28.4%	45	36.9%		
Support groups	11	5.2%	6	4.9%		
Other (e.g. Hour, Service after hours)	2	0.9%	2	1.6%		
No response	3	1.4%	0	0.0%		
Total In Care Respondents	211	100%	122	100%		

#### Service Needs and Utilization

Survey respondents in care were asked to describe their level of utilization of the twenty-seven service categories prioritized by the planning council. The respondents in care described their utilization of each survey categories as one of the following:

- "I received this service" if they utilize the service
- "I did not need this service" if they do not utilize the service
- "I needed this service but was unable to get it" to show possible gaps in services
- "I needed this service but was unaware if it was offered or how to access" to show barriers in service utilization

#### Utilization: "I received this service"

Among African-American heterosexual respondents in care, laboratory diagnostic testing was the most highly utilized services (by 97% of in care African-American heterosexuals) followed by primary medical care (92%), medications (90%) and case management (82%).

The following table summarizes the most frequently utilized service categories by in care African-American heterosexuals and all in care respondents.

The most highly utilized services are highlighted in the following table.

Utilized Service Categories	All in Care Respondents (N=211) rank number percent		h	ican-Ame eterosex are Respo (N=122)	uals ndents			
			rank	number	percent			
CORE SERVICES								
Primary Medical Care	2	196	92.9%	2	112	91.8%		
Laboratory Diagnostic Testing	1	202	95.7%	1	118	96.7%		
Medical Specialist	6	159	75.4%	5	92	75.4%		
Case Management	4	172	81.5%	4	100	82.0%		
Medications	3	190	90.0%	3	110	90.2%		
Dental/Oral Health	5	160	75.8%	6	89	73.0%		

#### Comparison of Service Utilization "I Received this Service "

See the table on the next page for a complete summary of utilization data.

Utilized Service Categories	All in	All in Care Respondents (N=211)			•		•		het	African American terosexuals in Care spondents (N=122)	
	rank	number	percent	rank	number	percent					
CORE SERVICES											
Outpatient Medical Care											
Primary Medical Care	2	196	92.9%	2	112	91.8%					
Laboratory Diagnostic Testing	1	202	95.7%	1	118	96.7%					
Medical Specialist		159	75.4%	5	92	75.4%					
Nurse Care Coordination		72	34.1%		41	33.6%					
Case Management	4	172	81.5%	4	100	82.0%					
Medications	3	190	90.0%	3	110	90.2%					
Dental /Oral Health	5	160	75.8%		89	73.0%					
Health Insurance		83	39.3%		37	30.3%					
Mental Health Services		84	39.8%		41	33.6%					
Substance Abuse Treatment					· · · · · ·						
Substance Abuse Residential		34	16.1%		18	14.8%					
Substance Abuse Outpatient		23	10.9%		11	9.0%					
Nutrition Counseling		112	53.1%		65	53.3%					
Early Intervention Services		57	27.0%		39	32.0%					
Home Health Care		15	7.1%		7	5.7%					
Hospice		3	1.4%		2	1.6%					
SUPPORT SERVICES											
Food Bank or Food Vouchers		113	53.6%		67	54.9%					
Transportation		103	48.8%		66	54.1%					
Outreach		32	15.2%		19	15.6%					
Health Education/Risk Reduction		94	44.5%		64	52.5%					
Treatment Adherence		98	46.4%		66	54.1%					
Legal Support		69	32.7%		44	36.1%					
Rehabilitation		22	10.4%		15	12.3%					
Emergency Financial Assistance		61	28.9%		41	33.6%					
Linguistics Services		19	9.0%		7	5.7%					
Peer Mentoring		67	31.8%		34	27.9%					
Housing		65	30.8%		50	41.0%					
Support groups		79	37.4%		48	39.3%					
Other		0	0.0%		0	0.0%					

Comparison of Service Utilization "I Received this Service "

# Service Gaps: "I Needed This Service But Was Unable To Get It"

Some African-American heterosexuals respondents in care identified service gaps, of which the most selected were housing, food, transportation, and legal support.

The following table highlights the most frequently reported service gaps.

All ir Service Categories		All in Care Respondents (N=211)			frican-Ame erosexuals pondents (	in Care
	rank	number	percent	rank	number	percent
CORE SERVICES						
Outpatient Medical Care						
Primary Medical Care		4	1.9%		2	1.6%
Laboratory Diagnostic Testing		4	1.9%		2	1.6%
Medical Specialist		5	2.4%	5	5	4.1%
Nurse Care Coordination		8	3.8%	5	5	4.1%
Case Management	5	15	7.1%	3	8	6.6%
Medications		5	2.4%		1	0.8%
Dental/Oral Health		12	5.7%	5	5	4.1%
Health Insurance		9	4.3%		3	2.5%
Mental Health Services		4	1.9%		2	1.6%
Substance Abuse Treatment						
Substance Abuse Residential		4	1.9%		3	2.5%
Substance Abuse Outpatient		3	1.4%		2	1.6%
Nutrition Counseling		7	3.3%		3	2.5%
Early Intervention Services		5	2.4%		3	2.5%
Home Health Care		3	1.4%		3	2.5%
Hospice		0	0.0%		0	0.0%
SUPPORT SERVICES						
Food Bank or Food Vouchers	2	21	10.0%	1	14	11.5%
Transportation	3	20	9.5%	4	7	5.7%
Outreach		3	1.4%		2	1.6%
Health Education/Risk Reduction		4	1.9%		3	2.5%
Treatment Adherence		4	1.9%		4	3.3%
Legal Support		11	5.2%	3	8	6.6%
Rehabilitation		3	1.4%		2	1.6%
Emergency Financial Assistance	4	18	8.5%	2	13	10.7%
Linguistics Services		4	1.9%		3	2.5%
Peer Mentoring		7	3.3%		4	3.3%
Housing	1	29	13.7%	1	14	11.5%
Support groups		5	2.4%		2	1.6%
Other		1	0.5%		1	0.8%

*Barriers to Services: "I Needed This Service But Was Unaware If It Was Offered Or How To Access"* Food was one of the most frequently mentioned services in care African-American heterosexuals "needed this service but was unaware it was offered or how to access". The next most frequently mentioned service in this category was emergency financial assistance. The most frequent responses to this survey item are highlighted in the following table.

Service Categories	All in	All in Care Respondents (N=211)			•		Af hete	frican-Ame erosexuals pondents (	in Care
	rank	number	percent	rank	number	percent			
CORE SERVICES			1						
Outpatient Medical Care									
Primary Medical Care		1	0.5%		1	0.8%			
Laboratory Diagnostic Testing		1	0.5%		1	0.8%			
Medical Specialist		9	4.3%		5	4.1%			
Nurse Care Coordination		10	4.7%		7	5.7%			
Case Management		5	2.4%		2	1.6%			
Medications		5	2.4%		4	3.3%			
Oral/Dental Health		11	5.2%		8	6.6%			
Health Insurance		12	5.7%		8	6.6%			
Mental Health Services		11	5.2%		9	7.4%			
Substance Abuse Treatment									
Substance Abuse Residential		7	3.3%		3	2.5%			
Substance Abuse Outpatient		10	4.7%		6	4.9%			
Nutrition Counseling		11	5.2%		8	6.6%			
Early Intervention Services		10	4.7%		9	7.4%			
Home Health Care		7	3.3%		6	4.9%			
Hospice		1	0.5%		1	0.8%			
SUPPORT SERVICES									
Food Bank or Food Vouchers	2	32	15.2%	1	20	16.4%			
Transportation		18	8.5%	4	13	10.7%			
Outreach		10	4.7%		6	4.9%			
Health Education/Risk Reduction		13	6.2%		8	6.6%			
Treatment Adherence		10	4.7%		6	4.9%			
Legal Support	3	28	13.3%	3	14	11.5%			
Rehabilitation Services		14	6.6%		8	6.6%			
Emergency Financial Assistance	1	36	17.1%	2	19	15.6%			
Linguistics Services		12	5.7%		7	5.7%			
Peer Mentoring		18	8.5%	5	10	8.2%			
Housing	4	21	10.0%		8	6.6%			
Support groups	5	20	9.5%	4	13	10.7%			
Other		6	2.8%		4	3.3%			

#### Comparison of Barriers "I Needed This Service But Was Unaware If It Was Offered Or How To Access"

# Focus Group Findings: Themes and Notable Quotes

# Reasons for not going to the doctor for HIV/AIDS medical care

- Lack of knowledge about appropriate care and treatment services "Some of them don't know where to go now since there is no more nonprofit agencies in PBC that they can walk to or catch the bus to."
- Fear

"Some people are afraid to find out their results, their status"

- Waiting list
- High cost of medications
- Time

"A lot of people don't want to go and sit at the clinic. They don't have the time and patience. Going here there and running around, on a day-to-day basis trying to stay health..."

• Stigma and shame

## What will it take to persuade individuals to go back to the doctor for HIV/AIDS medical care?

- Insurance "...you have funds, insurance, someone willing to pay for that."
- Trust and Confidence

"...some nurses out there, doctors out there, patient in there that might be nosey, they'll tell the whole world you got it."

• Confidentiality

## For in care participants, what has helped to get in care and stay in care?

In care participants said continued funding of services have helped to get and stay in care:

• "Funding, case management, if you know that you got insurance, you can get the help, other than that you can't get service."

"If I had insurance I would be more of a person that would stay in care."

# In the past 3 years, have services improved, declined, or remain the same?

Participants felt that over the past 3 years services have declined due to reduced funding:

- "Declined, because I ain't got no help."
- "Cost of living is going up, funding is going down."

• "They're cutting all of the funds, if they're cutting it, what can we do?"

# Quantity and Quality of Services

Participants felt that services have been inadequate in quantity and quality:

- "No." (Consensus)
- "If there was more funding, a lot of people will want and go get the help."
- "Sometimes you be there all day, get frustrated, you want to leave."

## Additional Comments

Participants shared the need to have more nonprofit agencies in the area.

- "We need another nonprofit agency right here in the center of West Palm Beach to help people of color, don't have to worry about getting their information all over town."
- "I would like to know since some of these services are listed here, what happens to the funding that agencies are holding, needs to go to other nonprofits that are doing things to help people of color..."

# 2. MEN WHO HAVE SEX WITH MEN (MSM)

#### Unique Challenges

The unique challenges of serving the MSM population include stigma and denial, including fear of learning one's HIV status or disclosing one's HIV-positive status; discrimination and homophobia, including fear of disclosure of being a MSM; and rejection by family, church, or loss of employment. Psychosocial health issues, such as depression, partner violence, and low self-esteem can contribute to neglect of HIV care.<sup>12</sup>

#### Service Gaps

The Comprehensive Needs Assessment 2013-2016 included 45 respondents who identified themselves as MSM. 49% of these were in care. 16% had an eighth grade education or less, 67% were at or below 100% of the federal poverty level, and 58% were unemployed during the prior 12 months.

#### Out of Care MSM Respondents

When out of care MSM were asked to describe their situation, 83% said they had been receiving medical care for HIV, but had stopped more than 12 months previously. Their most frequently identified reasons for being out of care were "I did not feel sick" and "I was depressed" (52% each). When out of care MSM respondents were asked to identify the services that they need in order to get into primary medical care, the four most frequently selected services were financial assistance (70%), substance abuse treatment (65%), food (61%), housing (57%), and treatment adherence services (52%).

#### In Care MSM Respondents

Among MSM in care respondents, the most frequently reported service gaps ("I needed this service but was unable to get it") were transportation and housing (9% each). The most frequently cited barriers to services ("I needed this service but was unaware if it was offered or how to access it") were peer mentoring (32%), support groups (27%), legal support (23%), housing (18%), and outreach and linguistic services (14% each).

#### MSM Focus Group Findings

Respondents reported that reasons for not getting care include fear, labeling, stigma, and religious approbation. Factors that would help PLWHA get into care were reported to be getting seriously ill, encouragement from peers, support groups, assurance of confidentiality, counseling, and mentoring. Most of the participants were in care and they reported that factors that helped them get in care were availability of care, insurance, having a good doctor, having a will to survive, having a support group, case management, therapy, and the ADAP program. Cumbersome and lengthy referral processes were reported to be a challenge to getting services. Overall, the focus group participants felt that over the past 3 years services have improved, their quantity and quality has been adequate, and they have been able to access the services they need.

## Data Highlights Related to MSM Survey Respondents

<sup>&</sup>lt;sup>12</sup>Florida Department of Health Bureau of HIV/AIDS (2007). *Out in the Open: The Continuing Crisis of HIV/AIDS Among Florida's Men Who Have Sex with Men.* 

- 12.3% (45) of all respondents identified themselves as MSM.
- 23 (51.1%) are out of care and 22 (48.9%) are in care.
- 1 (2.2%) identified as Transgender (male to female)
- 40 (88.9%) identified English and 5 (11.1%) identified Spanish as their primary language.
- 5 (11.1%) identified themselves as Hispanic/Latino.
- 30 (66.7%) are at or below 100% of the federal poverty level.
- 26 (57.8%) had been unemployed during the past 12 months.
- 1 (2.2%) reported being a migrant or seasonal worker.

Please see the following pages for additional data and analysis.

When out of care MSM were asked to describe their situation, 82.6% said they had been receiving medical care for HIV but stopped more than 12 months ago, compared to 72.9% among all out of care respondents. The rate of MSM who had been recently diagnosed with HIV and have not entered medical care was about the same rate as among all out of care respondents (11.6% and 8.7% respectively). Out of care MSM who have not been recently diagnosed but have never been in care accounted for only 4.3% of all out of care MSM respondents. This category accounted for 12.3% of all out of care respondents. The following table displays all responses to this survey question.

Survey Question 21A. What best describes your situation? (check only one)							
Out of Care Situation	-	of Care ndents 155)	MSM Out of Care Respondents (N=23)				
	number	percent	number	percent			
I have recently been diagnosed with HIV, and have not entered medical care.	18	11.6%	2	8.7%			
I have <u>not</u> been recently diagnosed but have never been in care.	19	12.3%	1	4.3%			
I had been receiving medical care for HIV, but I stopped more than 12 months ago.	113	72.9%	19	82.6%			
Other	5	3.2%	*1	4.3%			
Drug user When I found out that I had HIV I just gave up on everything Heavy drug user Just so tired of all these meds and doctors appointments *The medicine made me sick so I stopped after I was diagnosed							
Total	155	100.0%	23	100.0%			

#### Out of Care Circumstances

When out of care MSM were asked to identify the reasons that they are not in HIV/AIDS medical care during the past 12 months, the most frequently identified reason was the same as those most frequently mentioned by all out of care respondents, specifically, "I did not feel sick". Among out of care MSM, the subsequent frequently mentioned reason was "I was depressed" (52.2%) while this response was given at a lower rate (38.7%) by all out of care respondents.

Other reasons most frequently cited by both groups include "I did not want people to know that I have HIV", and "I was not ready to deal with having HIV".

The following table summarizes the responses to this question from both groups.

Survey Question 22A. If you did not get HIV/AIDS medical care during the past 12 months, please indicate the reason/s why? (check any or all that apply)							
Possons for Not Cotting Medical Care	All Out Respo	of Care ndents	MSM Out of Care Respondents				
Reasons for Not Getting Medical Care	(n=1	L55)	(n=	23)			
	number	percent	number	percent			
This does not apply to me. I got HIV/AIDS related medical care in the past 12 months.	0	0.0%	0	0.0%			
I did not know where to go.	12	7.7%	1	4.3%			
I could not get an appointment.	17	11.0%	3	13.0%			
I could not get transportation.	38	24.5%	9	39.1%			
I could not get childcare.	8	5.2%	0	0.0%			
I could not pay for services.	22	14.2%	4	17.4%			
I did not want people to know that I have HIV.	58	37.4%	9	39.1%			
I was not ready to deal with having HIV.	57	36.8%	9	39.1%			
I did not feel sick.	89	57.4%	12	52.2%			
I could not get time off work.	7	4.5%	0	0.0%			
I was depressed.	60	38.7%	12	52.2%			
I had a bad experience with the medical staff.	20	12.9%	3	13.0%			
Other (specify)	30	19.4%	*4	17.4%			
Drug user (5) No private place to go When I got out of jail they gave me Pravastatin Everybody knows your business at the clinic People I knew at health center Appointments not available when I could go Scared to go get help I get angry sometimes with my husband I am very hurt My family is ashamed of me Newly diagnosed Lazy							

**Reasons for Not Getting Medical Care** 

Could not get Medicaid, denied medical services		
My money too important		
I believe I'm okay		
I feel I don't have it		
Right now it's too late		
I did not feel sick other than fatigue and nausea		
so made no relationship to HIV		
13 years positive, I was in the hospital when I		
found out		
I don't care		
Child's mother on drugs		
HIV isn't going anywhere, in a few years		
everybody is going to have it		
*I hate to go to the clinic		
*Ready to give up		
*No interest in life anymore		
*I am happy I talked to this nice lady today, I am		
going to start back doing the right thing		

When out of care MSM respondents were asked to identify services to get into HIV/AIDS medical care, the five most frequently selected services were the same as those selected by all out of care respondents. Compared to all out of care respondents, a higher percentage of MSM selected the five most frequent services.

The following table summarizes all responses to this survey question.

Survey Question 24A. What services would help you to get HIV/AIDS medical care? (check any or all that apply)							
Services	All Out of Care MSM Out of Care Respondents (N=155) (N=23)			ndents			
	number	percent	number	percent			
Financial assistance	76	49.0%	12	52.2%			
Food	67	43.2%	14	60.9%			
Housing	89	57.4%	16	69.6%			
Case management	46	29.7%	6	26.1%			
Transportation	83	53.4%	13	56.5%			
Substance abuse treatment	90	58.1%	15	65.2%			
Mental health services	46	29.7%	6	26.1%			
Treatment Adherence	33	21.3%	1	4.3%			
Other (e.g. more caring people, privacy, insurance)	26	16.8%	2	8.7%			

#### Services Needed to Get Into Primary Medical Care

When out of care MSM respondents were asked to identify reasons they would enter care, the most frequently mentioned factor was "I get sick and know I need care". Out of care MSM mentioned this reason more often as all out of care respondents (87.0% and 77.4% respectively). Additionally, all out of care respondents as well as out of care MSM frequently identified "I get sick and know I need care" and "Someone arranges to have my care paid for."

The table below highlights the most frequently selected reasons identified by out of care MSM and all out of care respondents.

Survey Question 25A. What would be some of the reasons why you would go to the doctor for HIV/AIDS medical care? (check any or all that apply)							
Reasons to Enter Primary Medical Care		f Care ndents 155)	Respo	t of Care ndents 23)			
	number	percent	number	percent			
I get sick and know I need care.	120	77.4%	20	87.0%			
I am ready to deal with my illness.	67	43.2%	6	26.1%			
Someone else with HIV/AIDS reaches out to me.	44	28.4%	11	47.8%			
I get transportation to go to a doctor or clinic.	47	30.3%	4	17.4%			
Someone arranges to have my care paid for.	37	23.9%	6	26.1%			
Other (explain)	13	8.4%	*1	4.3%			
A private place to go							
He want help							
Have some one walk me through it							
Just found out status							
All the help available							
People like this lady staying in my life, who did this							
survey							
Help with money							
I will go when I am ready							
I guess if I am about to die							
Do not want to be judged and able to be self,							
prefer one-on-one							
No partiality							
Maybe if I am about to die							
*Too sick to do for myself							

#### **Reasons to Enter Primary Medical Care**

When asked to rate the five most important services, in care MSM rated medications, case management, primary medical care, laboratory diagnostic testing, and food as the top five. This prioritization is similar to all in care respondents, but in different order. For example, 68.2% of in care MSM said laboratory diagnostic testing were one of the most important services, but only 54.0% of all in care respondents did so. Although 60.2% of all in care respondents said primary medical care were one of the five most important services, only 59.1% of in care MSM agreed.

The following table highlights the most highly ranked service priorities among in care MSM and all in care respondents.

Survey Question 36A. Which five services do you think are most important for people with HIV/AIDS?							
Service Category	In Care Respondents (N=211)		Respo	n Care ndents 22)			
	number	percent	number	percent			
Primary Medical Care	127	60.2%	13	59.1%			
Laboratory Diagnostic Testing	114	54.0%	15	68.2%			
Medications	112	53.1%	12	54.5%			
Case Management	100	47.4%	12	54.5%			
Food Bank or Food Vouchers	80	37.9%	9	40.9%			

#### **Five Most Important Services**

The table on the next page summarizes all responses to this question.

#### **Five Most Important Services**

Survey Question 36A. Which five services do you think are most important for people with HIV/AIDS?

with HIV/AIDS?							
Service Category	In Care MSM In Care In Care Respondents (N=211) (N=22)		In Care In Ca Respondents Respond (N=211) Respond				
	number	percent	number	percent			
Primary Medical Care	127	60.2%	13	59.1%			
Laboratory Diagnostic Testing	114	54.0%	15	68.2%			
Medical Specialist	42	19.9%	7	31.8%			
Nurse Care Coordination	10	4.7%	1	4.5%			
Case Management	100	47.4%	12	54.5%			
Medications	112	53.1%	12	54.5%			
Dental /Oral Health	38	18.0%	4	18.2%			
Health Insurance	22	10.4%	1	4.5%			
Mental Health Services	27	12.8%	0	0.0%			
Substance Abuse Residential	4	1.9%	0	0.0%			
Substance Abuse Outpatient	3	1.4%	0	0.0%			
Nutrition Counseling	9	4.3%	0	0.0%			
Early Intervention Services	21	10.0%	2	9.1%			
Home Health Care	4	1.9%	0	0.0%			
Hospice Services	1	0.5%	0	0.0%			
Food Bank or Food Vouchers	80	37.9%	9	40.9%			
Transportation	41	19.4%	1	4.5%			
Outreach	19	9.0%	2	9.1%			
Health Education/Risk Reduction	7	3.3%	0	0.0%			
Treatment Adherence	18	8.5%	2	9.1%			
Legal Support	19	9.0%	1	4.5%			
Rehabilitation	2	0.9%	0	0.0%			
Emergency Financial Assistance	15	7.1%	0	0.0%			
Linguistics Services	2	0.9%	0	0.0%			
Peer Mentoring	12	5.7%	2	9.1%			
Housing	60	28.4%	2	9.1%			
Support groups	11	5.2%	2	9.1%			
Other (e.g. Hour, Service after hours)	2	0.9%	0	0.0%			
No response	3	1.4%	1	4.5%			
Total In Care Respondents	211	100%	22	100%			

#### Service Needs and Utilization

Survey respondents in care were asked to describe their level of utilization of the twenty-seven service categories prioritized by the planning council. The respondents in care described their utilization of each survey categories as one of the following:

- "I received this service" if they utilize the service
- "I did not need this service" if they do not utilize the service
- "I needed this service but was unable to get it" to show possible gaps in services
- "I needed this service but was unaware if it was offered or how to access" to show barriers in service utilization

## Utilization: "I Received this Service"

Among MSM respondents in care, laboratory diagnostic testing was the most highly utilized services (by 100.0% of in care MSM) followed by primary medical and case management (95.5%), and medications (90.9%).

The following table summarizes the most frequently utilized service categories by in care MSM and all in care respondents.

The most highly utilized services are highlighted in the following table.

Utilized Service Categories	All in Care Respondents (N=211)			ndents MSM in Care Respondents (N=22)			
	rank	rank number percent			number	percent	
CORE SERVICES							
Medical Care							
Primary Medical Care	2	196	92.9%	2	21	95.5%	
Laboratory Diagnostic Testing	1	202	95.7%	1	22	100.0%	
Medical Specialist	6	159	75.4%	4	17	77.3%	
Case Management	4	172	81.5%	2	21	95.5%	
Medications	3	190	90.0%	3	20	90.9%	
Oral/Dental Health	5	160	75.8%	4	17	77.3%	

#### Comparison of Service Utilization "I Received this Service "

See the table on the next page for a complete summary of utilization data.

Utilized Service Categories	All in	All in Care Respondents (N=211)		MSM	in Care Res (N=22)	pondents
	rank	number	percent	rank	number	percent
CORE SERVICES						
Medical Care						
Primary Medical Care	2	196	92.9%	2	21	95.5%
Laboratory Diagnostic Testing	1	202	95.7%	1	22	100.0%
Medical Specialist		159	75.4%	4	17	77.3%
Nurse Care Coordination		72	34.1%		7	31.8%
Case Management	4	172	81.5%	2	21	95.5%
Medications	3	190	90.0%	3	20	90.9%
Dental /Oral Health	5	160	75.8%	4	17	77.3%
Health Insurance		83	39.3%		9	40.9%
Mental Health Services		84	39.8%		13	59.1%
Substance Abuse Treatment						
Substance Abuse Residential		34	16.1%		6	27.3%
Substance Abuse Outpatient		23	10.9%		4	18.2%
Nutrition Counseling		112	53.1%		14	63.6%
Early Intervention Services		57	27.0%		6	27.3%
Home Health Care		15	7.1%		3	13.6%
Hospice		3	1.4%		0	0.0%
SUPPORT SERVICES						
Food Bank or Food Vouchers		113	53.6%	5	16	72.7%
Transportation		103	48.8%		11	50.0%
Outreach		32	15.2%		4	18.2%
Health Education/Risk Reduction		94	44.5%		12	54.5%
Treatment Adherence		98	46.4%		11	50.0%
Legal Support		69	32.7%		7	31.8%
Rehabilitation		22	10.4%		3	13.6%
Emergency Financial Assistance		61	28.9%		8	36.4%
Linguistics Services		19	9.0%		6	27.3%
Peer Mentoring		67	31.8%		7	31.8%
Housing		65	30.8%		7	31.8%
Support groups		79	37.4%		8	36.4%

Comparison of Service Utilization "I Received this Service "

# Service Gaps: "I Needed This Service But Was Unable To Get It"

Some MSM respondents in care identified service gaps in transportation, housing, nurse care coordination, and etc.

The following table highlights the most frequently reported service gaps.

Service Categories		All in Care Respondents (N=211)			Unable To Get It" MSM in Care Respondents (N=22)			
	rank	number	percent	rank	number	percent		
CORE SERVICES								
Medical Care								
Primary Medical Care		4	1.9%		0	0.0%		
Laboratory Diagnostic Testing		4	1.9%		0	0.0%		
Medical Specialist		5	2.4%		0	0.0%		
Nurse Care Coordination		8	3.8%	2	1	4.5%		
Case Management	5	15	7.1%		0	0.0%		
Medications		5	2.4%		0	0.0%		
Dental/ Oral Health		12	5.7%	2	1	4.5%		
Health Insurance		9	4.3%	2	1	4.5%		
Mental Health Services		4	1.9%	2	1	4.5%		
Substance Abuse Treatment								
Substance Abuse Residential		4	1.9%		0	0.0%		
Substance Abuse Outpatient		3	1.4%		0	0.0%		
Nutrition Counseling		7	3.3%		0	0.0%		
Early Intervention Services		5	2.4%	2	1	4.5%		
Home Health Care		3	1.4%		0	0.0%		
Hospice		0	0.0%		0	0.0%		
SUPPORT SERVICES								
Food Bank or Food Vouchers	2	113	53.6%		0	0.0%		
Transportation	3	103	48.8%	1	2	9.1%		
Outreach		32	15.2%		0	0.0%		
Health Education/Risk Reduction		94	44.5%		0	0.0%		
Treatment Adherence		98	46.4%		0	0.0%		
Legal Support		69	32.7%		0	0.0%		
Rehabilitation		22	10.4%		0	0.0%		
Emergency Financial Assistance	4	61	28.9%		0	0.0%		
Linguistics Services		19	9.0%		0	0.0%		
Peer Mentoring		67	31.8%		0	0.0%		
Housing	1	65	30.8%	1	2	9.1%		
Support groups		79	37.4%		0	0.0%		

## Comparison of Gaps "I Needed This Service But Was Unable To Get It"

# Barriers to Services: "I Needed this Service but was Unaware if it was Offered or how to Access"

As with all in care respondents, legal support, housing, and support groups were mentioned services that in care MSM "needed but was unaware if it was offered or how to access". The most frequent responses to this survey item are highlighted in the following table.

Service Categories	All in	All in Care Respondents (N=211)			MSM in Ca pondents	
	rank	number	percent	rank	number	percent
CORE SERVICES						
Medical Care						
Primary Medical Care		1	0.5%		0	0.0%
Laboratory Diagnostic Testing		1	0.5%		0	0.0%
Medical Specialist		9	4.3%		1	4.5%
Nurse Care Coordination		10	4.7%		0	0.0%
Case Management		5	2.4%		1	4.5%
Medications		5	2.4%		1	4.5%
Dental /Oral Health		11	5.2%		1	4.5%
Health Insurance		12	5.7%		2	9.1%
Mental Health Services		11	5.2%		1	4.5%
Substance Abuse Treatment						
Substance Abuse Residential		7	3.3%		1	4.5%
Substance Abuse Outpatient		10	4.7%		1	4.5%
Nutrition Counseling		11	5.2%		2	9.1%
Early Intervention Services		10	4.7%		0	0.0%
Home Health Care		7	3.3%		0	0.0%
Hospice		1	0.5%		0	0.0%
SUPPORT SERVICES						
Food Bank or Food Vouchers	2	32	15.2%		2	9.1%
Transportation		18	8.5%		2	9.1%
Outreach		10	4.7%		3	13.6%
Health Education/Risk Reduction		13	6.2%		2	9.1%
Treatment Adherence		10	4.7%		2	9.1%
Legal Support	3	28	13.3%	3	5	22.7%
Rehabilitation		14	6.6%		1	4.5%
Emergency Financial Assistance	1	36	17.1%	4	4	18.2%
Linguistics Services		12	5.7%		3	13.6%
Peer Mentoring		18	8.5%	1	7	31.8%
Housing	4	21	10.0%	4	4	18.2%
Support groups	5	20	9.5%	2	6	27.3%
Other		6	2.8%		1	4.5%

Comparison of Barriers "I Needed this Service but was Unaware if it was Offered or How to Access"

# Focus Group Findings: Themes and Notable Quotes

# Reasons for not going to the doctor for HIV/AIDS medical care

• Fear

"Maybe individuals are afraid, don't know that it is an anonymous type of thing, think they'll be labeled"

- Religion "Have very strong religious principles"
- Stigma "Unaccepting, hateful stance, homosexual"

What will it take to persuade individuals to go back to the doctor for HIV/AIDS medical care? Participants reported getting seriously ill, encouragement, confidentiality, counseling and mentoring would persuade PLWHA to go back to HIV/AIDS medical care.

• Illness

"If he were to get an HIV/AIDS related illness, unfortunately I think that's what a lot of people what for, passively get forced."

"Severe illness, that's what's going to take him there...other substances so that's another problem..."

• Encouragement

"I believe that encouragement, that person associating themselves, in that same situation, open that door for him to see the medical attention that he needs (support groups or one-on-one) one-on-one."

"In my experience as a volunteer peer facilitator, group setting builds comradery and trust, ask advice, led back to treatment."

• Confidentiality

"Confidentiality, key factor for anyone-we need to let these people know everything we do is confidential."

Counseling and Mentoring

"One-on-One counseling (as well as one-on-one mentoring) as well..."

"By meeting one-on-one with the person, someone already positive (mentoring type), yes."

"By using a mental health counselor or professional that can communicate effectively with the person."

## For in care participants, what has helped to get in care and stay in care?

In care participants expressed availability of care, insurance, support, and assistance programs would help to get PLWHA in care and stay in care.

• Availability of Care and Insurance

"Availability of medical care and insurance was a major factor, at the time for me there were no financial barriers, Dr. referred me immediately, medical community was very important."

"I was diagnosed but I didn't have the need for meds for 8 years, seeing the doctor, getting blood work (what kept you)services, eligibility, you want to be alive, bottom line."

• Support

"Initially got me into treatment was a wonderful doctor, full blown, started meds right away, undetectable in less than a year, reason I stayed in, my need to survive, to beat this, I'm too young to die, just a self will to survive."

"Social support group."

Assistance Programs

"...case management, the therapy, his doctor (learn about disease through the doctor)."

"The assistance programs because with that, the availability of drugs, in my case, was much easier..."

# In the past 3 years, have services improved, declined, or remain the same?

Overall respondents said services in the past 3 years have improved.

• "I think for the size and population, I think PBC does a very good job."

## Quantity and Quality of Services

Participants shared quantity and quality of services has been adequate, and they have been able to access the services they need.

- "PBC, doing an excellent job."
- "My limited experience of accessing services here, pretty impressed so far."
- "Everything is okay."

#### Additional Comments

Participants requested additional services be added to the system of care, and expressed challenges in the referral process to services.

• Request of additional services "What about like a gym? Some sort of passes since our physical health is so important, gym memberships." "One service that I received, Chicago, acupuncture."

"Alternative medical treatment, holistic? Even Yoga."

• Challenges in the referral process to services "Services here are wonderful, support groups, can do better, outreach, get more people in here, for support, help a lot more people."

# 3. HAITIAN MEN AND WOMEN

#### Unique Challenges

Providing services to PLWHA of Haitian descent can be extremely complicated, given the community's mistrust of government activities and apprehension in accessing the medical care system. A persistent feeling of stigma about HIV/AIDS in this population, a sense of vulnerability to deportation and/or incarceration, and a complex non-western system of beliefs about health behavior all make treatment of HIV/AIDS difficult. Further complicating factors include a low educational level, a low level of English ability, and illiteracy in either Creole or English. All of this translates into late entry into care and difficulty in keeping appointments and following treatment instructions. Most Haitians are diagnosed in the public hospital inpatient or emergency room units where they present with serious illness. A significant number of older persons of this population use non-traditional healing methods such as Haitian herbalists and spiritual healers before seeking western medical care, and then only when their symptoms have seriously progressed.<sup>13</sup>

Additional challenges arise from immigration status. In Florida, only people with an AIDSdefining diagnosis plus a documented disability are eligible for Medicaid. This policy excludes a significant number of legal immigrants living with AIDS who are not disabled and thousands of HIV positive clients. Many immigrants are not connected to care and lack basic knowledge of the American health care system. Undocumented immigrants are ineligible for most public assistance programs. This places additional pressure on the Ryan White program and creates challenges for getting people tested and into treatment. In addition, undocumented immigrants are often reluctant to seek care largely because they fear deportation. When they do seek care, they are likely to be late presenters who are sicker and thus more costly to treat.<sup>14</sup>

## Service Gaps

The Comprehensive Needs Assessment 2013-2016 survey included 28 Haitian respondents. 82% of the respondents were in care. Half were unemployed during the prior 12 months, nearly one-half (46%) had either no schooling or an education level of grade 8 or less, and 86% lived at or below the poverty level.

#### Out of Care Haitian Respondents

When out of care Haitians were asked to describe their situation, 80% said they had been receiving medical care for HIV, but had stopped more than 12 months previously. Their most frequently identified reasons for being out of care were "I did not want people to know that I have HIV" (60%), "I could not pay for services" and "I was not ready to deal with having HIV" (40% each). When out of care Haitian respondents were asked to identify the services that they need in order to get into primary medical care, the most frequently selected services were treatment adherence services (60%) and case management (40%).

<sup>&</sup>lt;sup>13</sup>Miami-Dade HIV/AIDS Partnership (2009). Comprehensive Plan for HIV/AIDS 2009-2011.

<sup>&</sup>lt;sup>14</sup>Miami-Dade HIV/AIDS Partnership (2009). *Comprehensive Plan for HIV/AIDS 2009-2011*.

#### In Care Haitian Respondents

Among Haitian in care respondents, the most frequently reported service gaps ("I needed this service but was unable to get it") were emergency financial assistance (17%) and housing and legal support (9% each). The most frequently cited barriers to services ("I needed this service but was unaware if it was offered or how to access it") were food bank or food vouchers (39%); emergency financial assistance, linguistics services, and transportation (17% each); and legal support (9%).

#### Haitian Focus Group Findings

Participants reported that reasons for not getting care included fear, stigma, not knowing where to go, family obligations, and not having anyone to help. They felt that counseling, moral support, having a place to go, and having leaders talk about HIV positive people to dispel fear of getting help, would help PLWHA get into care. A desire to live was reported to be the reason for getting care. Challenges to getting care were reported to be beliefs in the supernatural and lack of insurance. Respondents felt that over the past 3 years, services have declined and their quantity and quality has been inadequate.

## Data highlights related to Haitian survey respondents:

- 28 (7.6% of all respondents) indicated they were Haitian.
- 27 (96.4%) said they are straight (heterosexual)
- 23 (82.1%) are in care, compared to 211 (57.7%) of all respondents.
- 5 (17.9%) are out of care, compared to 155 (42.3%) of all respondents.
- 23 (82.1%) said Creole is their primary language.
- 13 (46.4%) of Haitian respondents had either no schooling or an education level of 8<sup>th</sup> grade less compared to 60 (16.4%) of all respondents.
- 14 (50.0%) described their work situation in the past year as "unemployed" compared to 219 (59.8%) of all respondents.
- 2 (7.1%) reported being a migrant or seasonal worker.
- 24 (85.7%) were living at or below 100% FPL compared to 283 (77.3%) of all respondents.

Findings regarding selected risk factors and co-morbidities are summarized in the tables below:

Selected Demographic and Secience mic Variables		ondents	Haitian Respondents		
Selected Demographic and Socioeconomic Variables	(N=3	366)	(N=	28)	
	Number	Percent	Number	Percent	
Male	190	51.9%	13	46.4%	
Female	174	47.5%	15	53.6%	
Straight (heterosexual)	256	69.9%	27	96.4%	
In care	211	57.7%	23	82.1%	
Out of care	155	42.3%	5	17.9%	
Primary Language					
English	311	85.0%	5	17.9%	
Creole	25	6.8%	23	82.1%	
Education Completed - none or 8th grade or less	60	16.4%	13	46.4%	
Work situation in the past year - unemployed	219	59.8%	14	50.0%	
Below 100% Federal Poverty Level	283	77.3%	24	85.7%	

#### Comparison of Haitian Survey Respondents with All Respondents

- 3.6% had been diagnosed with other STD within the past 12 months compared to 2.5% of all respondents.
- 3.6% had been diagnosed with cancer within the past 12 months compared to 2.7% of all respondents.
- 3.6% had been diagnosed with Hepatitis B within the past 12 months compared to 2.2% of all respondents.

	All Resp	ondents	Haitian Respondents		
Selected Risk Factors and Co-morbidities	(N=3	<b>3</b> 66)	(N=28)		
	Number	Percent	Number	Percent	
Survey Question 19A. Diagnosed in the past 12 mo	nths				
AIDS	53	14.5%	5	17.9%	
Hepatitis A	1	0.3%	0	0.0%	
Hepatitis B	8	2.2%	1	3.6%	
Hepatitis C	24	6.6%	0	0.0%	
Tuberculosis	2	0.5%	0	0.0%	
Syphilis	13	3.6%	0	0.0%	
Gonorrhea	13	3.6%	0	0.0%	
Chlamydia	15	4.1%	0	0.0%	
Other STD	9	2.5%	1	3.6%	
Cancer	10	2.7%	1	3.6%	
High Cholesterol	32	8.7%	2	7.1%	
Liver Disease	11	3.0%	0	0.0%	
Diabetes	19	5.2%	2	7.1%	
Coronary Heart Disease	13	3.6%	0	0.0%	

#### Comparison of Haitian Survey Respondents with All Respondents

Respondents were asked to identify their situation regarding being out of primary medical care.

- Among survey respondents, the rate of Haitian out of care respondents was lower than the out of care rate of all respondents (17.9% compared to 42.3%).
- The out of care rate of those who have recently been diagnosed with HIV was higher among Haitian respondents than among all recently diagnosed out of care respondents (20.0% compared to 11.6%)
- While 72.9% of all out of care respondents had been receiving care but had stopped more than 12 months ago, 80% of the Haitian out of care respondents reported that situation.

Survey Question 21A. What best describes your situation (check one only)							
Out of Care Situation	All Out o Responden		Haitian Out of Care Respondents (N=5)				
	number	percent	number	percent			
I have recently been diagnosed with HIV, and have not entered medical care.	18	11.6%	1	20.0%			
I have <u>not</u> been recently diagnosed but have never been in medical care.	19	12.3%	0	0.0%			
I had been receiving medical care for HIV, but I stopped more than 12 months ago.	113	72.9%	4	80.0%			
Other	5	3.2%	0	0.0%			
No Response	0	0.0%	0	0.0%			
Total	155	100.0%	5	100.0%			

#### **Out of Care Circumstances**

When asked why they did not get HIV/AIDS related medical year during the past 12 months, out of care Haitian respondents most frequently mentioned "I did not want people to know that I have HIV" (60.0%, 3).

The most frequently mentioned reasons among all respondents were "I did not feel sick" (57.4%, 89), "I was depressed" (38.7%, 60), and "I did not want people to know that I have HIV"(37.4%, 58)

As shown in the following table, Haitian out of care respondents cited the following reasons at notably higher rates than all out of care respondents:

- I could not pay for services
- I did not want people to know that I have HIV.
- I was not ready to deal with having HIV.

please indicate the reason/s why? (check any or all that apply)							
Out of Care Reasons	All Out of Care Respondents (N= 155)		All Out of Care Respondents (N= 155)		Out of Care Respondents Respondents		f Care ndents
	number	percent	number	percent			
I did not know where to go.	12	7.7%	0	0.0%			
I could not get an appointment.	17	11.0%	0	0.0%			
I could not get transportation.	38	24.5%	0	0.0%			
I could not get childcare.	8	5.2%	0	0.0%			
I could not pay for services.	22	14.2%	2	40.0%			
I did not want people to know that I have HIV.	58	37.4%	3	60.0%			
I was not ready to deal with having HIV.	57	36.8%	2	40.0%			
I did not feel sick.	89	57.4%	1	20.0%			
I could not get time off work.	7	4.5%	1	20.0%			
I was depressed.	60	38.7%	1	20.0%			
I had a bad experience with the medical staff.	20	12.9%	0	0.0%			
Other (e.g. shame, denied medical services)	30	19.4%	3	60.0%			

Survey Question 22A. If you did not get HIV/AIDS medical care during the past 12 months, please indicate the reason/s why? (check any or all that apply)

Overall, the services Haitian out of care respondents indicated they need to get into medical care were very similar to those needed by all out of care respondents. Respondents in both groups most frequently mentioned the same three services. However, a larger percentage of Haitian out of care respondents indicated that these services were needed as follows:

- Financial assistance (All, 49.0%; Haitian, 60.0%)
- Treatment Adherence (All, 21.3%, Haitian 40.0%)

The following table summarizes a comparison of all responses to this question.

Services N	leeded to	Get Into	Medical	Care
------------	-----------	----------	---------	------

Survey Question 24A. What services would help you get HIV/AIDS medical care? (check any or all that apply)						
Services	All Out Care Respondents (N=155)		Services Respon		Out	tian Care ndents =5)
	number	percent	number	percent		
Financial assistance	76	49.0%	3	60.0%		
Food	67	43.2%	1	20.0%		
Housing	89	57.4%	1	20.0%		
Case management	46	29.7%	1	20.0%		
Transportation	83	53.5%	1	20.0%		
Substance abuse treatment	90	58.1%	1	20.0%		
Mental health services	46	29.7%	1	20.0%		
Treatment Adherence	33	21.3%	2	40.0%		
Other	26	16.8%	3	60.0%		

When asked "What would be some reasons you enter primary medical care?" the most frequently cited reason among all out of care and Haitian out of care respondents was "I get sick and know I need care".

For Haitian out of care respondents, the next most important factors were "Someone arranges to have my care paid for," "I am ready to deal with my illness," and "Someone else with HIV/AIDS reaches out to me."

The table below summarizes all responses to this question.

Survey Question 25A. What would be some of the reasons why you would go to the doctor for HIV/AIDS medical care? (check any or all that apply)					
Reasons	Out of Care Respondents (N=155)				
	number	percent	number	percent	
I get sick and know I need care.	120	77.4%	3	60.0%	
I am ready to deal with my illness.	67	43.2%	2	40.0%	
Someone else with HIV/AIDS reaches out to me.	44	28.4%	2	40.0%	
I get transportation to go to a doctor or clinic.	47	30.3%	1	20.0%	
Someone arranges to have my care paid for.	37	23.9%	3	60.0%	
Other	13	8.4%	0	0.0%	

#### **Reasons to Enter Medical Care**

# **Prioritization of Service Categories**

Haitian respondents who are in care, as well as all in care respondents, included Primary Medical Care, Laboratory Diagnostic Testing, Medications, Case Management, and Food in their top five choices. Unlike all in care respondents, Haitian in care respondents identified Treatment Adherence among the top five.

Survey Question 36A. Which five services do you think are most important for people with HIV/AIDS?						
Service Category	All In Care Respondents (N=211)		Respondents		Haitian In Care Respondents (N=23)	
	number	percent	number	percent		
Primary Medical Care	127	61.1%	12	52.2%		
Laboratory Diagnostic Testing	114	54.8%	11	47.8%		
Medications	112	53.8%	16	69.6%		
Case Management	100	48.1%	11	47.8%		
Food Bank/Home Delivered Meals	80	38.5%	14	60.9%		
Treatment Adherence	18	8.5%	10	43.5%		

#### **Five Most Important Services**

The table on the next page summarizes all responses to this question.

Five Most Important Services					
Service Category	Respoi (N=2	In Care Respondents (N=211)		Haitian In Care Respondents (N=23)	
	Number	percent	Number	percent	
Primary Medical Care	127	60.2%	12	52.2%	
Laboratory Diagnostic Testing	114	54.0%	11	47.8%	
Medical Specialist	42	19.9%	3	13.0%	
Nurse Care Coordination	10	4.7%	1	4.4%	
Case Management	100	47.4%	11	47.8%	
Medications	112	53.1%	16	69.6%	
Dental /Oral Health	38	18.0%	3	13.0%	
Health Insurance	22	10.4%	2	8.7%	
Mental Health Services	27	12.8%	1	4.4%	
Substance Abuse Residential	4	1.9%	0	0.0%	
Substance Abuse Outpatient	3	1.4%	0	0.0%	
Nutrition Counseling	9	4.3%	1	4.4%	
Early Intervention Services	21	10.0%	4	17.4%	
Home Health Care	4	1.9%	0	0.0%	
Hospice Services	1	0.5%	0	0.0%	
Food Bank or Food Vouchers	80	37.9%	14	60.9%	
Transportation	41	19.4%	2	8.7%	
Outreach	19	9.0%	1	4.4%	
Health Education/Risk Reduction	7	3.3%	1	4.4%	
Treatment Adherence	18	8.5%	10	43.4%	
Legal Support	19	9.0%	1	4.3%	
Rehabilitation	2	0.9%	0	0.0%	
Emergency Financial Assistance	15	7.1%	1	4.3%	
Linguistics Services	2	0.9%	1	4.3%	
Peer Mentoring	12	5.7%	0	0.0%	
Housing	60	28.4%	9	39.1%	
Support groups	11	5.2%	0	0.0%	
Other (e.g. Hour, Service after hours)	2	0.9%	0	0.0%	
No response	3	1.4%	0	0.0%	
Total In Care Respondents	211	100%	23	100%	

#### Service Needs and Utilization

Survey respondents in care were asked to describe their level of utilization of the twenty-seven service categories prioritized by the planning council. The respondents in care described their utilization of each survey categories as one of the following:

- "I received this service" if they utilize the service
- "I needed this service but was unable to get it" to show possible gaps in services
- "I needed this service but was unaware if it was offered or how to access" to show barriers to service utilization
- "I did not need this service" if they do not utilize the service

#### Utilization: "I received this service"

While there were differences in utilization patterns between all in care respondents and Haitian in care respondents, both groups cited laboratory diagnostic testing as the most frequently utilized service category. As highlighted in the following table, Haitian in care respondents also mentioned medications, case management, dental/oral health, primary medical care, and health education/risk reduction.

comparison of Service Offiziation - I Received this Service								
Utilized Service Categories	In C	All are Respo (N=211)		In	Haitian Care Respo (N=23)			
	rank	number	percent	rank	number	percent		
CORE SERVICES								
Medical Care								
Primary Medical Care	2	196	92.9%	5	17	73.9%		
Laboratory Diagnostic Testing	1	202	95.7%	1	22	95.7%		
Case Management	4	172	81.5%	3	20	87.0%		
Medications	3	190	90.0%	2	21	91.3%		
Dental /Oral Health	5	160	75.8%	4	19	82.6%		
Health Education/Risk Reduction	10	94	44.5%	5	17	73.9%		

#### Comparison of Service Utilization "I Received this Service "

The table on the next page summarizes all responses to this question.

Utilized Service Categories	In C	All In Care Respondents (N=211)			Haitian In Care Respondents (N=23)				
	rank	number	percent	rank	number	percent			
CORE SERVICES									
Medical Care	Medical Care								
Primary Medical Care	2	196	92.9%	5	17	73.9%			
Laboratory Diagnostic Testing	1	202	95.7%	1	22	95.7%			
Medical Specialist		159	75.4%		14	60.9%			
Nurse Care Coordination		72	34.1%		4	17.4%			
Case Management	4	172	81.5%	3	20	87.0%			
Medications	3	190	90.0%	2	21	91.3%			
Dental /Oral Health	5	160	75.8%	4	19	82.6%			
Health Insurance		83	39.33%		1	4.3%			
Mental Health Services		84	39.8%		6	26.1%			
Substance Abuse Treatment									
Substance Abuse Residential		34	16.1%		0	0.0%			
Substance Abuse Outpatient		23	10.9%		0	0.0%			
Nutrition Counseling		112	53.1%		13	56.5%			
Early Intervention Services		57	27.0%		13	56.5%			
Home Health Care		15	7.1%		0	0.0%			
Hospice		3	1.4%		0	0.0%			
SUPPORT SERVICES									
Food Bank or Food Vouchers		113	53.6%		6	26.1%			
Transportation		103	48.8%		7	30.4%			
Outreach		32	15.2%		1	4.3%			
Health Education/Risk Reduction		94	44.5%	5	17	73.9%			
Treatment Adherence		98	46.4%		7	30.4%			
Legal Support		69	32.7%		3	13.0%			
Rehabilitation		22	10.4%		2	8.7%			
Emergency Financial Assistance		61	28.9%		3	13.0%			
Linguistics Services		19	9.0%		3	13.0%			
Peer Mentoring		67	31.8%		2	8.7%			
Housing		65	30.8%		6	26.1%			
Support groups		79	37.4%		3	13.0%			

# Comparison of Service Utilization "I Received this Service "

# Service Gaps: "I needed this service but was unable to get it"

Like all in care respondents, Haitian respondents in care most frequently mentioned gaps in access to Emergency Financial Assistance and Housing. Unlike all in care respondents, Haitian in care respondents also indicated gaps in Legal Support and Linguistic Services.

Utilized Service Categories		All Care Respo (N=211)	ndents		Haitian Care Respor (N=23)	
	rank	number	percent	rank	number	percent
CORE SERVICES						
Medical Care						
Primary Medical Care		4	1.9%		0	0.0%
Laboratory Diagnostic Testing		4	1.9%		0	0.0%
Medical Specialist		5	2.4%		0	0.0%
Nurse Care Coordination		8	3.8%	3	1	4.3%
Case Management	5	15	7.1%	3	1	4.3%
Medications		5	2.4%		0	0.0%
Dental /Oral Health		12	5.7%		0	0.0%
Health Insurance		9	4.3%	3	1	4.3%
Mental Health Services		4	1.9%		0	0.0%
Substance Abuse Treatment					· · · · · ·	
Substance Abuse Residential		4	1.9%		0	0.0%
Substance Abuse Outpatient		3	1.4%		0	0.0%
Nutrition Counseling		7	3.3%		0	0.0%
Early Intervention Services		5	2.4%		0	0.0%
Home Health Care		3	1.4%		0	0.0%
Hospice		0	0.0%		0	0.0%
SUPPORT SERVICES						
Food Bank or Food Vouchers	2	21	10.0%	3	1	4.3%
Transportation	3	20	9.5%		0	0.0%
Outreach		3	1.4%		0	0.0%
Health Education/Risk Reduction		4	1.9%		0	0.0%
Treatment Adherence		4	1.9%		0	0.0%
Legal Support		11	5.2%	2	2	8.7%
Rehabilitation		3	1.4%	3	1	4.3%
Emergency Financial Assistance	4	18	8.5%	1	4	17.4%
Linguistics Services		4	1.9%	3	1	4.3%
Peer Mentoring		7	3.3%		0	0.0%
Housing	1	29	13.7%	2	2	8.7%
Support Groups		5	2.4%		0	0.0%
Other		1	0.5%		0	0.0%

# Comparison of Service Utilization "I needed this service but was unable to get it"

*Barriers to Services: "I needed this service but was unaware if it was offered or how to access"* Like all respondents in care, Haitian in care respondents most frequently reported barriers in food and emergency financial assistance. The services most frequently mentioned by Haitian respondents in care include linguistics services and transportation.

All In Care Respondents Haitian In Care (N=211) **Respondents (N=23) Service Categories** number rank percent rank number percent **CORE SERVICES** Medical Care **Primary Medical Care** 0.5% 0.0% 1 0 1 0.5% 0 0.0% Laboratory Diagnostic Testing 9 Medical Specialist 4.3% 0 0.0% 4.7% 4.3% Nurse Care Coordination 10 1 **Case Management** 5 2.4% 0 0.0% 5 Medications 2.4% 0 0.0% Dental /Oral Health 11 5.2% 3 2 8.7% Health Insurance 5.7% 0 0.0% 12 Mental Health Services 11 5.2% 0 0.0% Substance Abuse Treatment Substance Abuse Residential 7 3.3% 0 0.0% Substance Abuse Outpatient 10 4.7% 0 0.0% 4.3% **Nutrition Counseling** 11 5.2% 1 10 4.7% 4.3% **Early Intervention Services** 1 Home Health Care 7 3.3% 1 4.3% 0.0% Hospice 1 0.5% 0 SUPPORT SERVICES Food Bank/Home Delivered Meals 2 32 15.2% 1 9 39.1% 8.5% 4 17.4% Transportation 18 2 Outreach 10 4.7% 4.3% 1 Health Education/Risk Reduction 4.3% 13 6.2% 1 **Treatment Adherence** 10 4.7% 1 4.3% Legal Support 3 28 13.3% 3 2 8.7% **Rehabilitation Services** 14 6.6% 0 0.0% **Emergency Financial Assistance** 1 36 17.1% 2 4 17.4% **Linguistics Services** 12 5.7% 2 4 17.4% **Peer Mentoring** 18 8.5% 0 0.0% 21 10.0% 0 0.0% Housing 4 Support Groups 5 20 9.5% 0.0% 0 Other 6 0.0% 2.8% 0

The following table summarizes all responses to this question:

Comparison of Barriers "I needed this service but was unaware if it was offered or how to access"

#### Focus Group Findings: Themes and Notable Quotes

#### Reasons for not going to the doctor for HIV/AIDS medical care

• Fear

"A lot of people, yeaha, afraid to go to the doctor, they feel that if they go people will know and it's offending."

• Lack of Knowledge and Assistance

"I know some people, different problem, if you have a good job, good insurance, when they go to the clinic, they say I cannot accept, after a couple days, he lose the job, not going to the doctor, still sick, doesn't know where to go to get help."

"Some people have family, you sick too, got Medicaid, some people don't have people to help them, he does not know what kind of Medicaid the clinic carries, don't know where to go, some people need to take care of themselves but done' have help, Haitian community, they don't know."

What will it take to persuade individuals to go back to the doctor for HIV/AIDS medical care? Participants shared counseling, moral support, and knowing where to go will persuade individuals to go back to the doctor for HIV/AIDS medical care.

- Counseling "They need some people to talk to."
- Moral Support

"They don't like people to know about it because they are afraid, afraid to let other people help them. If you don't speak up, how are you going to get help? They think if one person know, they think everybody will know. Our culture, they worried about, who give it to me, I am going to give it to somebody else. They don't worry about the circumstances. What can we do if they don't want help?"

• Knowing Where to Go

"You should know some place they can go, agency. If people don't know where they can go, you can't help them, (if they don't know) they will say let me try."

"Some of them don't know where to go to."

#### For in care participants, what has helped to get in care and stay in care?

Participants expressed a desire to live life as the motivation to get in care and stay in care.

- Desire to Live Life
  - "Because we want to live, want to see my grandkids."

"I was undetectable too, 5 years, no medical, but I'm always going to the doctor, other problems, high blood pressure, cholesterol, asthma. Some people don't want to know. I need my life."

# In the past 3 years, have services improved, declined, or stayed the same?

Participants felt that services have declined in the past 3 years.

- "Down, down, down."
- "Service has decreased, people don't take time anymore."
- "No."

# Quantity and Quality of Services

Participants all agreed the quantity and quality of services have been inadequate.

- "Used to receive all of services, new manager, doesn't receive them, have not gotten medication for 3 months, blood pressure."
- "No, it's not enough, not anymore."
- "We don't have them, not receiving them."

#### Additional Comments

Participants shared their belief in the supernatural and a request to obtain more services.

- "She thinks that it could be supernatural, but she is still going to the doctor."
- "I need more services than I'm getting."
- "Need transportation, help with my doctor, making appointments, on list for housing 3-4 years ago, still haven't called, can't afford where I'm staying now with my kids, no food voucher, no bus voucher, nothing.
- "If we don't have a case manager, we not going to know..."

## 4. HISPANICS

#### Unique Challenges

The challenges of serving Hispanic PLWHA are similar to those for the Haitian population, such as stigma about both HIV/AIDS and homosexuality, immigration issues, and linguistic barriers. Also, similar to Haitians, there is a reliance on folk medicines and healers (botanicas and curanderas) as a means of treatment and there is substantial misinformation concerning the transmission of HIV/AIDS along with a high incidence of "no symptom, no problem" thinking in this population. Some Hispanic immigrants travel back and forth from the United States to their homeland, and some are seasonal migrant workers, complicating care and follow-up to treatment, thereby increasing the cost of care.<sup>15</sup>

#### Service Gaps

60 Hispanic respondents participated in the Comprehensive Needs Assessment 2013-2016 survey. 60% of these were in care. 40% were not working during the prior year, 23% had less than an eighth grade education, and nearly two-thirds lived at or below the poverty level.

#### Out of Care Hispanic Respondents

When out of care Hispanics were asked to describe their situation, 67% said they had been receiving medical care for HIV, but had stopped more than 12 months previously. Their most frequently identified reasons for being out of care were "I did not feel sick" (54%) and "I could not get transportation" and "I could not get time off work" (33% each). When out of care Hispanic respondents were asked to identify the services that they need in order to get into primary medical care, the most frequently selected services were substance abuse treatment, housing, and financial assistance (54% each).

#### In Care Hispanic Respondents

Among Hispanic in care respondents, the most frequently reported service gaps ("I needed this service but was unable to get it") were transportation (19%); food bank or food vouchers and housing (14% each); and case management (8%). The most frequently cited barriers to services ("I needed this service but was unaware if it was offered or how to access it") were legal support (31%); food bank or food vouchers (22%); emergency financial assistance and housing (20% each); and transportation (11%).

#### Hispanic Focus Group Findings

Reasons that PLWHA don't get care were reported to be fear, not being able to take time off work, not having enough time due to holding two jobs, and fear of being fired from work if the supervisor finds out they are HIV positive. Factors that would get PLWHA into care were reported to be getting sick, and being reminded that family members depend on the PLWHA. Factors that helped participants stay in care were knowing that their family is important and needs them, wanting to set an example for family members, not having to pay for medication, and having a health care navigator. A challenge to getting and staying in care was reported to be transportation. Overall, respondents felt that in the past 3 years services had improved, were adequate in quantity and quality, and the respondents were able to access the services they needed.

<sup>&</sup>lt;sup>15</sup>Miami-Dade HIV/AIDS Partnership (2009). Comprehensive Plan for HIV/AIDS 2009-2011.

#### Data related to Hispanic respondents:

- 60 (16.4% of all respondents) indicated they were Hispanic.
- 15 (25.0%) reported Puerto Rico as their country of origin, and 14 (23.3%) said the US.
- 41 (68.3%) said they are straight (heterosexual).
- 36 (60.0%) are in care, compared to 211 (57.7%) of all respondents.
- 24 (40.0%) are out of care, compared to 155 (42.3%) of all respondents.
- 31 (51.7%) said English is their primary language, and 28 (46.7%) said Spanish.
- 14 (23.3%) of Hispanic respondents had either no schooling or an education level of 8<sup>th</sup> grade less compared to 60 (16.4%) of all respondents.
- 24 (40.0%) described their work situation in the past year as "unemployed" compared to 219 (59.8%) of all respondents.
- 4 (6.7%) reported being a migrant or seasonal worker.
- 38 (63.3%) were living at or below 100% FPL compared to 283 (77.3%) of all respondents.

Please see the following pages for additional data and analysis.

All out of care respondents were asked to describe their current situation regarding being out of care. As with all out of care respondents, the most frequently mentioned description by Hispanics was, "I have been receiving medical care for HIV, but I stopped more than 12 months ago" (72.9% and 66.7%, respectively).

The following table summarizes responses from Hispanics who are out of care as well as the responses of all respondents who are out of care.

Out of Care Circuinstances								
Survey Question 21A. What best describes your situation (check one only)								
Out of Care Situation	Out o Respo	All of Care ndents	Hispanic Out of Care Respondents					
	(N=	155)	(N=24)					
	number	percent	number	percent				
I have recently been diagnosed with HIV, and have not entered medical care.	18	11.6%	3	12.5%				
I have <u>not</u> been recently diagnosed but have never been in medical care.	19	12.3%	4	16.7%				
I had been receiving medical care for HIV, but I stopped more than 12 months ago.	113	72.9%	16	66.7%				
Other (e.g. Medications; Drug use)	5	3.2%	1	4.2%				
Total	155	100.0%	24	100.0%				

Out	of	Care	Circumstances
040	<b>U</b> .	Curc	Chicamoco

Respondents were asked to identify the reasons for being out of care. In each group (all out of care respondents and Hispanic out of care respondents); responses were fairly evenly distributed among five reasons. The most frequently cited reason in both groups was, "I did not feel sick."

٦

Survey Question 22A. If you did not get HIV/AIDS n please indicate the reason/s why? (check any or all		•	ne past 12	months,	
Out of Care Reasons		ll f Care ndents 155)	Hispanic Out of Care Respondents (N=24)		
		percent	number	percent	
I did not know where to go.	12	7.7%	2	8.3%	
I could not get an appointment.	17	11.0%	4	16.7%	
I could not get transportation.	38	24.5%	8	33.3%	
I could not get childcare.	8	5.2%	6	25.0%	
I could not pay for services.	22	14.2%	5	20.8%	
I did not want people to know that I have HIV.	58	37.4%	6	25.0%	
I was not ready to deal with having HIV.	57	36.8%	7	29.2%	
l did not feel sick.	89	57.4%	13	54.2%	
I could not get time off work.	7	4.5%	2	8.3%	
I was depressed.	60	38.7%	8	33.3%	
I had a bad experience with the medical staff.	20	12.9%	3	12.5%	
Other (e.g. drugs; recently diagnosed; fear)	30	19.4%	5	20.8%	

The following table summarizes all responses to this question.

Г

When asked what services they needed to get into primary medical care, out of care respondents and Hispanic out of care respondents mentioned the same top five service categories. In nearly every category (except transportation), a larger percentage of out of care respondents indicated the need for specific services to get into care than Hispanic out of care respondents.

The table below displays all responses to this question.

Survey Question 24A. What services would help you get HIV/AIDS medical care? (check any or all that apply)								
Services	All Out of Care Respondents (N=155)		Hisp Out of Respor (N=	f Care ndents				
	number	percent	number	percent				
Financial assistance	76	49.0%	11	45.8%				
Food	67	43.2%	10	41.7%				
Housing	89	57.4%	13	54.2%				
Case management	46	29.7%	9	37.5%				
Transportation	83	53.5%	13	54.2%				
Substance abuse treatment	90	58.1%	13	54.2%				
Mental health services	46 29.7%		6	25.0%				
Treatment Adherence	33	33 21.3% 6						
Other (e.g. job, late appointments, fear)	26	16.8%	2	8.3%				

#### Services Needed to Get Into Medical Care

The reasons cited by out of care Hispanic respondents regarding why they would enter medical care were similar to the reasons cited by all out of care respondents. The most frequently cited reasons were, "I get sick and know I need care," and "I am ready to deal with my illness."

The following table summarizes all responses to this question.

Reasons to Enter Med	ical Care							
Survey Question 25A. What would be some of the reasons why you would go to the doctor for HIV/AIDS medical care? <i>(check any or all that apply)</i>								
Reasons	Out of Respoi (N=1	ndents	Hisp Out of Respor (N=	f Care ndents				
	number	percent	number	percent				
I get sick and know I need care.	120	77.4%	17	70.8%				
I am ready to deal with my illness.	67	43.2%	11	45.8%				
Someone else with HIV/AIDS reaches out to me.	44	28.4%	9	37.5%				
I get transportation to go to a doctor or clinic.	47	30.3%	7	29.2%				
Someone arranges to have my care paid for.	37	23.9%	7	29.2%				
Other (e.g. just found out status, need a place to go)	13	8.4%	1	4.2%				

#### Reasons to Enter Medical Care

# **Prioritization of Service Categories**

Hispanic in care respondents and all in care respondents selected the same five service categories as their top priorities. Both groups identified primary medical care as their most important service category.

Five Most Impo	rtant Servic	es		
Survey Question 77A. Which five services do with HIV/AIDS?	you think a	re most im	portant for	people
Service Category	In Care Respondents		In C	anic Care ndents 36)
	number	percent	number	percent
Primary Medical Care	127	60.2%	25	69.4%
Laboratory Diagnostic Testing	114	54.0%	18	50.0%
Medications	112	53.1%	21	58.3%
Case Management	100	47.4%	17	47.2%
Food	80	37.9%	14	38.9%

Please see the table on the next page for a summary of all responses to this question.

#### **Five Most Important Services**

Survey Question 36A. Which five services do you think are most important for people with HIV/AIDS? (please check 5 services)						
Service Category	In C Respon (N=2	ndents	Hispanic In Care Respondents (N=36)			
	number	percent	number	percent		
Primary Medical Care	127	60.2%	25	69.4%		
Laboratory Diagnostic Testing	114	54.0%	18	50.0%		
Medical Specialist	42	19.9%	2	5.6%		
Nurse Care Coordination	10	4.7%	1	2.8%		
Case Management	100	47.4%	17	47.2%		
Medications	112	53.1%	21	58.3%		
Dental /Oral Health	38	18.0%	8	22.2%		
Health Insurance	22	10.4%	7	19.4%		
Mental Health Services	27	12.8%	6	16.7%		
Substance Abuse Residential	4	1.9%	1	2.8%		
Substance Abuse Outpatient	3	1.4%	1	2.8%		
Nutrition Counseling	9	4.3%	1	2.8%		
Early Intervention Services	21	10.0%	2	5.6%		
Home Health Care	4	1.9%	3	8.3%		
Hospice Services	1	0.5%	0	0.0%		
Food Bank or Food Vouchers	80	37.9%	14	38.9%		
Transportation	41	19.4%	10	27.8%		
Outreach	19	9.0%	5	13.9%		
Health Education/Risk Reduction	7	3.3%	1	2.8%		
Treatment Adherence	18	8.5%	0	0.0%		
Legal Support	19	9.0%	3	8.4%		
Rehabilitation	2	0.9%	0	0.0%		
Emergency Financial Assistance	15	7.1%	1	2.8%		
Linguistics Services	2	0.9%	0	0.0%		
Peer Mentoring	12	5.7%	5	13.9%		
Housing	60	28.4%	4	11.1%		
Support groups	11	5.2%	2	5.6%		
Other (e.g. Hour, Service after hours)	2	0.9%	0	0.0%		
No response	3	1.4%	1	2.8%		
Total In Care Respondents	211	100%	36	100%		

#### Service Needs and Utilization

Survey respondents in care were asked to describe their level of utilization of the twenty-seven service categories prioritized by the planning council. The respondents in care described their utilization of each survey categories as one of the following:

- "I received this service" if they utilize the service
- "I needed this service but was unable to get it" to show possible gaps in services
- "I needed this service but was unaware if it was offered or how to access" to show barriers to service utilization
- "I did not need this service" if they do not utilize the service

#### Utilization: "I received this service"

When asked to identify the services they need and use, in care Hispanic respondents and all in care respondents identified similar service categories. The services most frequently utilized by both groups are "Core Services" rather than "Support Services". As highlighted in the following table, among both groups, primary medical care, laboratory diagnostic testing, and medications were the three most frequently utilized services by both groups.

Utilized Service Categories	All in Care Respondents (N=211) rank number percent			Hispanic in Care Respondents (N=36)				
				rank	number	percent		
CORE SERVICES								
Medical Care								
Primary Medical Care	2	196	92.9%	1	36	100.0%		
Laboratory Diagnostic Testing	1	202	95.7%	1	36	100.0%		
Medical Specialist		159	75.4%	4	30	83.3%		
Case Management	4	172	81.5%	5	27	75.0%		
Medications	3	190	90.0%	2	34	94.4%		
Dental /Oral Health	5	160	75.8%	3	31	86.1%		

#### Comparison of Service Utilization "Need and Use"

The table on the next page summarizes all responses to this question.

Utilized Service Categories	All in	Care Resp (N=211)			Hispanic in ( spondents (	
	rank	number	percent	rank	number	percent
CORE SERVICES						
Medical Care						
Primary Medical Care	2	196	92.9%	1	36	100.0%
Laboratory Diagnostic Testing	1	202	95.7%	1	36	100.0%
Medical Specialist		159	75.4%	4	30	83.3%
Nurse Care Coordination		72	34.1%		12	33.3%
Case Management	4	172	81.5%	5	27	75.0%
Medications	3	190	90.0%	2	34	94.4%
Dental /Oral Health	5	160	75.8%	3	31	86.1%
Health Insurance		83	39.3%		25	69.4%
Mental Health Services		84	39.8%		10	27.8%
Substance Treatment						
Substance Abuse Residential		34	16.1%		0	0.0%
Substance Abuse Outpatient		23	10.9%		1	2.8%
Nutrition Counseling		112	53.1%		18	50.0%
Early Intervention Services		57	27.0%		5	13.9%
Home Health Care		15	7.1%		1	2.8%
Hospice		3	1.4%		0	0.0%
SUPPORT SERVICES						
Food Bank or Food Vouchers		113	53.6%		12	33.3%
Transportation		103	48.8%		12	33.3%
Outreach		32	15.2%		4	11.1%
Health Education/Risk Reduction		94	44.5%		10	27.8%
Treatment Adherence		98	46.4%		10	27.8%
Legal Support		69	32.7%		6	16.7%
Rehabilitation		22	10.4%		1	2.8%
Emergency Financial Assistance		61	28.9%		5	13.9%
Linguistics Services		19	9.0%		8	22.2%
Peer Mentoring		67	31.8%		14	38.9%
Housing		65	30.8%		2	5.6%
Support groups		79	37.4%		9	25%

Comparison of Service Utilization "I Received this Service "

# Service Gaps: "I needed this service but was unable to get it"

Hispanic in care respondents and all in care respondents most frequently identified the leading service gaps to be food, housing, and transportation. The following table displays all responses to this survey item.

· · ·		All			Hispanie			
Utilized Service Categories	In C	In Care Respondents			In Care Respondents			
		(N=211)			(N=23)			
	rank	number	percent	rank	number	percent		
CORE SERVICES								
Medical Care								
Primary Medical Care		4	1.9%		0	0.0%		
Laboratory Diagnostic Testing		4	1.9%		0	0.0%		
Medical Specialist		5	2.4%		0	0.0%		
Nurse Care Coordination		8	3.8%		1	4.3%		
Case Management	5	15	7.1%	3	3	4.3%		
Medications		5	2.4%		1	0.0%		
Dental /Oral Health		12	5.7%		1	0.0%		
Health Insurance		9	4.3%		1	4.3%		
Mental Health Services		4	1.9%		1	0.0%		
Substance Abuse Treatment								
Substance Abuse Residential		4	1.9%		1	0.0%		
Substance Abuse Outpatient		3	1.4%		1	0.0%		
Nutrition Counseling		7	3.3%	4	2	0.0%		
Early Intervention Services		5	2.4%		1	0.0%		
Home Health Care		3	1.4%		0	0.0%		
Hospice		0	0.0%		0	0.0%		
SUPPORT SERVICES		-						
Food Bank or Food Vouchers	2	21	10.0%	2	5	4.3%		
Transportation	3	20	9.5%	1	7	0.0%		
Outreach		3	1.4%		1	0.0%		
Health Education/Risk Reduction		4	1.9%		0	0.0%		
Treatment Adherence		4	1.9%		0	0.0%		
Legal Support		11	5.2%		0	8.7%		
Rehabilitation		3	1.4%		0	4.3%		
Emergency Financial Assistance	4	18	8.5%		1	17.4%		
Linguistics Services		4	1.9%		1	4.3%		
Peer Mentoring		7	3.3%	4	2	0.0%		
Housing	1	29	13.7%	2	5	8.7%		
Support Groups		5	2.4%		1	0.0%		
Other		1	0.5%		0	0.0%		

Comparison of Gaps "I needed this service but was unable to get it"

#### Barriers to Services: "I needed this service but was unaware if it was offered or how to access"

All in care respondents and Hispanic respondents reported similar barriers to services. The barrier most frequently cited by Hispanic respondents was legal support.

Service Categories		All In Care Respondents (N=211)			Hispanic In Care Respondents (N=36)		
	rank	rank number percent		rank	number	percent	
CORE SERVICES		1		1		1	
Medical Care							
Primary Medical Care		1	0.5%		1	2.8%	
Laboratory Diagnostic Testing		1	0.5%		1	2.8%	
Medical Specialist		9	4.3%	5	4	11.1%	
Nurse Care Coordination		10	4.7%	5	4	11.1%	
Case Management		5	2.4%		3	8.3%	
Medications		5	2.4%		0	0.0%	
Dental /Oral Health		11	5.2%	5	4	11.1%	
Health Insurance		12	5.7%	5	4	11.1%	
Mental Health Services		11	5.2%		2	5.6%	
Substance Abuse Treatment							
Substance Abuse Residential		7	3.3%		2	5.6%	
Substance Abuse Outpatient		10	4.7%		1	2.8%	
Nutrition Counseling		11	5.2%		1	2.8%	
Early Intervention Services		10	4.7%		0	0.0%	
Home Health Care		7	3.3%		1	2.8%	
Hospice		1	0.5%		0	0.0%	
SUPPORT SERVICES			<u> </u>				
Food Bank/Home Delivered Meals	2	32	15.2%	2	9	25.0%	
Transportation		18	8.5%	4	5	13.9%	
Outreach		10	4.7%		2	5.6%	
Health Education/Risk Reduction		13	6.2%		3	8.3%	
Treatment Adherence		10	4.7%		2	5.6%	
Legal Support	3	28	13.3%	1	12	33.3%	
Rehabilitation Services		14	6.6%		3	8.3%	
Emergency Financial Assistance	1	36	17.1%	3	8	22.2%	
Linguistics Services		12	5.7%		3	8.3%	
Peer Mentoring		18	8.5%		3	8.3%	
Housing	4	21	10.0%	3	8	22.2%	
Support Groups	5	20	9.5%		1	2.8%	
Other		6	2.8%		0	0.0%	

Comparison of Barriers "I needed this service but was unaware if it was offered or how to access"

#### Focus Group Findings: Themes and Notable Quotes

#### Reasons for not going to the doctor for HIV/AIDS medical care

Participants expressed that fear and time were factors in not going to the doctor for HIV/AIDS medical care.

• Time

"He can't get time off from work to make lab and Dr's appointments."

• Fear

"I got a letter from the federal government, you could be fired for being HIV positive, this was in Pennsylvania."

"Maybe because he's afraid to tell his boss that he has HIV and he will get fired."

# What will it take to persuade individuals to go back to the doctor for HIV/AIDS medical care?

Participants voiced that family and getting sick would persuade individuals to go back to the doctor for HIV/AIDS medical care.

• Family

"I think you have to remind people, your whole family it affects, that's so important, doesn't mean you're not valid, I have a niece and a nephew. I want them to grow up to do the right thing. I think there's a lot of fear. A lot of people don't want to know, you need to know. Point out to them, you're valid...finding the right way to get through to them, you have to keep trying, that's about the most you can do, you can't pull someone down by the ear.

"You life depends on them having to go to the doctor."

• Sickness

"Infection..."

"Social worker or nurse to come to the house, and then to help him out, realize what his diagnosis is, she has 2 kids, who's going to take care of them."

#### For in care participants, what has helped to get in care and stay in care?

Participants shared family and extra support has helped to get in care and stay in care.

• Family

"I thought I had the flu, in hospital with 3 months, wasn't suppose to live, my family is more important, being an example, I'm here, I'm open about it. First of all, I saw there was an example for my niece and nephew, you take care of yourself."

"Well I was diagnosed, I was freaking out, handicapped boy, 2 other girls, my son needs me a lot. I take my medicine, to this day, vitals got higher, my son really needs me." • Extra Support

"...has been a big part of being a support system, people in this clinic, wanted to give up plenty of time, people who are behind you, whenever you need them.

# In the past 3 years, have services improved, declined, or remain the same?

Hispanic participants expressed that services have improved in the area.

- "Back a year and a half, improved, learning the right time to come in for appointment."
- "Improved a lot."

# Quantity and Quality of Services

Participants shared that services in both quantity and quality have been adequate and that they have been able to access the services they need.

- "I think they're fine, it's just a matter of a lot of people getting to them, people are very caring here, they know your name."
- "They've got people who speak difference languages here, morning, pregnant women...99% of people here are very accommodating."
- "Good programs."

#### Additional Comments

Participants said they felt as though they were treated poor, they would like that to change.

- "All created for low-income, they treat you like low-income, like a third-world country, like you're poor."
- "Coming here makes me feel poor, not like if I go to private Dr's office, just the way that it is."
- "I've seen it happen, I've gotten upset..."

#### 5. INDIVIDUALS WHO HAVE BEEN RECENTLY INCARCERATED (IN THE PAST 12 MONTHS)

#### Unique Challenges

Unique challenges in serving recently incarcerated PLWHA include concerns regarding confidentiality, stigma, long waits for appointments for dental care, difficulty accessing housing services with a criminal record, stress of worrying about future services, and fear of becoming homeless.<sup>16</sup> Further unique challenges are substance abuse, lack of transportation, and not being ready to deal with one's HIV status.<sup>17</sup> Reportedly, some PLWHA engage in a cycle of going into jail and prison sick and coming out healthy. When they are released, they focus on looking for work and spending time with family and friends; their health is not a priority and they become sick. Doing this rotation many times creates drug resistance.

#### Service Gaps

The Comprehensive Needs Assessment 2013-2016 survey included 17 respondents who had been incarcerated in the previous 12 months. All of these were in care. 6% had less than an 8<sup>th</sup> grade education, 82% lived at or below 100% of the federal poverty level, and 59% were unemployed.

#### In Care Incarcerated Respondents

Among incarcerated respondents (all of whom were in care), the most frequently reported service gaps ("I needed this service but was unable to get it") were transportation (29%), food bank or food vouchers (24%), and housing (18%). The most frequently cited barriers to services ("I needed this service but was unaware if it was offered or how to access it") were legal support (24%), dental /oral health, substance abuse treatment, emergency financial assistance, and support groups (12% each).

#### Recently Incarcerated Focus Group Findings

Reported barriers to care were red tape, getting denied, paperwork, and inability to pay. A reported factor that got PLWHA into care was having their family pay for treatment. Inadequate funding was reported to be the challenge to getting people to get and stay in care. Respondents felt that over the past 3 years, funding had been cut. They were concerned about funeral costs.

# Data highlights related to In Care Recently Incarcerated (in the past 12 months) survey respondents:

- 17 (8.1% of all in care respondents) indicated they were incarcerated in the past 12 months.
- 11 (64.7%) said they received HIV/AIDS related medical care while in jail/prison.
- 13 (76.5%) said they are straight (heterosexual).
- 17 (100.0%) said English is their primary language.
- 1 (5.9%) of recently incarcerated in care respondents had either no schooling or an education level of 8<sup>th</sup> grade less compared to 29 (13.7%) of all in care respondents.
- 10 (58.8%) described their work situation in the past year as "unemployed" compared to 115 (54.5%) of all in care respondents.
- 1 (5.9%) reported being a migrant or seasonal worker.

<sup>&</sup>lt;sup>16</sup> Treasure Coast Health Council (2007). *Comprehensive Needs Assessment 2007-2010.* 

<sup>&</sup>lt;sup>17</sup> Treasure Coast Health Council (2010). *PLWHA Released from Jail/Prison in last 12 months.* 

- 14 (82.4%) were living at or below 100% FPL compared to 158 (74.9%) of all in care respondents.
- 9 (52.9%) received a supply of HIV medication to take with them when released from jail/prison, and 5 (29.4%) received a referral to case management.

Please see the following pages for additional data and analysis.

Selected Demographic and Socioeconomic Variables		Care ndents 211)	Recently Incarcerated In Care Respondents (N=17)		
	number	percent	number	percent	
Male	113	53.6%	8	47.1%	
Female	96	45.5%	8	47.1%	
Straight (heterosexual)	150	71.1%	13	76.5%	
Primary Language					
English	172	81.5%	17	100.0%	
Education Completed - none or 8th grade or less	29	13.7%	1	5.9%	
Work situation in the past year - unemployed	115	54.5%	10	58.8%	
Below 100% Federal Poverty Level	158	74.9%	14	82.4%	

Comparison of Recently Incarcerated In Care Survey Respondents with All In Care Respondents

- 11.8% had been diagnosed with Hepatitis B within the past 12 months compared to 2.8% of all in care respondents.
- 11.8% had been diagnosed with Chlamydia within the past 12 months compared to 3.3% of all in care respondents.
- 11.8% had been diagnosed with Syphilis within the past 12 months compared to 4.7% of all in care respondents.

Selected Risk Factors and Co-morbidities		ll are ndents 211)	Recently Incarcerated In Care Respondents (N=17)		
	Number	Percent	Number	Percent	
Survey Question 19A. Diagnosed in the past 12 mo	nths				
AIDS	46	21.8%	5	29.4%	
Hepatitis A	0	0.0%	0	0.0%	
Hepatitis B	6	2.8%	2	11.8%	
Hepatitis C	21	10.0%	2	11.8%	
Tuberculosis	2	0.9%	0	0.0%	
Syphilis	10	4.7%	2	11.8%	
Gonorrhea	6	2.8%	2	11.8%	
Chlamydia	7	3.3%	2	11.8%	
Other STD	5	2.4%	0	0.0%	
Cancer	8	3.8%	0	0.0%	
High Cholesterol	30	14.2%	2	11.8%	
Liver Disease	10	4.8%	1	5.9%	
Diabetes	15	7.1%	0	0.0%	
Coronary Heart Disease	12	5.7%	0	0.0%	

Comparison of Recently Incarcerated In Care Survey Respondents with All In Care Respondents

#### **Prioritization of Service Categories**

Recently incarcerated respondents who are in care and all in care respondents identified medications and primary medical care as the most important service, (58.8%, 60.2%) respectively.

Additional services that were also in the top five for both groups include laboratory diagnostic testing and case management.

The table below highlights the services most frequently mentioned by both groups.

Survey Question 77A. Which five services do you think are most important for people with HIV/AIDS?								
Service Category		Care ndents 211)	Recently Incarcerated In Care Respondents (N=17)					
	number	percent	number	percent				
Primary Medical Care	127	60.2%	9	52.9%				
Laboratory Diagnostic Testing	114	54.0%	6	35.3%				
Medications	112	53.1%	10	58.8%				
Case Management	100	47.4%	8	47.1%				
Food Bank or Food Vouchers	80	37.9%	6	35.3%				
Transportation	41	19.4%	4	23.5%				
Legal Support	19	9.0%	4	23.5%				
Housing	60	28.4%	8	47.1%				

#### **Five Most Important Services**

The table on the next page summarizes all responses to this survey item.

Survey Question 36A. Which five services do you think are most important for people with HIV/AIDS? (please check 5 services)							
Service Category	•	Care ndents 211)	Recently Incarcerated In Care Respondents (N=17)				
	number	percent	number	percent			
Primary Medical Care	127	60.2%	9	52.9%			
Laboratory Diagnostic Testing	114	54.0%	6	35.3%			
Medical Specialist	42	19.9%	3	17.6%			
Nurse Care Coordination	10	4.7%	0	0.0%			
Case Management	100	47.4%	8	47.1%			
Medications	112	53.1%	10	58.8%			
Dental /Oral Health	38	18.0%	3	17.6%			
Health Insurance	22	10.4%	2	11.8%			
Mental Health Services	27	12.8%	3	17.6%			
Substance Abuse Residential	4	1.9%	0	0.0%			
Substance Abuse Outpatient	3	1.4%	0	0.0%			
Nutrition Counseling	9	4.3%	1	5.9%			
Early Intervention Services	21	10.0%	2	11.8%			
Home Health Care	4	1.9%	0	0.0%			
Hospice Services	1	0.5%	0	0.0%			
Food Bank or Food Vouchers	80	37.9%	6	35.3%			
Transportation	41	19.4%	4	23.5%			
Outreach	19	9.0%	3	176%			
Health Education/Risk Reduction	7	3.3%	0	0.0%			
Treatment Adherence	18	8.5%	1	5.9%			
Legal Support	19	9.0%	4	23.5%			
Rehabilitation	2	0.9%	0	0.0%			
Emergency Financial Assistance	15	7.1%	1	5.9%			
Linguistics Services	2	0.9%	0	0.0%			
Peer Mentoring	12	5.7%	1	5.9%			
Housing	60	28.4%	8	47.1%			
Support groups	11	5.2%	1	5.9%			
Other (e.g. Hour, Service after hours)	2	0.9%	0	0.0%			
No response	3	1.4%	0	0.0%			
Total In Care Respondents	211	100%	17	100%			

#### **Five Most Important Services**

#### Service Needs and Utilization

Survey respondents in care were asked to describe their level of utilization of the twenty-seven service categories prioritized by the planning council. The respondents in care described their utilization of each survey categories as one of the following:

- "I received this service" if they utilize the service
- "I needed this service but was unable to get it" to show possible gaps in services
- "I needed this service but was unaware if it was offered or how to access" to show barriers to service utilization
- "I did not need this service" if they do not utilize the service

#### Utilization: "I received this service"

Recently incarcerated in care respondents reported a similar pattern of service utilization as all respondents who are in care. Both groups reported primary medical care, laboratory diagnostic testing, and medications as the three most highly utilized services.

The following table highlights the most frequently utilized services.

Utilized Service Categories	All in Care Respondents (N=211)		Recently Incarcerated in Care Respondents (N=17)				
	rank	number	percent	rank	number	percent	
CORE SERVICES							
Medical Care							
Primary Medical Care	2	196	92.9%	1	17	100.0%	
Laboratory Diagnostic Testing	1	202	95.7%	2	16	94.1%	
Medical Specialist		159	75.4%	4	13	76.5%	
Case Management	4	172	81.5%	3	14	82.4%	
Medications	3	190	90.0%	3	14	82.4%	
Dental /Oral Health	5	160	75.8%		8	47.1%	
Mental Health Services		84	39.8%	5	9	52.9%	
Nutrition Counseling		112	53.1%	5	9	52.9%	

#### Comparison of Service Utilization "I received this service"

The table on the next pages summarizes all responses to this question.

Utilized Service Categories		All Care Respo (N=211)		in	ently Incare Care Respo (N=17)	ndents			
CORE SERVICES	rank	number	percent	rank	number	percent			
Medical Care									
Primary Medical Care	2	196	92.9%	1	17	100.0%			
Laboratory Diagnostic Testing	1	202	95.7%	2	16	94.1%			
Medical Specialist		159	75.4%	4	13	76.5%			
Nurse Care Coordination	_	72	34.1%		8	47.1%			
Case Management	4	172	81.5%	3	14	82.4%			
Medications	3	190	90.0%	3	14	82.4%			
Dental /Oral Health	5	150	75.8%		8	47.1%			
Health Insurance		83	39.3%		8	47.1%			
Mental Health Services	_	84	39.8%	5	9	52.9%			
Substance Treatment		01	00.070			021070			
Substance Abuse Residential		34	16.1%		4	23.5%			
Substance Abuse Outpatient	_	23	10.9%		2	11.8%			
Nutrition Counseling		112	53.1%	5	9	52.9%			
Early Intervention Services		57	27.0%		3	17.6%			
Home Health Care		15	7.1%		1	5.9%			
Hospice		3	1.4%		1	5.9%			
SUPPORT SERVICES		1	1	1					
Food Bank or Food Vouchers		113	53.6%		7	41.2%			
Transportation		103	48.8%		7	41.2%			
Outreach		32	15.2%		8	47.1%			
Health Education/Risk Reduction		94	44.5%		6	35.3%			
Treatment Adherence		98	46.4%		7	41.2%			
Legal Support		69	32.7%		2	11.8%			
Rehabilitation		22	10.4%		3	17.6%			
Emergency Financial Assistance		61	28.9%		4	23.5%			
Linguistics Services		19	9.0%		1	5.9%			
Peer Mentoring		67	31.8%		5	29.4%			
Housing		65	30.8%		6	35.3%			
Support groups		79	37.4%		7	41.2%			

Comparison of Service Utilization "I received this service"

#### Service Gaps: "I needed this service but was unable to get it"

Recently incarcerated in care respondents and all in care respondents most frequently reported a service gap regarding food. Respondents in this special population mentioned transportation as the service most needed but were unable to get.

Utilized Service Categories	In C	All In Care Respondents (N=211)			In Care Respondents		Care Respondents		Recently Incar In Care Respo (N=17)		ondents	
	rank	number	percent	rank	number	percent						
CORE SERVICES												
Medical Care												
Primary Medical Care		4	1.9%		0	0.0%						
Laboratory Diagnostic Testing		4	1.9%		0	0.0%						
Medical Specialist		5	2.4%		0	0.0%						
Nurse Care Coordination		8	3.8%		0	0.0%						
Case Management	5	15	7.1%	4	2	11.8%						
Medications		5	2.4%	5	1	5.9%						
Dental /Oral Health		12	5.7%	5	1	5.9%						
Health Insurance		9	4.3%		0	0.0%						
Mental Health Services		4	1.9%		0	0.0%						
Substance Abuse Treatment												
Substance Abuse Residential		4	1.9%	5	1	5.9%						
Substance Abuse Outpatient		3	1.4%	5	1	5.9%						
Nutrition Counseling		7	3.3%	4	2	11.8%						
Early Intervention Services		5	2.4%	4	2	11.8%						
Home Health Care		3	1.4%		0	0.0%						
Hospice		0	0.0%		0	0.0%						
SUPPORT SERVICES												
Food Bank or Food Vouchers	2	21	10.0%	2	4	23.5%						
Transportation	3	20	9.5%	1	5	29.4%						
Outreach		3	1.4%		0	0.0%						
Health Education/Risk Reduction		4	1.9%		0	0.0%						
Treatment Adherence		4	1.9%	4	2	11.8%						
Legal Support		11	5.2%	5	1	5.9%						
Rehabilitation		3	1.4%		0	0.0%						
Emergency Financial Assistance	4	18	8.5%	4	2	11.8%						
Linguistics Services		4	1.9%		0	0.0%						
Peer Mentoring		7	3.3%		0	0.0%						
Housing	1	29	13.7%	3	3	17.6%						
Support Groups		5	2.4%		0	0.0%						
Other	-	1	0.5%		0	0.0%						

#### Comparison of Gaps "I needed this service but was unable to get it"

## Barriers to Services: "Needed But Didn't Know About Services"

The most frequently mentioned barrier reported by recently incarcerated in care respondents was legal support. The responses most frequently mentioned by all in care respondents and recently incarcerated in care respondents are highlighted in the following table.

Service Categories	All In	All In Care Respondents (N=211)			Recently Incarcerated In Care Respondents (N=17)			
-	rank	number	percent	rank	number	percent		
CORE SERVICES		1	1		11			
Medical Care								
Primary Medical Care		1	0.5%		0	0.0%		
Laboratory Diagnostic Testing		1	0.5%		0	0.0%		
Medical Specialist		9	4.3%		0	0.0%		
Nurse Care Coordination		10	4.7%		0	0.0%		
Case Management		5	2.4%	3	1	5.9%		
Medications		5	2.4%		0	0.0%		
Dental /Oral Health		11	5.2%	2	2	11.8%		
Health Insurance		12	5.7%	3	1	5.9%		
Mental Health Services		11	5.2%	3	1	5.9%		
Substance Abuse Treatment					· · · ·			
Substance Abuse Residential		7	3.3%	3	1	5.9%		
Substance Abuse Outpatient		10	4.7%	2	2	11.8%		
Nutrition Counseling		11	5.2%		0	0.0%		
Early Intervention Services		10	4.7%	3	1	5.9%		
Home Health Care		7	3.3%		0	0.0%		
Hospice		1	0.5%		0	0.0%		
SUPPORT SERVICES								
Food Bank/Home Delivered Meals	2	32	15.2%	3	1	5.9%		
Transportation		18	8.5%	3	1	5.9%		
Outreach		10	4.7%	3	1	5.9%		
Health Education/Risk Reduction		13	6.2%		0	0.0%		
Treatment Adherence		10	4.7%		0	0.0%		
Legal Support	3	28	13.3%	1	4	23.5%		
Rehabilitation Services		14	6.6%		0	0.0%		
Emergency Financial Assistance	1	36	17.1%	2	2	11.8%		
Linguistics Services		12	5.7%		0	0.0%		
Peer Mentoring		18	8.5%	3	1	5.9%		
Housing	4	21	10.0%	3	1	5.9%		
Support Groups	5	20	9.5%	2	2	11.8%		
Other		6	2.8%		0	0.0%		

#### Focus Group Findings: Themes and Notable Quotes

#### Reasons for not going to the doctor for HIV/AIDS medical care

Participants reported frustration with the system as a reason for not going to the doctor for HIV/AIDS medical care.

- "When you are trying to get help, you have to jump through so much red tape to get help. That gets you frustrated."
- "Because you have to go through so much."
- "They tell you, you gotta get this paper from there, go here, go there."

# *What will it take to persuade individuals to go back to the doctor for HIV/AIDS medical care?* Participants expressed a stable environment and enough funding will persuade individuals to go back to the doctor for HIV/AIDS medical care.

- "Funding! That's our number one priority."
- "You gotta allocate your funds. Being in care also means a stable environment. Once a person gets in a stable environment, they start thinking about themselves."

#### For in care participants, what has helped to get in care and stay in care?

Participants stated that the help from family has helped to get in care and stay in care.

- "I was in care for maybe 16 years...about 10 years, then I got out of care because I got pregnant, couldn't get no help. My family paying to get me back into care to make sure my son wasn't positive-not out of care now.
- "With my family helping me go through the paperwork, got me back into care..."

#### In the past 3 years, have services improved, declined, or remain the same?

Participants said that over the past three years services have declined.

- "Because funding got cut."
- "They cut a lot of things that were needed, kept things that weren't needed."
- "For instance, one of my medications, Lipitor, Medicaid stopped paying for it, but my doctor knew how to find something to pay for that medicine for me but she had to know that, if she didn't know it, I would have been without."

#### Quantity and Quality of Services

Participants shared a neutral stance when determining the quantity and quality of services.

• "They have a lot of services, but there may be a lot more that's required."

• "One minute they are, one minute they aren't."

#### Additional Comments

Participants expressed sharing of information will be helpful for the future.

- "Group sessions like this are very beneficial, I'm sure someone today learned, having sessions like this more often, constantly being diagnosed, keep them educated-doing this, down the line, keep HIV population down-I learned a whole lot today that I didn't know."
- "Sharing of information is very beneficial, we need social activities for us, network."

#### 6. INDIVIDUALS AGED 50 AND OVER

#### Unique Service Delivery Challenges

There are numerous unique challenges to serving PLWHA age 50 and over. HIV/AIDS is generally regarded as a young person's disease in the U.S. Older persons may get back into dating after divorce or the death of a spouse and may not consider that they need to use condoms. Both patients and health care providers may mistake the symptoms of HIV/AIDS for the aches and pains of normal aging. Older persons may not be considered for testing by medical professionals, even when they exhibit symptoms for HIV/AIDS. Older persons are most likely to be in denial and refuse treatment because they cannot identify with the disease. Older persons may be at higher risk for social isolation, including depression and social stigma, which might prevent identification of symptoms or access to testing and care. Older persons with HIV/AIDS are more likely to live alone. Older persons tend to die sooner than younger age groups after an AIDS diagnosis because the disease has progressed without treatment. Late identification is partially due to the reasons mentioned above.<sup>18</sup>

An additional challenge in serving PLWHA ages 50 years and over is providing support to this aging population due to antiretroviral treatments. Today with access to new antiretroviral therapies there have been significant reductions in morbidity and mortality enabling PLWHA ages 50 years and over to live more productive lives and a potentially normal life span, increasing the need for financial support to provide care for an aging patient population.

#### Service Gaps

127 respondents aged 50 and over participated in the Comprehensive Needs Assessment 2013-2016 survey. 70% of these were in care. 65% were not working during the prior year, 18% had less than an eighth grade education, and 78% lived at or below the poverty level.

#### Out of Care Respondents Age 50+

When out of care respondents aged 50 and over were asked to describe their situation, 81% said they had been receiving medical care for HIV, but had stopped more than 12 months previously. Their most frequently identified reasons for being out of care were "I did not feel sick" (54%), "I did not want people to know that I have HIV" (46%), and "I was depressed" (38%). When out of care respondents aged 50 and over were asked to identify the services that they need in order to get into primary medical care, the most frequently selected services were substance abuse treatment (57%), treatment adherence services (49%), and housing (46%).

#### In Care Respondents Age 50+

Among in care respondents aged 50 and over, the most frequently reported service gaps ("I needed this service but was unable to get it") were housing (13%), nurse care coordination, transportation, food bank or food vouchers, legal support, and emergency financial assistance (6% each). The most frequently cited barriers to services ("I needed this service but was unaware if it was offered or how to access it") were food bank or food vouchers (16%); emergency financial assistance (14%); and peer mentoring and transportation (8% each).

<sup>&</sup>lt;sup>18</sup>Florida Department of Health Bureau of HIV/AIDS (2012). *HIV/AIDS Among Persons Aged 50 and Over*.

#### Respondents Age 50+ Group Findings

Reported reasons for PLWHA being out of care were shame and lack of privacy at the clinics. Factors that would get PLWHA into care were reported to be knowledge about the disease and social support. Desires to live and to help others were reported reasons for being and staying in care. Reported challenges to getting and staying in care were red tape, paperwork, waits, financial cost, and stress. Respondents felt that over the past 3 years services have improved a little, but are inadequate in quantity and quality. Accessing services has been difficulty due to case manager turnover and phone calls not being returned.

#### Additional Data Regarding Age 50+ Survey Respondents:

- 127 (34.7% of all respondents) indicated they were age 50 and over.
- 105 (82.7%) said they are straight (heterosexual)
- 90 (70.9%) are in care, compared to 211 (57.7%) of all respondents.
- 37 (29.1%) are out of care, compared to 155 (42.3%) of all respondents.
- 108 (85.0%) said English is their primary language, 9 (7.1%) said Spanish, 9 (7.1%) said Creole.
- 23 (18.1%) of age 50 and over respondents had either no schooling or an education level of 8<sup>th</sup> grade less compared to 60 (16.4%) of all respondents.
- 83 (65.4%) described their work situation in the past year as "unemployed" compared to 219 (59.8%) of all respondents.
- 11 (8.7%) reported being a migrant or seasonal worker.
- 100 (78.7%) were living at or below 100% FPL compared to 283 (77.3%) of all respondents.

Please see the following pages for additional data and analysis.

When asked, "What best describes your situation?" the most frequent circumstance by all out of care respondents and age 50+ out of care respondents was "I had been receiving medical care for HIV, but I stopped more than 12 months ago" (72.9% and 81.1%, respectively). The following table summarizes all responses to this survey item.

Out of Care Circuinstances							
Survey Question 24A. What best describes your situation (check one only)							
Out of Care Situation		of Care ndents 155)	50+ Out of Care Respondents (N=37)				
	number	percent	number	percent			
I have recently been diagnosed with HIV, and have not entered medical care.	18	11.6%	1	2.7%			
I have <u>not</u> been recently diagnosed but have never been in care.	19	12.3%	6	16.2%			
I had been receiving medical care for HIV, but I stopped more than 12 months ago.	113	72.9%	30	81.1%			
Other	5	3.2%	0	0.0%			
No Response	0	0.0%	0	0.0%			
Total	155	100.0%	37	100.0%			

As with all out of care respondents, out of care age 50+ respondents most frequently said that the reason they did not get HIV/AIDS medical care during the past 12 months was because they "...did not feel sick." Both groups also cited depression and not wanting others to know that they have HIV. The following table summarizes all reasons cited.

Survey Question 22A. If you did not get HIV/AIDS medical care during the past 12 months, please indicate the reason/s why? (check any or all that apply)							
Out of Care Reasons	All Out of Care Respondents		Age 50+ Out of Care Respondents				
	(N=155)		(N=37)				
	number	percent	number	percent			
I did not know where to go.	12	7.7%	3	8.1%			
I could not get an appointment.	17	11.0%	1	2.7%			
I could not get transportation.	38	24.5%	11	29.7%			
I could not get childcare.	8	5.2%	1	2.7%			
I could not pay for services.	22	14.2%	4	10.8%			
I did not want people to know that I have HIV.	58	37.4%	17	45.9%			
I was not ready to deal with having HIV.	57	36.8%	12	32.4%			
I did not feel sick.	89	57.4%	20	54.1%			
I could not get time off work.	7	4.5%	2	5.4%			
I was depressed.	60	38.7%	14	37.8%			
I had a bad experience with the medical staff.	20	12.9%	4	10.8%			
Other (e.g. drugs; recently diagnosed; in process)	30	19.4%	6	16.2%			

#### **Reasons for Not Getting Medical Care**

When asked what services would help get into HIV?AIDS medical care, Age 50+ respondents, like all out of care respondents most frequently mentioned substance abuse treatment. Other services needed by both groups include housing, financial assistance, and transportation. The table below displays the most frequently selected services by all out of care respondents as well as age 50+ out of care respondents.

Services Needed to Get Into Primary Medical Care							
Survey Question 24A. What services would help you get HIV/AIDS medical care? (check any or all that apply)							
Services	All Out of Care Respondents (N=155)		Age 50+ Out of Care Respondents (N=37)				
	number	percent	number	percent			
Financial assistance	76	49.0%	18	48.6%			
Food	67	43.2%	13	35.1%			
Housing	89	57.4%	16	43.2%			
Case management			16	43.2%			
Transportation	83	53.5%	17	45.9%			
Substance abuse treatment	90	58.1%	21	56.8%			
Mental health services	46	29.7%	11	29.7%			
Treatment Adherence	33	21.3%	4	10.8%			
Other (e.g. everything that would help me, insurance)	26	16.8%	4	10.8%			

#### Services Needed to Get Into Primary Medical Care

Age 50+ respondents who are out of care most frequently select the following reasons they would enter primary medical care:

- I get sick and know I need care.
- I am ready to deal with my illness.
- I get transportation to go to a doctor or clinic.

The table below displays the most frequent responses from all out of care respondents as well as the age 50+ out of care respondents.

Survey Question 28A. What would be some reasons you enter primary medical care? (check any or all that apply)						
Reasons	Respo	f Care ndents 155)		of Care ndents		
	number	percent	number	percent		
I get sick and know I need care.	120	77.4%	27	73.0%		
I am ready to deal with my illness.	67	43.2%	12	32.4%		
Someone else with HIV/AIDS reaches out to me.	44	28.4%	8	21.6%		
I get transportation to go to a doctor or clinic.	47	30.3%	11	29.7%		
Someone arranges to have my care paid for.	37	23.9%	5	13.5%		
Other (insurance)	13	8.4%	0	0.0%		

#### **Reasons to Enter Primary Medical Care**

# **Prioritization of Service Categories**

As summarized in the table to the right, the most highly prioritized services identified by Age 50+ respondents in care were similar to those identified by all respondents in care.

Survey Question 77A. Which five services do you think are most important for people with HIV/AIDS?						
Service Category	In C Respor (N=2	ndents	In Care Re	50+ spondents 90)		
	number	percent	number	percent		
Primary Medical Care	127	60.2%	63	70.0%		
Laboratory Diagnostic Testing	114	54.0%	59	65.6%		
Medications	112	53.1%	48	53.3%		
Case Management	100	47.4%	43	47.8%		
Food Bank or Food Vouchers	80	37.9%	39	43.3%		

#### Five Most Important Services

The table on the following page summarizes all responses to this survey question.

#### **Five Most Important Services**

Survey Question 36A. Which five services do you think are most important for people with HIV/AIDS? (please check 5 services)					
Service Category	Respo	Care ndents 211)	Age 50+ In Care Respondents (N=90)		
	number	percent	number	percent	
Primary Medical Care	127	60.2%	63	70.0%	
Laboratory Diagnostic Testing	114	54.0%	59	65.6%	
Medical Specialist	42	19.9%	24	26.7%	
Nurse Care Coordination	10	4.7%	6	6.7%	
Case Management	100	47.4%	48	53.3%	
Medications	112	53.1%	43	47.8%	
Dental /Oral Health	38	18.0%	14	15.6%	
Health Insurance	22	10.4%	4	4.4%	
Mental Health Services	27	12.8%	9	10.0%	
Substance Abuse Residential	4	1.9%	3	3.3%	
Substance Abuse Outpatient	3	1.4%	2	2.2%	
Nutrition Counseling	9	4.3%	4	4.4%	
Early Intervention Services	21	10.0%	6	6.7%	
Home Health Care	4	1.9%	0	0.0%	
Hospice Services	1	0.5%	0	0.0%	
Food Bank or Food Vouchers	80	37.9%	39	43.3%	
Transportation	41	19.4%	16	17.8%	
Outreach	19	9.0%	2	2.2%	
Health Education/Risk Reduction	7	3.3%	1	1.1%	
Treatment Adherence	18	8.5%	5	5.6%	
Legal Support	19	9.0%	9	10.0%	
Rehabilitation	2	0.9%	0	0.0%	
Emergency Financial Assistance	15	7.1%	8	8.9%	
Linguistics Services	2	0.9%	0	0.0%	
Peer Mentoring	12	5.7%	2	2.2%	
Housing	60	28.4%	27	30.0%	
Support groups	11	5.2%	4	4.4%	
Other (e.g. Hour, Service after hours)	2	0.9%	0	0.0%	
No response	3	1.4%	0	0.0%	
Total In Care Respondents	211	100%	90	100.0%	

# Service Needs and Utilization

Survey respondents in care were asked to describe their level of utilization of the twenty-seven service categories prioritized by the planning council. The respondents in care described their utilization of each survey categories as one of the following:

- "I received this service" if they utilize the service
- "I needed this service but was unable to get it" to show possible gaps in services
- "I needed this service but was unaware if it was offered or how to access" to show barriers to service utilization
- "I did not need this service" if they do not utilize the service

#### Utilization: "I received this service"

Among age 50+ respondents in care, the most frequently utilized services include laboratory diagnostic testing, medications, primary medical care, and case management. Age 50+ in care respondents reported utilization of nurse care coordination at a higher rate as all in care respondents (78.9% compared to 75.4%).

The table below highlights the most frequently utilized services by Age 50+ in care respondents and all in care respondents.

Utilized Service Categories	All In Care Respondents (N=211)			Age 50+ In care Respondents (N=90)		
	rank	number	percent	rank	number	percent
CORE SERVICES						
Medical Care						
Primary Medical Care	2	196	92.9%	2	85	94.4%
Laboratory Diagnostic Testing	1	202	95.7%	1	86	95.6%
Medical Specialist		159	75.4%	4	71	78.9%
Nurse Care Coordination		72	34.1%		33	36.7%
Case Management	4	172	81.5%	3	79	87.8%
Medications	3	190	90.0%	1	86	95.6%
Dental /Oral Health	5	160	75.8%	5	70	77.8%
Health Insurance		83	39.3%		45	50.0%
Mental Health Services		84	39.8%		39	43.3%
Substance Abuse Treatment						
Substance Abuse Residential		34	16.1%		13	14.4%
Substance Abuse Outpatient		23	10.9%		7	7.8%
Nutrition Counseling		112	53.1%		52	57.8%
Early Intervention Services		57	27.0%		27	30.0%
Home Health Care		15	7.1%		8	8.9%
Hospice		3	1.4%		2	2.2%
SUPPORT SERVICES						
Food Bank or Food Vouchers		113	53.6%		52	57.8%
Transportation		103	48.8%		48	53.3%
Outreach		32	15.2%		17	18.9%
Health Education/Risk Reduction		94	44.5%		44	48.9%
Treatment Adherence		98	46.4%		44	48.9%
Legal Support		69	32.7%		40	44.4%
Rehabilitation		22	10.4%		10	11.1%
Emergency Financial Assistance		61	28.9%		35	38.9%
Linguistics Services		19	9.0%		7	7.8%
Peer Mentoring		67	31.8%		34	37.8%
Housing		65	30.8%		35	38.9%
Support groups		79	37.4%		48	53.3%

Comparison of Service Utilization "I Received this Service "

Service Gaps: "I needed this service but was unable to get it"

As with all out of care respondents, age 50+ in care respondents reported service gaps in housing, food, and transportation. Unlike all in care respondents, age 50+ in care respondents also reported gaps in legal support and nurse care coordination.

The most frequently identified services are highlighted in the following table of all responses to this survey item.

Utilized Service Categories		All In Care Respondents (N=211)			unable to get it" Age 50+ In Care Respondents (N=90)		
		number	percent	rank	number	percent	
CORE SERVICES							
Medical Care		1					
Primary Medical Care		4	1.9%	5	2	2.2%	
Laboratory Diagnostic Testing		4	1.9%		1	1.1%	
Medical Specialist		5	2.4%	5	2	2.2%	
Nurse Care Coordination		8	3.8%	2	5	5.6%	
Case Management	5	15	7.1%	3	4	4.4%	
Medications		5	2.4%		1	1.1%	
Dental /Oral Health		12	5.7%	3	4	4.4%	
Health Insurance		9	4.3%	5	2	2.2%	
Mental Health Services		4	1.9%	5	2	2.2%	
Substance Abuse Treatment					· · · · ·		
Substance Abuse Residential		4	1.9%	4	3	3.3%	
Substance Abuse Outpatient		3	1.4%	5	2	2.2%	
Nutrition Counseling		7	3.3%		1	1.1%	
Early Intervention Services		5	2.4%	5	2	2.2%	
Home Health Care		3	1.4%	4	3	3.3%	
Hospice		0	0.0%		0	0.0%	
SUPPORT SERVICES		1		1	11		
Food Bank or Food Vouchers	2	21	10.0%	2	5	5.6%	
Transportation	3	20	9.5%	2	5	5.6%	
Outreach		3	1.4%		0	0.0%	
Health Education/Risk Reduction		4	1.9%		0	0.0%	
Treatment Adherence		4	1.9%	4	3	3.3%	
Legal Support		11	5.2%	2	5	5.6%	
Rehabilitation		3	1.4%	5	2	2.2%	
Emergency Financial Assistance	4	18	8.5%	2	5	5.6%	
Linguistics Services		4	1.9%	5	2	2.2%	
Peer Mentoring		7	3.3%		1	1.1%	
Housing	1	29	13.7%	1	11	12.2%	
Support Groups		5	2.4%		1	1.1%	
Other		1	0.5%		0	0.0%	

Comparison of Gaps "I needed this service but was unable to get it"

*Barriers to Services: "Needed This Service But Was Unaware If It Was Offered Or How To Access"* Like all in care respondents, Age 50+ respondents most frequently reported barriers regarding food and emergency financial assistance. The table below highlights the most frequent responses to this survey item.

Service Categories	All In Care Respondents (N=211)			In (	ndents	
	rank	Number	percent	rank	number	percent
CORE SERVICES						
Medical Care				-		
Primary Medical Care		1	0.5%		0	0.0%
Laboratory Diagnostic Testing		1	0.5%		1	1.1%
Medical Specialist		9	4.3%		3	3.3%
Nurse Care Coordination		10	4.7%		2	2.2%
Case Management		5	2.4%		0	0.0%
Medications		5	2.4%		0	0.0%
Dental /Oral Health		11	5.2%		3	3.3%
Health Insurance		12	5.7%		1	1.1%
Mental Health Services		11	5.2%	5	4	4.4%
Substance Abuse Treatment						
Substance Abuse Residential		7	3.3%		1	1.1%
Substance Abuse Outpatient		10	4.7%		3	3.3%
Nutrition Counseling		11	5.2%	5	4	4.4%
Early Intervention Services		10	4.7%	5	4	4.4%
Home Health Care		7	3.3%		1	1.1%
Hospice		1	0.5%		0	0.0%
SUPPORT SERVICES		1				
Food Bank/Home Delivered Meals	2	32	15.2%	1	14	15.6%
Transportation		18	8.5%	3	7	7.8%
Outreach		10	4.7%	5	4	4.4%
Health Education/Risk Reduction		13	6.2%	5	4	4.4%
Treatment Adherence		10	4.7%		1	1.1%
Legal Support	3	28	13.3%	4	6	6.7%
Rehabilitation Services		14	6.6%		0	0.0%
Emergency Financial Assistance	1	36	17.1%	2	12	13.3%
Linguistics Services		12	5.7%		3	3.3%
Peer Mentoring		18	8.5%	3	7	7.8%
Housing	4	21	10.0%	4	6	6.7%
Support Groups	5	20	9.5%	4	6	6.7%
Other		6	2.8%		1	1.1%

Comparison of Barriers "Needed This Service But Was Unaware If It Was Offered Or How To Acce
----------------------------------------------------------------------------------------------

# Focus Group Findings: Themes and Notable Quotes

# Reasons for not going to the doctor for HIV/AIDS medical care

• Shame

"They are ashamed that they might need someone that knows them and exposes themhappened to me, friend recognized me and told the whole world. Not fair. Feel insecure, feel ashamed. It's rough. That's the main reason. It's your personal problem, not the worlds.

• Lack of Privacy

"Some people talk about other people, they have the same thing, they don't look at themselves. Don't turn the mirror on the other person when the mirror turned on you too. Things can happen to anybody.

"Not really stop them, they would like to have the care, but, private, not exposed to a lot of people. I think that would never happen. Private appointment."

# *What will it take to persuade individuals to go back to the doctor for HIV/AIDS medical care?* Participants shared that knowledge about the disease and support from others can persuade individuals to go back to the doctor for HIV/AIDS medical care.

• Knowledge

"If they really knows the facts of what the virus carries, health issues it brings, they would go to the doctor if they want to live longer."

• Support

"Think positive, it could happen to anyone. The support of others would help, make you feel better."

# For in care participants, what has helped to get in care and stay in care?

Participants said that the want to live and helping others in the same situation is what has helped to get in care and stay in care.

• Desire to Live

"Want to live, get better, it could happen to anybody, take care of yourself, take meds, eat right, exercise.

• Helping Others "Just get up and focus on life. I still try to help others."

# In the past 3 years, have services improved, declined, or remain the same?

Overall participants shared that services have improved a little in the past 3 years.

• "To me, it improved a little bit."

• "A little not much, it's still hard to get what you need, it will never end-it's expensive."

# Quantity and Quality of Services

Participants expressed that services have been inadequate in quantity and quality of service.

- "If you don't know where the services at, you don't know."
- "Lack of knowing is very difficult."
- "A lot of times when you call, you're getting a machine, have to leave a message, wait for them to call you back."
- "No, it's not." (quality)
- "It's a process."

# Additional Comments

Participants reported that awareness, good support and confidentiality is needed in this area.

- "More awareness, get it out there."
- "Also, we need someone like yourself, that works with us, takes us through the steps, to help ourselves, disease itself will stress you out, your help is needed a lot."
- "When I found out and you came to me, you told me I give you my word, they need more people like you, no matter what time of the day, if I don't get you, you;; call me right back, I commend you."

Appendix A.

# SURVEY OF PEOPLE LIVING WITH HIV/AIDS PALM BEACH COUNTY 2013

Please mark the box beside the demographics that correspond to this survey. Date N=366 Variable Sample Size Time Out of Care In Care n=209 n=157 57% 43% Name of interviewer (please print clearly and sign This This name) Race/Ethnicity n n Survey Survey Black 132 99 White 50 38 Print Hispanic 20 27 157 Total 209 Signature This This Gender n n Survey Survey Venue (i.e. provider and/or location, such as Male 130 97 "respondents home") Female 79 60 Transgender --209 Total 157 Survey # This This Age n n Survey Survey 0-24 9 7 25-29 GIFT CARD #: \_\_\_\_\_ 9 6 30-39 35 27 40-44 29 22 45-49 29 38 50-59 58 44 60+ 31 22 Total 209 157 This This **Special Populations** n n Survey Survey MSM 102 77 **Ouestions? Contact Nadia Barreto-Najarro** IDU 15 11 Haitian 38 28 **Community Services Department** Mayan --810 Datura Street WCBA 38 28 West Palm Beach, FL 33401 Heterosexual 121 91 (561) 355-4785 Office Phone: Cell Phone: (561) 531-9671 This This **Geographic Location** n n Survey Survey Fax: (561) 355-3863

North East

South East

Central East

West

Total

12

60

106

31

209

9

45

79

24

157

# Introduction

- 1. The Palm Beach County HIV CARE Council is conducting a survey on the needs of PLWHA who reside in Palm Beach County. This survey is one of the tools being used to gather information. The survey will serve as the basis for planning to better accommodate Persons Living with HIV/AIDS in Palm Beach County.
- 2. This survey is strictly voluntary and anonymous. Please do not write your name anywhere on this survey.
- 3. Please complete only one survey.
- 4. It will take about 15-20 minutes to complete this survey.
- 5. As a token of our appreciation, the interviewer will give you a \$10.00 gift certificate after you complete the entire survey.

Thank you for taking the time to help us with this important project. Your answers will provide valuable information for the planning and delivery of vital services to our community.

# Notes to the Interviewer

There are a number of advantages in having a questionnaire administered by an interviewer rather than self-administered the respondent. Most importantly, interview surveys give higher response rates than mail or phone surveys. Second, respondents seem more reluctant to turn down interviewers. Third, interviewers can answer questions for respondents, probe for answers and clarify confusing matters, thereby obtaining relevant responses. Finally, interviewers can observe behavior and pace the questioning if the respondent becomes tired or upset.

# **General Guidelines for Interviewing:**

#### 1. Try to have fun.

Relax and enjoy yourself. This is an opportunity to forget about your worries for a while and concentrate on someone else. Take a couple of deep breaths and "meet the respondents where they are".

#### 2. Have a pleasant and appropriate appearance and demeanor.

Dress in a fashion similar to those you're interviewing. If unsure how you should dress, dress modestly. Your demeanor should be pleasant and communicate a genuine interest in getting to know the respondent. Relax and be friendly.

<u>3. Provide a private and confidential setting.</u> Try to do the interview in a private place where no one will overhear your discussion. If you must do the interview in a public setting, be sure no one is near enough to hear.

<u>4. Read the Introduction to the respondent</u> to emphasize that all survey material is strictly anonymous. No names will be used in gathering or reporting the information.

# 5. Become thoroughly familiar with the Survey

Study the survey carefully - maybe five or six times. Practice by reading aloud. The goal is to be able to read the survey without error and without stumbling over words. Think of yourself as an actor studying lines for a play. Also, be prepared to give guidance when a respondent doesn't understand a particular question.

#### 6. Read the wording of each question exactly

Be careful with your wording, even when clarifying questions or probing for answers so that your wording doesn't distort the answer. In other words, try not to "lead the witness".

# 7. Record each response exactly

Record answers. Include details for "other" responses as they are stated by the respondent. Please do not summarize, paraphrase or correct bad grammar.

#### 8. Probe for responses when necessary

Sometimes respondents will respond to a question with an obviously inappropriate answer. This might simply indicate they misunderstood the question. You may have to repeat the question or

rephrase the question and check to make sure the respondent understands. If a respondent answers "Other" to any question, please ask them to be specific.

9. Coordinate efforts to make sure the situation is well controlled.

Whenever more than one interviewer is involved in a survey (e.g. with the help of an interpreter), it is essential that efforts be carefully coordinated and controlled to ensure that everyone is working from the same page.

10. Before the respondent leaves, please validate each survey by reviewing the entire survey (including the cover page) for missing information, unanswered questions, or inappropriate responses. If you find any, re-ask the question or probe for clarification in order to complete that item.

11. Return surveys to Nadia Barreto-Najarro:810 Datura Street, West Palm Beach, FL 33401office phone:561-355-4785cell phone:561-531-9671fax:561-355-3863email:nbarreto@pbcgov.org

#### Palm Beach County EMA COMMUNITY NEEDS ASSESSMENT

#### Anonymous Persons Living with HIV/AIDS (PLWHA) Survey 2013

INTERVIEWER READ: "We are having PLWHA fill out this survey so that you are able to tell your local HIV/AIDS Planning Group what services <u>YOU</u> need. Your input will help the Planning Group make important decisions about how federal and other funds are used in Palm Beach County.

Some questions are personal; however, the information you provide helps us better determine how to make our services better. To ensure your privacy, we will combine all the information we receive so no one will be able to identify you as an individual.

Please tell your friends about this survey. We want to hear from as many people who are living with HIV/AIDS as possible.

If you have completed this survey within the past month, do not complete it again."

Please check the appropriate box like this 🗸	when answering multiple choice questions.
----------------------------------------------	-------------------------------------------

# SECTION A: DEMOGRAPHICS

INTERVIEWER SAY: "Let's begin by f you will never be identified as an individ survey." Read the following questions. Probe to c	ual but rather as par		
1A. Survey #			
2A. What is your Zip Code?			
<b>8B</b> . Where do you live? County:			
3A/1B. What is your gender? (check one	only)		
□ Male □ Female □ Trans	gender (Male to Fem	ale)	r (Female to Male)
4A/ <b>2B</b> . How do you identify yourself? ( <i>c</i>	heck one only)		
□ Straight □ Gay □ Lesbian	□ Bisexual	$\Box$ MSM (men who have s	sex with men)
5A/ <b>4B</b> . What is your race? ( <i>check one on</i> )	ly)		
□ White/Caucasian	$\Box$ Black or $A$	African American	
□ Asian	□ Native H	Iawaiian or Pacific Island	er
□ American Indian or Alaskan Native	□ Mixed/m	nore than one race	
6A/ <b>3B.</b> What is your ethnicity? ( <i>check on</i>	e only)		
□ Hispanic/Latina/o	□ Non-Hispanic/L	atina/o	□ Haitian
7A. If you answered "Hispanic or Latina/	o", what is your cour	ntry of origin? (check one o	only)
□ N/A I did not answer "Hispanic or Lat	ina/o"	□ Mexico	
Puerto Rico		□ Guatemala	
□ El Salvador		U.S.A	
Dominican Republic		□ Other (Specify:	)
8A. What is your primary language? (che	ck one only)		
	□ Spanish	□ Portuguese	
□ French	□ Creole	□ Central American	Dialect
Other (Specify:	)		

9A/5B. What year were you born'	?			
10A. What is the highest level of	education that you have comple	eted? (check one only	)	
$\Box$ No formal schooling	$\Box$ Eighth grade or less	$\Box$ Less than high sc	hool graduation	
□ High school graduation	□ Technical/trade school	□ GED (high schoo	l equivalency)	
□ Some college	□ College graduate			
11A. Are you a migrant or season	al worker?			
□ Yes	□ No			
12A/ <b>6B.</b> What best describes your	r work situation in the <b>past 12</b>	months? (check one o	only)	
□ Working full-time job	$\Box$ Working pa	art-time job	$\Box$ Self employed	
$\Box$ Working off and on	□ Not workin	ıg		
13A/ <b>7B.</b> Why were you unable to	work during the past 12 month	ns? (check one only)		
$\Box$ This does not apply to me. I	worked during the past 12 i	months.		
□ Student	$\Box$ Looking for a job/un	able to find employ	ment	
□ Attending job training	$\Box$ For health reasons, or	n disability		
$\Box$ Retired $\Box$ For health reasons, NOT on disability				
□ Other:				
14A. In 2012, how many family	members (including yourself) l	ived in your househol	d?	
15A. In 2012, what was the total a	annual family household incom	he before taxes? \$		
16A. (Leave blank, for data entry	use only.)	(FPL from 20	12) DO NOT READ	

#### SECTION B: HIV/AIDS STATUS AND CARE

#### INTERVIEWER SAY, "Now, let's talk about the first time you learned you were HIV positive." Read:

17A/ <b>9B</b> . How old	d were you when you first teste	ed positive for HIV?	years of age
18A/10B. Where	were you living when you first	st tested positive for HIV	? (check one only)
$\Box$ In the same co	ounty I live in now		
$\Box$ In another cou	inty in Florida		
$\Box$ In another stat	te		
$\Box$ Outside of the	United States		
19A. Has a docto (Check any or all	or told you in the past 12 month <i>that apply.</i> )	ns that you had any of the	e following?
$\Box$ AIDS	□ Hepatitis A	□ Hepatitis B	□ Hepatitis C
□ Tuberculosis	□ Syphilis	□ Gonorrhea	□ Chlamydia
□ Other STD	□ High Cholesterol	□ Cancer	□ Liver Disease
□ Diabetes	Coronary Heart Disease	$\Box$ Other condition (Sp	ecify:)
<b>11B.</b> Did you get <b>12 months</b> ?	HIV/AIDS medical care OR a	a CD-4 T-cell count OR a	a viral load lab test during the <b>past</b>
□ Yes		□ No	
20A. Have you re	eceived a prescription for Anti	-Retroviral Therapy (AR	T) within the <b>past 12 months</b> ?
$\Box$ Yes			
$\Box$ No			

# **INTERVIEWER NOTE:** If the respondent answered YES to at least one of the last two questions please skip to Question 26A. **INTERVIEWER NOTE:** If participant answered NO to all of the last two questions, please answer questions 21A-25A.

# **SECTION C: OUT OF CARE**

21A. What best describes your situation? (check one only	v)					
$\Box$ I have recently been diagnosed with HIV, and have not entered medical care.						
$\Box$ I have <u>not</u> been recently diagnosed but have neve	er been in medical care.					
$\Box$ I had been receiving medical care for HIV, but I stopped more than 12 months ago.						
Other (Specify:	)					
22A/ <b>15B</b> . If you did not get HIV/AIDS medical care during reason/s why? (check any or all that apply)						
□ This does not apply to me. I got HIV/AIDS relate	ed medical care in the past 12 months.					
$\Box$ I did not know where to go.	$\Box$ I did not feel sick.					
$\Box$ I could not get an appointment.	$\Box$ I could not get time off work.					
$\Box$ I could not get transportation.	□ I was depressed.					
$\Box$ I could not get childcare.	$\Box$ I had a bad experience with the medical					
$\Box$ I could not pay for services.	staff.					
$\Box$ I did not want people to know that I have HIV.	□ Other:					
$\Box$ I was not ready to deal with having HIV.						
23A. When was the last time you saw the doctor for HIV	/AIDS medical care? (check one only)					
$\Box$ Less than one month	$\Box$ 1-5 months					
$\Box$ 6 months to 1 year	$\Box$ 2-5 years					
$\Box$ I have not seen the doctor						
24A. What services would help you to get HIV/AIDS me	edical care? (check any or all that apply)					
□ Substance abuse treatment	□ Transportation					
□ Mental health services	□ Housing					
□ Food	□ Treatment adherence					
□ Case management	□ Financial assistance					
□ Other (specify)						

25A. What would be some of the reasons ( <i>check any or all that apply</i> )	why you would go to the doctor for HIV/AIDS m	edical care?
$\Box$ I get sick and know I need care.	$\Box$ I get transportation to go to a	doctor or clinic.
$\Box$ I am ready to deal with my illness.	□ Someone arranges to have my	v care paid for.
□ Someone else with HIV/AIDS reaches me.	out to	
SECTION D: ACCESS AND AVAILA	BILITY ACCORDING TO NEEDS	
26A. During the past five years has there	een a period of at least 12 months when you did	<i>not</i> go to the
doctor for HIV/AIDS medical care?	$\Box$ Yes $\Box$ No	
If you answered NO to the last question	skip to Question 32A.	
27A. If yes, for approximately how long c	id you not go to the doctor for HIV/AIDS medica	al care?
□ Less than one month	$\Box$ 6 months to 1 year	
$\Box$ 1-5 months	$\Box$ 2-5 years	
28A. What zip code did you live in during medical care?	the period you were not going to the doctor for H	HIV/AIDS
29A. What prevented you from getting HI	V/AIDS medical care during this time? (Check a	ny or all that apply
$\Box$ I did not have medical insurance.		
$\Box$ I could not afford care.		
$\Box$ I had heard bad things about the medic	ations and their side effects.	
$\Box$ I knew where to go but I did not want	b go there.	
$\Box$ I was afraid of being identified as HIV	positive.	
$\Box$ I was using drugs or alcohol.		
$\Box$ I found it difficult to apply for insur	ance.	
□ Other (Specify:	)	
30A. While you were out of HIV/AIDS mail that apply)	edical care, what services did you need and not g	et? (check any or
□ Substance abuse treatment	□ Mental health services	
□ Food	□ Case management	
□ Transportation	□ Housing	
□ Treatment Adherence	□ Financial assistance	
□ Other (specify)	_	

31A. What are the reasons that you would go back to HIV/AIDS medical care? (check any or all that apply)

 $\Box$  I got sick and knew I needed care.

 $\Box$  I was ready to deal with my illness.

- $\Box$  I got a referral to get into care.
- □ Other (explain)\_\_\_\_\_

# → GO HERE for IN-CARE

32A/12B. Where did you regularly receive your HIV/AIDS medical care during the **past 12 months**? (*check one only*)

□ This does not apply to me. I did not receive HIV/AIDS-related medical care in the past 12 months?

□ Walk-In/Emergency Clinic

- $\Box$  Doctor's Office
- □ Hospital Emergency Room
- □ Veteran's Administration
- □ Public Clinic/Health Department
- □ HIV Specialty Clinic
- □ Other: \_\_\_\_\_

33A/**13B**. In which county did you get your HIV related medical care in the **past 12 months**? County: \_\_\_\_\_

34A/**14B**. If you get your HIV/AIDS medical care in a different county than you live, please indicate why. (*check one only*)

 $\Box$  This does not apply to me. I got medical care in the same county I live.

 $\Box$  Services were not available in my county.

- $\Box$  I did not want people to know that I have HIV
- $\Box$  I got care at a clinic that is located closer to where I live or work
- □ Other: \_\_\_\_\_

35A/16B. Have you been hospitalized for an HIV/AIDS related condition during the past 12 months?

 $\Box$  Yes

🗆 No

- $\Box$  An outreach worker found me and helped me get into care.
- $\Box$  I was able to deal with other problems in my life that kept me out of care.

36A. **PRIORITIES:** Which five (5) services do you think are most important for people with HIV/AIDS? Place a  $\checkmark$  by the most important services to you. 37A-64A/**17B-37B. NEED:** The services below MAY or MAY NOT be available. Please place a  $\checkmark$  in the box that tells how respondent feels about his/her personal level of need for each one. Please note any comments on the last page.

36A (check 5 services)	#A	#B	Service Category	I received this service	I needed this service but was unable to get it	I needed this service but was unaware if it was offered or how to access	I did not need this service
	CORE SERVICES						
		17	Outpatient Medical Care: Regular doctor visits to doctor's office or clinic for HIV medical care				
	37		Primary Medical: Regular doctor visits for HIV medical care				
	38		Laboratory Diagnostic Testing				
	39		Medical Specialist: Eye doctor, woman's doctor (GYN), Dermatology, etc.				
	40		Nurse Care Coordination: RN acts as clients' main link to medical services				
	41	18	Case Management: Case managers help clients receive services and then follow-up on their care	ase Management: Case managers help clients receive services and then follow-up on their care			
	42	19	Medications: Pills for HIV and related issues				
	43	20	Dental/Oral Health: General teeth and mouth care, dentures, oral surgery, etc.				
	44	21	Health Insurance: Helps pay insurance costs or co-pays if client has private insurance				
	45	22	Mental Health Services: Professional counseling, therapy, or support groups				
		23	Substance Abuse Treatment: Professional counseling for drug or alcohol addiction				
	46		Residential:				
	47		Outpatient:				
	48	24	Nutritional Counseling: Professional counseling for healthy eating habits				
	49	25	Early Intervention Services: Assistance getting a doctor appointment, HIV counseling and testing, linkage and referral to medical care				
	50	26	Home Health Care: Professional healthcare services in client's home by a licensed/certified home- health agency				
	51	27	Hospice Services: Nursing and counseling services for the terminally ill and their family				
			SUPPORT SERVICES				
	52	28	Food Bank or Food Vouchers: Food bags, grocery certificates, home-delivered meals, and nutritional supplements				
	53	29	Fransportation: Help getting to the doctor's office and other HIV related appointments				
	54	30	<b>Outreach:</b> Someone who finds people with HIV not in care and helps them to visit their doctor and get services they may need				
	55	31	<b>Health Education/Risk Reduction:</b> Someone who tells clients about HIV, how it's spread, current medications, and how to live with HIV				
	56	32	Treatment Adherence: Instructions on how to take HIV medications properly				
	57	33	Legal Support: Help clients with HIV related legal issues, SSI SSDI hearings (will, living will, etc.)				
	58	34	Rehabilitation: Physical therapy, speech therapy, low vision training, etc.				
	59		Emergency Financial Assistance: Help paying for utilities, appliances, etc.				
	60		Linguistics Services: Interpretation & translation services				
	61		Peer Mentoring:         Support and counseling from community members         163				
	62	36	Housing: Help finding and/or maintaining a place to live				
	63		Support groups				
	64	37	Other: A service that is not listed above				

65A/**38B.** What were some barriers to you getting the services you needed during the **past 12 months**? (*check all that apply*)

$\Box$ This does not apply to me. I did get the services I needed	a during the past 12 mor	iths.
-------------------------------------------------------------------	--------------------------	-------

$\Box$ I did not know where to get services		$\Box$ I could not get time off work		
$\Box$ I could not get an appointment		$\Box$ I was depressed		
		•		
$\Box$ I could not get transportation		$\Box$ I had a bad experience with the staff		
$\Box$ I could not get childcare		$\Box$ Services were not in my language		
$\Box$ I could not pay for services		□ I did not qualify for services		
☐ I did not want people to know that I have HIV				
□ Other:				
66A. Have you had any of the following problems while ( <i>check any or all that apply</i> )	trying to get	needed services?		
$\Box$ Didn't know <u>how</u> to apply	🗆 Tu	rned down/not eligible because:		
□ Didn't know <u>where</u> to apply				
□ Transportation problems	Did not have any problems trying to get needed services			
□ On wait list	□ Eligibility process to difficult			
		Giomey process to announ		
Other (Specify:				
<ul> <li>Other (Specify:</li></ul>		)		
<b>39B</b> . Which five services do you think are the most impo		)		
<ul> <li><b>39B</b>. Which five services do you think are the most imposite access throughout the state? (select ONLY 5)</li> <li>□ Outpatient medical care (doctor's office visits)</li> <li>□ Assistance receiving and accessing services</li> </ul>	ortant for peop	) ple living with HIV/AIDS to be able to Bank/Food Voucher □ Transportation to/from HIV-related		
<ul> <li><b>39B</b>. Which five services do you think are the most importances throughout the state? (select ONLY 5)</li> <li>□ Outpatient medical care (doctor's office visits)</li> </ul>	ortant for peop	ple living with HIV/AIDS to be able to Bank/Food Voucher □ Transportation to/from HIV-related care services		
<ul> <li><b>39B</b>. Which five services do you think are the most imposite access throughout the state? (select ONLY 5)</li> <li>□ Outpatient medical care (doctor's office visits)</li> <li>□ Assistance receiving and accessing services</li> </ul>	ortant for peop	<ul> <li>)</li> <li>ple living with HIV/AIDS to be able to</li> <li>Bank/Food Voucher</li> <li>□ Transportation to/from HIV-related care services</li> <li>□ Outreach to HIV patients who have</li> </ul>		
<ul> <li><b>39B</b>. Which five services do you think are the most importances throughout the state? (select ONLY 5)</li> <li>Outpatient medical care (doctor's office visits)</li> <li>Assistance receiving and accessing services</li> <li>Payment for medications</li> </ul>	ortant for peop	ple living with HIV/AIDS to be able to Bank/Food Voucher □ Transportation to/from HIV-related care services		
<ul> <li><b>39B</b>. Which five services do you think are the most importances throughout the state? (select ONLY 5)</li> <li>Outpatient medical care (doctor's office visits)</li> <li>Assistance receiving and accessing services</li> <li>Payment for medications</li> <li>Dental/Oral health services</li> </ul>	ortant for peop	<ul> <li>ple living with HIV/AIDS to be able to</li> <li>Bank/Food Voucher</li> <li>Transportation to/from HIV-related care services</li> <li>Outreach to HIV patients who have fallen out of care to get them back into</li> </ul>		
<ul> <li><b>39B.</b> Which five services do you think are the most importances throughout the state? (select ONLY 5)</li> <li>Outpatient medical care (doctor's office visits)</li> <li>Assistance receiving and accessing services</li> <li>Payment for medications</li> <li>Dental/Oral health services</li> <li>Private health insurance co-payment or premium</li> </ul>	ortant for peop	<ul> <li>ple living with HIV/AIDS to be able to</li> <li>Bank/Food Voucher</li> <li>Transportation to/from HIV-related care services</li> <li>Outreach to HIV patients who have fallen out of care to get them back into care</li> </ul>		
<ul> <li><b>39B.</b> Which five services do you think are the most importances throughout the state? (select ONLY 5)</li> <li>Outpatient medical care (doctor's office visits)</li> <li>Assistance receiving and accessing services</li> <li>Payment for medications</li> <li>Dental/Oral health services</li> <li>Private health insurance co-payment or premium assistance</li> </ul>	ortant for peop	<ul> <li>)</li> <li>ple living with HIV/AIDS to be able to</li> <li>Bank/Food Voucher</li> <li>□ Transportation to/from HIV-related care services</li> <li>□ Outreach to HIV patients who have fallen out of care to get them back into care</li> <li>□ Health education about risk reduction</li> </ul>		
<ul> <li><b>39B.</b> Which five services do you think are the most importances throughout the state? (select ONLY 5)</li> <li>Outpatient medical care (doctor's office visits)</li> <li>Assistance receiving and accessing services</li> <li>Payment for medications</li> <li>Dental/Oral health services</li> <li>Private health insurance co-payment or premium assistance</li> <li>Mental Health services</li> </ul>	ortant for peop	<ul> <li>)</li> <li>ple living with HIV/AIDS to be able to</li> <li>Bank/Food Voucher</li> <li>□ Transportation to/from HIV-related care services</li> <li>□ Outreach to HIV patients who have fallen out of care to get them back into care</li> <li>□ Health education about risk reduction</li> <li>□ Treatment adherence counseling</li> </ul>		
<ul> <li><b>39B.</b> Which five services do you think are the most importances throughout the state? (select ONLY 5)</li> <li>Outpatient medical care (doctor's office visits)</li> <li>Assistance receiving and accessing services</li> <li>Payment for medications</li> <li>Dental/Oral health services</li> <li>Private health insurance co-payment or premium assistance</li> <li>Mental Health services</li> <li>Substance abuse treatment</li> </ul>	ortant for peop	<ul> <li>ple living with HIV/AIDS to be able to</li> <li>Bank/Food Voucher</li> <li>Transportation to/from HIV-related care services</li> <li>Outreach to HIV patients who have fallen out of care to get them back into care</li> <li>Health education about risk reduction</li> <li>Treatment adherence counseling</li> <li>Legal services</li> </ul>		

 $\Box$  Hospice services

67A/41B. Were you in jail and/or prison during the past 12 months?

 $\Box$  Yes, I was in jail

 $\Box$  Yes, I was in prison

 $\Box$  Yes, I was in jail and prison

 $\Box$  No

(If you answered No, you can skip to Question 72A)

#### ONLY answer the next four questions if you answered yes to the question above.

68A/**42B.** Did the jail/prison medical staff know you had HIV?  $\Box$  Yes  $\Box$  No

69A/43B. Did you receive HIV/AIDS-related medical care while in jail/prison?

 $\Box$  Yes

 $\Box$  No

70A/**44B**. When you were released from jail/prison, which of the following did you receive? (*check all that apply*)

- $\hfill\square$  Information about finding housing
- $\Box$  Referral to medical care
- □ Referral to case management
- $\Box$  A supply of HIV medication to take with you
- □ Other: \_\_\_\_\_

71A/**45B**. What prevented you from getting the HIV/AIDS services you needed after you were released? (*check all that apply*)

- $\hfill\square$  This does not apply to me. I was able to get HIV services after my release.
- $\Box$  No insurance financial reasons
- $\Box$  I did not know where to go
- □ I did not want anyone to know I have HIV
- $\Box$  I could not get away from drugs
- $\hfill\square$  I was having trouble finding friends I could trust
- $\hfill\square$  I did not want to take off from work
- $\Box$  I did not have transportation to get services
- □ I did not have ID or documentation to qualify
- □ Other: \_\_\_\_\_

72A. Do you lack permanent housing?

 $\Box$  Yes

 $\Box$  No

**Homeless:** Per Section 330(h)(5)(A), the term "homeless individual" means "an individual who lacks housing (without regard to whether the individual is a member of a family), including an individual whose primary residence during the night is a supervised public or private facility that provides temporary living accommodations and an individual who is a resident in transitional housing."

73A. What problems have you had getting housing? (check all that apply)

- $\Box$  This does not apply to me. I did not have any problems getting housing.
- $\Box$  I did not have enough money for the deposit
- $\Box$  I had no transportation to search for housing
- $\hfill\square$  I had bad credit
- $\Box$  I had a criminal record
- □ I had a mental/physical disability
- $\Box$  I had substance use issues
- $\Box$  I was put on a waiting list
- $\Box$  I did not qualify for housing assistance
- $\Box$  I could not find affordable housing
- □ I feel I was discriminated against
- □ Other: \_\_\_\_\_

74A/40B. Is there anything else you would like to tell us that was not covered in this survey?

"THANK YOU for taking the time to provide this information. Your responses will affect how *your* local HIV/AIDS funding is spent." Present participant with a gift card.

#### Appendix B.

#### Comprehensive Needs Assessment 2013-2016 Focus Group Script

#### **Introduction:**

Facilitator: "Welcome to the 2013-2016 Comprehensive Needs Assessment Focus Group. My name is \_\_\_\_\_\_, and I will be facilitating this group. This is \_\_\_\_\_\_; he/she will be assisting with this session. Over the next hour we will be talking about HIV/AIDS care in Palm Beach County. At the end, each of you will receive a \$25.00 gift card to Wal-Mart for your participation."

#### Overview of the comprehensive needs assessment purpose and process:

Facilitator: "Every three years a large county-wide needs assessment is conducted in Palm Beach County. This needs assessment is required for all areas that receive Ryan White CARE Act funding. The information that you provide will help the CARE Council plan to meet the needs of People Living with HIV/AIDS in our county by prioritizing and allocating funding to service categories. Your input will help to identify service gaps, and help to assess the overall function of the HIV/AIDS system of care. Data in the needs assessment process is obtained through 5 focus groups; this is one of them, as well as 366 surveys."

#### Statement of confidentiality:

Facilitator: This focus group session will be recorded by \_\_\_\_\_\_ for accurate transcription of what is being said. Before I begin can everyone here agree that whatever is said during this focus group will be strictly confidential? PAUSE "Can we all agree to that?"

#### **Focus Group Guidelines and Definitions:**

Facilitator: "I would like to hear from all of you. In order to allow that to happen let's speak one at a time.

We will be talking about People Living with HIV/AIDS that are in and out of care in Palm Beach County. The federal government has adopted a definition for what is considered to be in primary medical care. This definition is written on your handout. People Living with HIV/AIDS are considered to be in primary medical care if they have had at least one of the following in the past 12 months 1.) a viral load test (blood test to see how much virus is in the system), 2). a CD4 test (blood test to see how strong the immune is) 3.) received anti-retroviral therapy."

# **Unmet Need:**

Facilitator:

- 1. "Do you know of any People Living with HIV/AIDS in Palm Beach County who know they are positive but are not in HIV/AIDS medical care?" *Allow participants to discuss.*
- "Why do you think they have not gone to the doctor for HIV/AIDS medical care?" Allow participants to discuss.
- "What do you think it would take to persuade them to go back to the doctor for HIV/AIDS medical care?" *Allow participants to discuss.*
- 4. "Now we are going to discuss your personal pattern of care. Since you were diagnosed with HIV/AIDS, have you been continuously going to the doctor for HIV/AIDS medical care?" *Allow participants to discuss.*
- "For those of you who have always been in care, what helped you to get in care and stay in care?" *Allow participants to discuss.*
- 6. "For those of you, who were out of care for sometime or are currently out of care, please tell us about your situation.

Out of care for sometime:

- $\Box$  If you have been in care at one point, how long were you in care?
- $\Box$  How long have you been out of care?
- □ What prevented you from receiving care?
- $\Box$  Are you still out of care?
- $\Box$  If yes, what would help you get back into care?
- $\Box$  If no, what helped you get you back into care?

Allow participants to discuss.

Currently out of care:

- $\Box$  How long have you been out of care?
- $\Box$  What prevents you from receiving care?
- Allow participants to discuss.
- 7. Do you have any additional comments about the difficulties and challenges to getting and staying in care and/or what would help people to get and stay in care?"

Allow participants to discuss.

# **HIV/AIDS Services**

Facilitator: "For those of you who have ever received HIV/AIDS services I would like to talk to you about your service needs and the quality of those services. On your handout there is a list of services. Let's focus on your own experiences as well as what you may have heard from friends.

- 8. "For the services that you ARE using:
  - $\Box$  Where are you currently getting these services?
  - $\Box$  Are these services meeting your needs?
  - $\Box$  How could these services be improved?
  - □ Are these services easy to access and easy to use?"

Allow participants to discuss.

- 9. "For the services you are NOT using:
  - □ Are they services that you want but are unable to get, unaware they are offered, or have difficulty signing up for?

□ What are the specific barriers you face in accessing these services?" *Allow participants to discuss.* 

10. "In the past 3 years do you think the services in general have improved, declined or remained the same?"

Allow participants to discuss.

"Has there been a sufficient amount of the services available (quantity)?" *Allow participants to discuss.* 

"Has the quality of the services been adequate?" *Allow participants to discuss.* 

"Have you been able to access the services that you need?" *Allow participants to discuss.* 

11. "Do you have any final thoughts or comments on HIV/AIDS services in Palm Beach County?" *Allow participants to discuss.* 

#### 1. Closure:

Facilitator: "I would like to thank each of you for attending this focus group. Your input is very valuable. Your responses will help the CARE Council plan for a system of care that works for all PLWHA in Palm Beach County.

# **Focus Group Handout**

#### **Definition for In Care**

The federal government has adopted a definition for what is considered to be in primary medical care. PLWHA are considered to be in primary medical care if they have had at least one of the following in the past 12 months 1.) a viral load test, 2). a CD4 test 3.) received anti-retro viral therapy.

# Service Category:

Service Category			
CORE SERVICES			
Outpatient Medical Care: Regular doctor visits to doctor's office or clinic for HIV medical care			
Primary Medical: Regular doctor visits for HIV medical care			
Laboratory Diagnostic Testing			
Medical Specialist: Eye doctor, woman's doctor (GYN), Dermatology, etc.			
Nurse Care Coordination: RN acts as clients' main link to medical services			
Case Management: Case managers help clients receive services and then follow-up on their care			
Medications: Pills for HIV and related issues			
Dental/Oral Health: General teeth and mouth care, dentures, oral surgery, etc.			
Health Insurance: Helps pay insurance costs or co-pays if client has private insurance			
Mental Health Services: Professional counseling, therapy, or support groups			
Substance Abuse Treatment: Professional counseling for drug or alcohol addiction			
Residential:			
Outpatient:			
Nutritional Counseling: Professional counseling for healthy eating habits			
Early Intervention Services: Assistance getting a doctor appointment, HIV counseling and			
testing, linkage and referral to medical care			
Home Health Care: Professional healthcare services in client's home by a licensed/certified home- health agency			
Hospice Services: Nursing and counseling services for the terminally ill and their family			
SUPPORT SERVICES			
Food Bank or Food Vouchers: Food bags, grocery certificates, home-delivered meals, and nutritional supplements			
Transportation: Help getting to the doctor's office and other HIV related appointments			
<b>Outreach:</b> Someone who finds people with HIV not in care and helps them to visit their doctor and get services they may need			
Health Education/Risk Reduction: Someone who tells clients about HIV, how it's spread, current medications, and how to live with HIV			
Treatment Adherence: Instructions on how to take HIV medications properly			
Legal Support: Help clients with HIV related legal issues, SSI SSDI hearings (will, living will, etc.)			
Rehabilitation: Physical therapy, speech therapy, low vision training, etc.			
Emergency Financial Assistance: Help paying for utilities, appliances, etc.			
Linguistics Services: Interpretation & translation services			
Peer Mentoring: Support and counseling from community members			
Housing: Help finding and/or maintaining a place to live			
Support groups			
Other: A service that is not listed above			

Appendix C.

# Needs Assessment 2013-2016 Provider Survey

The *Palm Beach County HIV CARE Council ('CARE Council')* is conducting a survey to identify service needs of persons living with HIV/AIDS in Palm Beach County. The information collected is vital to the needs assessment process. The questions in this survey are designed to identify the geographic location, types, and coordination of HIV-related services offered in Palm Beach County. The survey will help the *CARE Council* make decisions about the services needed in Palm Beach County, and to better understand met and unmet needs for HIV-related services.

#### Please complete this survey by June 5, 2013.

Thank you for taking the time to assist us with this project. If you have any further questions, please do not hesitate to contact Nadia Barreto-Najarro (telephone 561-355-4785, nbarreto@pbcgov.org).

Name of agency:			
Address:			
Zip code:			
Telephone:	Fax:	Email:	
Contact person and title:			

- 1. Which area in Palm Beach County does your agency provide HIV/AIDS care-related services? (circle all that apply)
  - a. North East
  - b. East Central
  - c. South Central
  - d. Western
- 2. Which of these best describes your agency? (*Circle one response only.*)
  - a. AIDS service organization
  - b. Health clinic
  - c. Community-based organization (not AIDS-specific)
  - d. Hospital
  - e. Multi-service agency that includes HIV/AIDS services
  - f. Substance abuse treatment facility
  - g. Public Health Department
  - h. Other (specify)\_\_\_\_
- 3. For how many years has your agency provided HIV/AIDS care-related services? (*Circle one response only.*)
  - a. Less than 1 year
  - b. 1 to 4 years
  - c. 5 to 9 years
  - d. 10 years or more

4. Do you target a particular population: (*Circle all that apply*)

- Race/ethnicity? (Specify:\_\_\_\_\_ a.
- Gender? (Specify:\_\_\_\_\_ b.
- Age group? (Specify:\_\_\_\_\_ c.
- Special needs or status (*e.g.*, injection drug users, homeless individuals)? d. (Specify:\_\_\_\_\_ )
- For the last fiscal year, please estimate the total number of patients/clients infected with 5. HIV/AIDS that you served:

i.

j.

k.

6. Which of the following does your agency most often provide?

- Primary medical care a.
- Medications/Pharmacy b.
- Mental health services c.
- Substance abuse treatment d.
- Dental/Oral health e.
- f. Case management
- Access services (e.g., transportation) g. h.
  - Benefits/Financial assistance
  - Housing
  - Family support services (e.g., legal assistance)
  - Other (specify)\_\_\_\_\_

# **Service Delivery**

7. How is your organization working to address racial, gender, and geographic disparities health outcomes for people living with HIV/AIDS?

- 8. What is the single most important change you would suggest to improve services for individuals or families infected with HIV?
- 9. List three barriers that your organization has faced when providing care to people living with HIV/AIDS.
  - a.
  - b.
  - c.

- 10. Which of the following services would help you to better serve your clients/patients living with HIV? (*Circle all that apply*)
  - a. Training in working with people from other cultures
  - b. Training to learn other languages
  - c. Opportunities for networking among providers to share information and HIV/AIDS care and available resources
  - d. Training to gain additional experience/knowledge about providing HIV care, such as antiretroviral treatments, dealing with opportunistic infections, and monitoring and explaining a patient's health status
  - e. Providing services in a more convenient manner (such as better office hours, quicker appointments, less waiting, in a location that is easier to get to)
  - f. Training on how to better advocate for clients/patients
  - g. Other (specify)\_\_\_\_\_
- 11. Which services do your clients need that are not available?

# **Coordination, Collaboration, and Planning**

12. What could the CARE Council do to help your agency better coordinate services with other providers in the area?

13. Is your agency planning to provide additional services and/or expanding capacity to provide current services for more clients living with HIV/AIDS? If so please describe below.

- 14. What are the most common reasons that people living with HIV/AIDS are not in primary medical care (not getting ART, CD4 and/or viral load lab work within the past 12 months)? (*check any or all that apply*)
  - $\Box$  Do not know where to go to get care.
  - $\Box$  Do not feel sick.
  - □ Can not get an appointment.
  - $\Box$  Have to work and can not ask for time off.
  - □ Do not have transportation.
  - □ Have feelings of depression.
  - □ Have to care for their children.
  - $\square$  Bad experience with medical staff.
  - $\Box$  Can not pay for services.
  - $\Box$  Do not want people to know they have HIV.
  - $\Box$  Not ready to deal with having HIV.
  - □ Other (Specify: \_\_\_\_\_)
- 15. What services, other than medical care and medication, do people living with HIV/AIDS need to get into primary medical care? (*check any or all that apply*)
  - $\Box$  Substance abuse treatment
  - $\square$  Food
  - □ Case management □ Transportation
  - □ Transportation
  - $\sqcap$  Financial assistance

- $\Box$  Mental health services □ Treatment adherence  $\Box$  Housing
- □ Other (specify) \_\_\_\_\_
- 16. What would be some reasons people living with HIV/AIDS would enter primary medical care? (*check any or all that apply*)
  - $\Box$  Get sick and know they need care.
  - □ Ready to deal with their illness.
  - □ Someone else with HIV/AIDS reaches out to them.
  - □ Get transportation to go to a doctor or clinic.
  - □ Someone else arranges to have their care paid for.
  - Other (explain)

17. If we have limited funding, what are the five (5) most important services? Place the number 1,2,3,4, or 5 next to the most important services. Please number them in order from 1 (most important) to 5 (least important).

number in order from 1 (most important) to 5 (least important)	Service Category
	CORE SERVICES
	Outpatient Medical Care: Regular doctor visits to doctor's office or clinic for HIV medical care
	Primary Medical: Regular doctor visits for HIV medical care
	Laboratory Diagnostic Testing
	Medical Specialist: Eye doctor, woman's doctor (GYN), Dermatology, etc.
	Nurse Care Coordination: RN acts as clients' main link to medical services
	Case Management: Case managers help clients receive services and then follow-up on their care
	Medications: Pills for HIV and related issues
	Dental/Oral Health: General teeth and mouth care, dentures, oral surgery, etc.
	Health Insurance: Helps pay insurance costs or co-pays if client has private insurance
	Mental Health Services: Professional counseling, therapy, or support groups
	Substance Abuse Treatment: Professional counseling for drug or alcohol addiction
	Residential:
	Outpatient:
	Nutritional Counseling: Professional counseling for healthy eating habits
	<b>Early Intervention Services:</b> Assistance getting a doctor appointment, HIV counseling and testing, linkage and referral to medical care
	Home Health Care: Professional healthcare services in client's home by a licensed/certified home- health agency
	Hospice Services: Nursing and counseling services for the terminally ill and their family
	SUPPORT SERVICES
	<b>Food Bank or Food Vouchers:</b> Food bags, grocery certificates, home-delivered meals, and nutritional supplements
	Transportation: Help getting to the doctor's office and other HIV related appointments
	<b>Outreach:</b> Someone who finds people with HIV not in care and helps them to visit their doctor and get services they may need
	<b>Health Education/Risk Reduction:</b> Someone who tells clients about HIV, how it's spread, current medications, and how to live with HIV
	Treatment Adherence: Instructions on how to take HIV medications properly
	Legal Support: Help clients with HIV related legal issues, SSI SSDI hearings (will, living will, etc.)
	Rehabilitation: Physical therapy, speech therapy, low vision training, etc.
	Emergency Financial Assistance: Help paying for utilities, appliances, etc.
	Linguistics Services: Interpretation & translation services
	Peer Mentoring: Support and counseling from community members
	Housing: Help finding and/or maintaining a place to live
	Support groups
	Other: A service that is not listed above

22. Is there anything else you would like to add?

THANK YOU FOR YOUR TIME!

# PALM BEACH COUNTY HIV CARE COUNCIL PART A - RYAN WHITE CARE ACT GRANT MARCH 1, 2012- FEBRUARY 28, 2013

#### SERVICE CATEGORY DEFINITIONS

#### CORE MEDICAL SERVICES

#### 1. Medical Care

#### a Outpatient/Ambulatory Medical Care

Provision of professional diagnostic and therapeutic services rendered by a physician, physician's assistant, registered nurse, or nurse practitioner in an outpatient setting. Settings include clinics, medical offices, and mobile vans where clients generally do not stay overnight. Emergency room services are not outpatient settings. Services includes diagnostic testing, early intervention and risk assessment, preventive care and screening, practitioner examination, medical history taking, diagnosis and treatment of common physical and mental conditions, prescribing and managing medication therapy, education and counseling on health issues, well-baby care, continuing care and management of chronic conditions, and referral to and provision of specialty care (includes all medical subspecialties). Primary medical care for the treatment of HIV infection includes the provision of care that is consistent with the Public Health Service's guidelines. Such care must include access to antiretroviral and other drug therapies, including prophylaxis and treatment of opportunistic infections and combination antiretroviral therapies.

#### **b** Laboratory Diagnostic Testing

HIV viral load testing, CD4/CD8, CBC with diff., blood chemistry profile, & other FDA approved routine tests for the treatment of patients with HIV disease. In addition, routine tests pertinent to the prevention of opportunistic infections (VDRL, IGRA, AFB, pap smear, toxoplasmosa, hepatitis B, & CMV serologies) & all other laboratory tests as clinically indicated (e.g. HCV serology) that are generally accepted to be medically necessary for the treatment of HIV disease & its complications and have an established Florida Medicaid or Medicare reimbursement rate, as well as new tests that may not have an established reimbursement rate.

#### c Drug Reimbursement Program

Local Supplemental Drug Program

Provision of injectable and non-injectable prescription drugs, at or below Public Health Service (PHS) price, and/or related supplies prescribed or ordered by a physician to prolong life, improve health, or prevent deterioration of health for HIV+ persons who do not have prescription drug coverage and who are not eligible for Medicaid, Health Care District, or other public sector funding, nor have any other means to pay. This service area also includes assistance for the acquisition of non-Medicaid reimbursable drugs.

#### ADAP Supplemental Drug Program

Program to expand Florida AIDS Drug Assistance Program (ADAP) locally by paying for FDA approved medications on the State of Florida ADAP formulary when the Florida ADAP is unable to pay for such medications for patients enrolled in the Florida ADAP program & patients are ineligible for other local health care programs which pay for these medications. Medications purchased under this program must be purchased at Public Health Services prices or less.

#### Nutritional Supplements

Provision of nutritional supplement prescribed as a treatment for diagnosed wasting syndrome. Counseling linked to Primary Medical Care, Nurse Care Management or Human Services Management.

#### d Specialty Outpatient Medical Care

Short term treatment of specialty medical conditions and associated diagnostic procedures for HIV positive patients based upon referral from a primary care provider, physician, physician assistant, registered nurse. Specialties may include, but are not limited to, outpatient rehabilitation, dermatology, oncology, obstetrics and gynecology, urology, podiatry, pediatrics, rheumatology, physical therapy, speech therapy, occupational therapy, developmental assessment, and psychiatry.

#### e Oral Health Care

Diagnostic, preventive, and therapeutic services provided by general dental practitioners, dental specialists, dental hygienists and auxiliaries, and other trained primary care providers.

Service caps approved by the CARE Council must be adhered to. Clinical decisions must be informed by the American Dental Association Dental Practice Parameters.

#### f Early Intervention Services (EIS)

Includes counseling individuals with respect to HIV/AIDS; testing (including tests to confirm the presence of the disease, tests to diagnose the extent of immune deficiency, tests to provide information on appropriate therapeutic measures); referrals to appropriate services based on HIV status; linkage to care and education and health literacy training for clients to help them navigate the HIV care system; other clinical and diagnostic services regarding HIV/AIDS; periodic medical evaluations for individuals with HIV/AIDS; and providing therapeutic measures. Services shall be provided at specific points of entry. Coordination with HIV prevention efforts and programs as well as prevention providers is required. Referrals to care and treatment must be monitored. Grantee may modify targeted areas to include additional key points of entry.

#### g Nurse Care Coordination

A range of client-centered services provided by a registered nurse and coordinated with the client's primary outpatient healthcare provider, providing the Ryan White patient's main link with ongoing medical services.

Key activities include: 1)provides primary care as part of the clinical team, 2)triage for new problems, 3)provide health education and self-care education, 4) coordinate medical plan and specialty referrals, 5) implement and monitor home-based service plans, including home visits if necessary, 6) facilitate access to clinical trials, 7) guarantee patient access to clinical care five days per week, 8)coordinate in-patient and outpatient care, 9) conduct chart reviews for evaluation of services to Ryan White funded patients.

#### h Health Insurance Premium & Cost Sharing Assistance

Provision of financial assistance for eligible individuals living with HIV to maintain a continuity of health insurance or to receive medical benefits under a health insurance program. This includes premium payments, risk pools, co-payments, and deductibles.

An annual cost benefit analysis that includes an illustration of the greater benefit of using Ryan White funds for Insurance/Costs-Sharing Program vs. having the client on ADAP. Documentation of the low-income status of the client must be available. Insurance programs must cover comprehensive primary care services and a full range of HIV medications. Funds may not be used for social security.

#### i Home Health Care

Includes the provision of services in the home by licensed health care workers such as nurses and the administration of intravenous and aerosolized treatment, parenteral feeding, diagnostic testing, and other medical therapies.

#### j Home and Community-Based Health Services

Includes skilled health services furnished to the individual in the individual's home based on a written plan of care established by a case management team that includes appropriate health care professionals. Services include durable medical equipment; home health aide services and personal care services in the home; day treatment or other partial

hospitalization services; home intravenous and aerosolized drug therapy (including prescription drugs administered as part of such therapy); routine diagnostics testing administered in the home; and appropriate mental health, developmental, and rehabilitation services. Inpatient hospitals services, nursing home and other long term care facilities are NOT included.

#### k Hospice Services

Includes end-of-life care provided to clients in the terminal stage of illness. Includes room, board, nursing care, counseling, physician services, and palliative therapeutics. Services may be provided in a residential setting, including a non-acute-care section of a hospital that has been designated and staffed to provide hospice services.

#### **I** Mental Health Services

Psychological and psychiatric treatment and counseling services offered to individuals with a diagnosed mental illness, conducted in a group or individual setting, and provided by a mental health professional licensed or authorized within the State to render such services. This typically includes psychiatrists, psychologists, and licensed clinical social workers.

#### m Medical Nutrition Therapy

Provided by a licensed registered dietitian outside of a primary care visit. The provision of food, nutritional services, and nutritional supplements may be provided pursuant to a physician's recommended and nutritional plan developed by a licensed, registered dietician.

#### n Medical Case management services (including treatment adherence)

A range of client-centered services that link clients with health care, psychosocial, and other services. The coordination and follow-up of medical treatments is a component of medical case management. These services ensure timely and coordinated access to medically appropriate levels of health and support services and continuity of care, through ongoing assessment of the client's and other key family members' needs and personal support systems. Medical case management includes the provision of treatment adherence counseling to ensure readiness for, and adherence to, complex HIV/AIDS treatments. Key activities include (1) initial assessment of service needs; (2) development of a comprehensive, individualized service plan; (3) coordination of services required to implement the plan; (4) client monitoring to assess the efficacy of the plan; and (5) periodic re-evaluation and adaptation of the plan as necessary over the life of the client. It includes client-specific advocacy and/or review of utilization of services. This includes all types of case management including face-to-face, phone contact, and any other forms of communication.

Case Management providers must be PAC Waiver providers or demonstrate that they have begun the PAC Waiver application process.

Medical Case Management services exclude determining/re-determining clients' eligibility.

#### **Peer Mentor Program**

The goal of the Peer Mentor program is to improve HIV-related health outcomes and reduce health disparities for at risk communities through HIV peer education.

Peers shall be persons living with HIV from the community, not working as licensed clinical professionals, who share key characteristics with target population which shall include: a. community membership, gender, race/ethnicity, b. disease status or risk factors, c. sexual orientation, d. salient experiences, e.g. former drug use, sex work, incarceration. The Peer Mentor will use shared characteristics/experiences to act effectively as a trusted educator, mentor for adopting health behavior, role model, and empathic source of social and emotional support.

The contributions of HIV-positive peers shall include: adherence to medical care (keeping appointments, responding to physician referrals, and picking up medications); linking to medical care and support services; self-management of disease; emotional support and reduced risk behaviors.

#### **Treatment Adherence**

Treatment adherence counseling to ensure readiness for, and adherence to, complex HIV/AIDS treatment.

#### o Substance Abuse Services-Outpatient

Provision of medical or other treatment and/or counseling to address substance abuse problems (i.e., alcohol and/or legal and illegal drugs) in an outpatient setting, rendered by a physician or under the supervision of a physician, or by other qualified personnel.

#### SUPPORT SERVICES

#### 2. Case Management (non-Medical)

#### **Supportive Case Management**

Includes the provision of advice and assistance in obtaining medical, social, community, legal, financial, and other needed services. Nonmedical case management does not involve coordination and follow-up of medical treatments, as medical case management does. Excludes determining/re-determing clients' eligibility.

# **Determining Eligibility**

Provision of eligibility screenings for clients.

# 3.<u>Referral for Health Care/Supportive Services</u>

The act of directing a client to a service in person or through telephone, written, or other type of communication. Referrals for health care/supportive services that were not part of Outpatient/Ambulatory services or case management services (medical or non-medical) should be reported under this item.

#### 4.<u>Housing Services</u>

Provision of short-term assistance to support emergency, temporary or transitional housing to enable an individual or family to gain or maintain medical care. Housing-related referral services include assessment, search, placement, advocacy, and the fees associated with them. Eligible housing can include both housing that does not provide direct medical or supportive services and housing that provides some type of medical or supportive services such as residential mental health services, foster care, or assisted living residential services.

#### 5. Substance Abuse Services- residential

Provision of treatment to address substance abuse problems (including alcohol and/or legal and illegal drugs) in a residential health service setting (short-term).

Provides room and board, substance abuse treatment and counseling, including specific HIV counseling in a secure, drug-free state-licensed residential (non-hospital) substance abuse detoxification and treatment facility. This treatment shall be short term. Anyone providing direct counseling services must under the supervision of staff possessing postgraduate degree in the appropriate counseling-related field, or a Certified Addiction Professional (CAP). Part A funds may not be used for hospital inpatient detoxification.

# 6.Food Bank/Home Delivered Meals

Provision of actual food or meals. It does not include finances to purchase food or meals. The provision of essential household supplies such as hygiene items and household cleaning supplies should be included in this item. Includes vouchers to purchase food.

# 7. Emergency Financial Assistance (EFA)

Provision of short-term payments to agencies or establishment of voucher programs to assist with emergency expenses related to essential utilities, housing, food (including groceries, food vouchers, and food stamps), and medication when other resources are not available. EFA funds are only to be used as a last resort. Clients may receive up to 12 accesses per year for no more than a combined total of \$1,000 during the grant year.

# 8.<u>Medical Transportation Services</u>

Includes conveyance services provided, directly or through voucher, to a client so that he or she may access health care services.

Records must be maintained that track both services provided and the purpose of the service (e.g., transportation to/from what type of medical or support service appointment). Clients shall not receive direct payment for transportation services.

# 9. Treatment Adherence Counseling

Provision of counseling or special programs to ensure readiness for, and adherence to, complex HIV/AIDS treatments by non-medical personnel outside of the medical case management and clinical setting.

# 10. Outreach Services

Programs that have as their principal purpose identification of people with unknown HIV disease or those who know their status so that they may become aware of, and may be enrolled in care and treatment services (i.e., case finding). Outreach services does not include HIV counseling and testing or HIV prevention education. These services may target high-risk communities or individuals. Outreach programs must be planned and delivered in coordination with local HIV prevention outreach programs to avoid duplication of effort; be targeted to populations known through local epidemiologic data to be at disproportionate risk for HIV infection; be conducted at times and in places where there is a high probability that individuals with HIV infection will be reached; and be designed with quantified program reporting that will accommodate local effectiveness evaluation.

# 11.Legal Services

Provision of services to individuals with respect to powers of attorney, do-not-resuscitate orders and interventions necessary to ensure access to eligible benefits, including discrimination or breach of confidentiality litigation as it relates to services eligible for funding under the Ryan White Program. It does not include any legal services that arrange for guardianship or adoption of children after the death of their normal caregiver.

# 12. Health Education/Risk Reduction

Provision of services that educate clients with HIV about HIV transmission and how to reduce the risk of HIV transmission. It includes the provision of information about medical and psychosocial support services and counseling to help clients living with HIV improve their health status.

# 13. Psychosocial Support Services

Provision of support and counseling activities, child abuse and neglect counseling, HIV support groups, pastoral care, caregiver support, and bereavement counseling. Includes nutrition counseling provided by a non-registered dietitian but excludes the provision of nutritional supplements.

# 14. Rehabilitation Services

Provided by a licensed or authorized professional in accordance with an individualized plan of care intended to improve or maintain a client's quality of life and optimal

capacity for self-care. Services include physical and occupational therapy, speech pathology, and low-vision training.

# 15. Linguistics Services

Provision of interpretation and translation services. Types of linguistic services to be provided include oral interpretation and written translation as needed to facilitate communications and services delivery. Training and qualifications based on available State and local certifications are required.

# 16.Child Care Services

Provision of care for the children of clients who are HIV-positive while the clients attend medical or other appointments or Ryan White Program-related meetings, groups, or training.

NOTE: This does not include child care while a client is at work.

# 17. <u>Respite Care</u>

Provision of community or home-based, non-medical assistance designed to relieve the primary caregiver responsible for providing day-to-day care of a client with HIV/AIDS.