

**COMPREHENSIVE NEEDS ASSESSMENT
2011-2014**



**PALM BEACH COUNTY
HIV CARE COUNCIL
PALM BEACH COUNTY, FLORIDA**

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Prepared by
Barbara Feeney, MPA
Questions? Call Sonja Swanson Holbrook, MPH
Ryan White Program Manager
Palm Beach County Department of Community Services
810 Datura Street
West Palm Beach, FL 33401
561-355-4730
sholbroo@pbcgov.org
www.carecouncil.org

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



ACKNOWLEDGEMENTS

The Palm Beach County HIV CARE Council would like to thank all of the people who contributed their time and effort to this project. We would like to especially thank the persons living with HIV/AIDS who participated in the survey and focus groups. Your comments are included in this report and enrich our understanding of the needs in the HIV/AIDS community. This report is dedicated to you.

This report would not exist without the Data Collection Team members. They did an outstanding job, particularly in gathering data from historically hard to reach populations. Their names are included below. Thank you for all of your hard work.

There were many others who assisted in this project including the Part A and Part B service providers, Planning Committee members and Grantee staff listed here. We would like to thank you for supporting this project.

We are especially grateful to Miriam Potocky, Ph.D. whose expertise lent exceptional clarity and depth to the epidemiological profile and analysis of populations of special concern.

Rafael Abadia	John Foley	Steven Misshula
William Albury	Tonya Fowler	Larry Osband
Victor Audige	Patricia Gavin	Rik Pavlescak, Ph.D
Cindy Barnes	Michael Green	Raymond Philmore
Shana Bayder	Bob Guarascio	Jennifer Piva
David Begley	Ron Haberle	Tony Plakas
Yolette Bonnet	Caroline Hill	Pat Priola
Kimberly Bradley	Don Hilliard	David Rafaidus
Yvette Branch	Alice Holmes	Mary Jane Reynolds
Sharon Brown	Sheron Hoo-Hing	Shoshana Ringer
Anita Byrd	Barbara Jacobowitz	Lorenzo Robertson
Robert Bytnar	Marlinda Jefferson	Hugo Rocchia
Barbara Carlson	Melissa Jenkins	Jose Rodriquez
Orlando Carrasquillo	Mary Piper Kannel	Shirley Samples
Sandra Chamblee	Linda Kane	Barry Smith
Bobby Cleveland	Glenn Krabec	Cecil Smith
Rosalyn Collins	Chris LaCharite	Julie Swindler
Renee Constantino	Linda Leary	Sandra White
Gayle Corso	Francois LeConte	Shirley White
Patricia Davis	Larry Leed	Channell Wilkins
Gayle Dempsey	Nicole Leidesdorf	Sarah Withrow
Mitchell Durant, Ph.D.	Beatrice Manning	Don Yost
Kimberly Enright	Sha' Wanda Manuel	
Barbara Feeney	Thomas McKissack	
Maggie Fleury	Pedro Medina	

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I. EXECUTIVE SUMMARY

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 2011-2014 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:

- Lab work for CD4 count
- Lab work for viral load count
- Prescription for Anti-Retroviral Therapy (ART).”

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

HIV/AIDS Epidemiology

The data sources for this section are Florida Department of Health, Bureau of HIV/AIDS Surveillance Section (2010), *Attachment 3: AIDS Incidence, AIDS Prevalence, and HIV (Not AIDS) Prevalence*. As of December 31, 2009, Of Palm Beach County’s 2009 mid-year population estimate of 1,289,159,

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

The 2009 mid-year population estimate for Palm Beach County was 1,289,159. As of December 31, 2009, the number of people living with HIV (not AIDS) (PLWH) in Palm Beach County was 2,959. This translates to an HIV prevalence rate of 230 per 100,000 (100,000 X 2,959/1,289,159). 60% of these people were non-Hispanic Blacks, 26% were non-Hispanic Whites, and 13% were Hispanics. Over one-half (58%) were males. 97% were adults age 20+. A greater proportion (51%) was in the younger adult age group

(20-44 years) than the older adult age group (age 45+; 46%). Among adults and adolescents, the most frequent exposure category was heterosexual (60%), followed by men having sex with men (MSM; 31%). Among the 28 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, 2009, the number of people living with AIDS (PLWA) in Palm Beach County was 4,589, representing an AIDS prevalence rate of 356 per 100,000 ($100,000 \times 4,589/1,289,159$). Approximately two-thirds (64%) of these people were non-Hispanic Blacks, 23% were non-Hispanic Whites, and 12% were Hispanics. About two-thirds (64%) were males, and 99% were adults age 20+. In contrast to the HIV (not AIDS) adult prevalence, a greater proportion of the people living with AIDS were older adults aged 45+ (62%) than younger adults age 20-44 (37%). The exposure categories are similar to those of people living with HIV. Among adults and adolescents, the most frequent exposure category was heterosexual (57%), followed by MSM (29%). All of the 15 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 2008 and 2009 was 648. 62% of these were non-Hispanic Blacks, 21% were non-Hispanic Whites, and 15% were Hispanics. 63% were males. Almost all (99%) of these cases were adults age 20+. 55% were age 20-44 and 44% were age 45+. Among adults and adolescents, the most frequent exposure category was heterosexual (65%), followed by MSM (27%). The one pediatric case (age 0-12) was 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, formerly-incarcerated individual. Analysis of ZIP code data shows that the populations residing in the ZIP codes along the eastern corridor and the southwestern area of the county have the highest number and rates of HIV/AIDS cases.

Overall, the HIV/AIDS prevalence rate in the general population of Palm Beach County is 585 per 100,000 population ($100,000 \times 7,548/1,289,159$). Examples of higher rates among specific populations include the following:

- Among non-Haitian Blacks, the HIV/AIDS prevalence rate is 3.6 times higher than among the general population.
- Among men who have sex with men (MSM), the HIV/AIDS prevalence rate is almost 12 times higher than among the general population.
- Among intravenous drug users (IDU), the HIV/AIDS prevalence rate is almost 25 times higher than among the general population.
- Among Haitian-born persons, the rate is 5 times higher than among the general population.
- HIV/AIDS is almost 2 times more prevalent among the homeless population than among the general population.
- Compared to the PLWH/A prevalence rate of 586 among the county's general population, the rate among the formerly incarcerated is almost 9 times higher.

Populations Underrepresented in the Ryan White Program

Underrepresented populations may be identified by comparing demographic characteristics of the PLWH/A population in the county with the characteristics of PLWH/A served by the Ryan White Program-funded system in the county. Analyses of demographic characteristics of PLWH/A in the county and PLWH/A served by the Ryan White Program show that the populations are similar, with the possible exceptions of Whites, Blacks, males, and persons age 13-44. Whites comprise 25% of the PLWH/A population, but 19% of the PLWH/A served. Blacks comprise 62% of the PLWH/A population, but 57% of the PLWH/A served. Males comprise 61% of the PLWH/A population, but 58% of the PLWH/A served. Persons age 13-44 comprise 46% of the PLWH/A population, but 42% of the PLWH/A served. These data suggest that these populations may be underserved.

HIV and AIDS Data Trends

HIV case data represent the most recent trends of the HIV/AIDS epidemic. The total number of HIV cases in Palm Beach County continues to increase and, while the number and rate of new cases decreased between 1999 and 2008, in 2007 the number and rate started to increase again. The data in the table to the right summarizes the decrease in the number of new cases from a high of 695 in 1999 to 358 in 2006 as well as a decrease in the rate, from 62.8 to 27.7 per 100,000 population. By 2008, the rate was up to 40.7 per 100,000 population (Florida Department of Health, CHARTS Community Health Assessment Resource Tool Set).

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 1996 to 2008, from 759, 74.3 per 100,000 to 339, 26.2 per 100,000 (Florida Department of Health, CHARTS Community Health Assessment Resource Tool Set).

As with new HIV and new AIDS cases, the number of age adjusted HIV/AIDS deaths has dramatically decreased since 1996, dropping from 306 deaths in 1996 to 118 deaths in 2008 with a concomitant decrease in rates per 100,000 population from 32.2 to 9.4.

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 149.5 in 1996 to 40.3 in 2008 but this rate is still 12.6 times higher than the rate for Whites and 10.9 times higher than the rate for Hispanics (Florida Department of Health, CHARTS Community Health Assessment Resource Tool Set).

Methodology

The Comprehensive Needs Assessment 2011-2014 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, and 2007 Comprehensive Needs Assessments. With the guidance and approval of the Planning Committee, additional components were added regarding utilization of medical care and case management, as well as from where and from whom the respondents receive medical care and HIV information. 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.

Key Findings

Characteristics of PLWHA Survey Respondents

Throughout the surveying process, sampling was monitored and adjusted 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. HIV/AIDS Case Prevalence data cited in this section were provided by the Florida Department of Health Bureau of HIV/AIDS.

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:

- Lab work for CD4 count
- Lab work for viral load count
- Prescription for Anti-Retroviral Therapy (ART).”

As summarized in the following table, most of the PLWH/A in the EMA are in care as are the survey respondents (69.6% of PLWHA in EMA and 81.1% of survey respondents).

**Comparison of In Care and Out of Care Survey Respondents with
PLWH/A in Palm Beach County EMA**

PLWH/A	Palm Beach EMA		Survey Respondents	
	number	percent	number	percent
In care	5,276	69.6%	296	81.1%
Out of Care	2309	30.4%	69	18.9%
Total	7,585	100.0%	365	100.0%

Highlights Regarding PLWHA Who Are Currently in Primary Medical Care

296 survey respondents indicated they are currently in primary medical care. When asked if their case manager always encourages and helps them get regular medical care, 53% said “always” and 16% said “sometimes”. 22% said they didn’t have a case manager.

Of those who have missed a medical appointment, 32.9% said that someone (case manager, clinic staff person, mental health counselor, etc.) “always” contacted them to try to reschedule, etc. 42.8% said that someone “sometimes” did so.

Of those who have been prescribed medications, 78.7% said they “always” take them as prescribed; another 16.7% said they took them as prescribed “most of the time”.

Of the 63 respondents who cited reasons for not taking medications as prescribed, the most frequent reasons were “I do not like taking medications” (49.2%) and “they make me feel really bad” (44.4%).

73.5% of women respondents said they had received a pelvic exam within the prior twelve months; 3.8% had been pregnant.

Nearly half (48.3%) were enrolled in one or more government programs (e.g. food stamps, Medicaid, Social Security Disability, etc.)

Of the 269 in care respondents who indicated where they receive HIV/AIDS medical care, 68.4% said Public Clinic/Health Department and 24.9% said “Doctor’s Office”.

10.4% had been hospitalized and 16.6% had received care at the Emergency Room for an HIV/AIDS related condition during the previous year.

38.5% said they did not have any problems receiving services. Among those who had problems trying to access services (n=148), the most frequently cited problems were “didn’t know how to apply” (44.6%), “didn’t know where to apply” (30.4%), “transportation problems” (24.3%), “turned down/not eligible” (18.2%).

Highlights regarding PLWHA Who Are Now In Care, But Have Been Out of Care within the Past Five Years

49 survey respondents who were currently in care indicated that, during the previous five years, there had been a period of at least 12 months when they were not receiving HIV-related primary medical care.

The most frequently cited circumstance (by 65.3%) was that they "...had been receiving medical care for HIV, but I decided to stop". 10/2% attributed their circumstances to "drug use/addiction."

When asked why they were not receiving care, the two most frequently identified reasons were "I did not have medical insurance and could not afford care" (36.7%) and "I knew where to go, but I did not want to go there" (24.5%). 32.7% mentioned one reason and 46.9% mentioned two to four reasons.

When asked what services they needed to get into primary medical care, the most frequently mentioned services included "food" (63.3%), "financial assistance" (51%), "housing" (42.9%), "transportation" (36.7%), and "case management" (34.7%). 10.2% indicated needing only one service, 49% needed two to four; and 26.5% needed more than four.

When asked to identify the reasons they returned to care, the most frequently cited reasons were "I got I got sick and knew I needed care" (59.2%), "I was ready to deal with my illness" (32.7%), "I got a referral to get into care" (20.4%), "An outreach worker found me and helped me get into care" (20.4%). 28.6% identified only one reason for returning to care; 57.1% identified two to four reasons, and 4.1% identified five to eight reasons.

Highlights Regarding PLWHA Who are Out of Care

An estimated 30.4% of PLWHA in Palm Beach County are out of care compared 18.9% of survey respondents.

Respondents were asked what best describes their situation regarding being out of care. Of the 69 respondents who were out of care, (68.1%) reported that they had never been in care including 44.9% who had recently been diagnosed with HIV and had not entered primary care and 23.2% who had not been recently diagnosed but had never been in care. More than a quarter (26.12%) had been receiving care for HIV but had stopped more than 12 months ago.

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

- I did not feel sick. (47.8%, 33)
- I did not want people to know that I have HIV. (42.0%, 29)
- I could not pay for services. (36.2%, 25)
- I was depressed. (36.2%, 25)

- I was not ready to deal with having HIV. (31.9%, 22)
- I did not know where to go. (31.9%, 18)
- I could not get transportation. (18.8%, 13)

82.6% identified more than one reason for being out of 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 to those cited by respondents who were out of care.

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 42% of out of care respondents cited “I did not want people to know that I have HIV”, 71.4% of providers cited that reason.

When respondents who are not in primary medical care were asked what services, other than medical care and medication, they needed to get into primary medical care, the three most frequently chosen responses were “financial assistance” (49.3%), “food” (46.4%), housing (44.9%), and case management (40.6%). 21.7% said they needed only one service to get into care and 72.5% said they needed more than one service.

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, 64.3% of provider respondents indicated that PLWHA need mental health services to get into care, while only 17.4% of out of care respondents did. Likewise, 50.0% of providers indicated that PLWHA need substance abuse treatment, compared to only 21.7% of out of care respondents who cited this service as necessary to get into care.

The most frequently cited reasons for entering care were:

- When I get sick and know I need care (65.2%)
- When I am ready to deal with my illness (29%)
- Someone else with HIV/AIDS reaches out to me (26.1%)
- I get transportation to go to a doctor or clinic (26.1%)
- Someone arranges to have my care paid for (26.1%)

72.5% cited more than one reason to enter care.

Providers and PLWHA alike most frequently cited the following two reasons as follows:

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

Highlights Regarding Prioritization of Service Categories

Respondents who are in care were asked 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 (73.6%)
- Laboratory Diagnostic Testing (62.8%)
- Medications (58.4%)
- Case Management (57.4%)
- Medical Specialist (41.6%)

All providers and 73.6% of PLWHA identified Primary Medical Care as the most important service.

Notable differences between PLWHA and providers include the following:

- Providers cited “Medications” as the second most important service, while PLWHA ranked “Laboratory Diagnostic Testing” as the second.
- 41.6% of PLWHA cited “Medical Specialists” one of the five most important services compared to 7.1% of providers who mentioned this service category
- Providers mentioned “Nurse Care Coordination” at more than twice the rate of PLWHA (28.6% compared to 12.8%).
- Food was mentioned by 21.6% of PLWHA but by 0% of providers.

Highlights Regarding Utilization, Gaps, and Barriers

Survey respondents in care were asked to describe their level of utilization of the twenty-six service categories prioritized by the planning council. The 296 respondents in care described their utilization of each survey categories as one of the following:

- “Need and Use” if they utilize the service
- “Need But Can’t Get” to show possible gaps in services
- “Needed But Didn’t Know about Service” to show barriers to service utilization
- “Don’t Need” if they do not utilize the service

Utilization

The five most frequently utilized, “Need and Use” services:

1. Medications (76.4%)
2. Primary Medical Care (76%)
3. Laboratory Diagnostic Testing (75.7%)
4. Medical Specialist (61.1%)
5. Oral/Dental Health, (59.5%)

Gaps

The five top ranked “Need But Can’t Get” services:

1. Food Bank/Home Delivered Meals (26.4%)
2. Emergency Financial Assistance (21.3%)
3. Transportation (14.2%)
4. Health Insurance (11.1%)
5. Legal Services/Permanency (8.1%)
5. Rehabilitation Services (8.1%)

In the Out of Care section of this report, data from respondents who are out of care report similar service gaps. When asked what supportive services the respondents who are out of care need in order to enter primary medical care, the most frequently named services included financial assistance (i.e., emergency financial services), food, housing, case management, and transportation.

Barriers

The top five services in the “Needed But Didn’t Know About Service” category were:

1. Emergency Financial Services (11.1%)
1. Legal Services/Permanency (11.1%)
2. Food Bank/Home Delivered Meals (9.5%)
3. Support Groups (7.4%)
4. Outreach (7.1%)
5. Transportation (6.4%)
5. Health Education/Risk Reduction (6.4%)

Highlights Regarding Findings from Provider Surveys

The fourteen providers who completed a 30-item on-line survey represented a broad range of types of organizations and agencies that provide services to PLWH/A in Palm Beach County

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.

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?” Their responses included variations on the following themes:

- Increase Service Capacity & Availability
- Promote Client Empowerment
- Improve Systematic Approach to Change

When providers were asked to, “List three barriers that their organization has faced when providing care to people living with HIV/AIDS,” their responses included conditions and circumstances related to the following:

- Systematic Issues
- Service Capacity & Availability

- Psychological and Cultural Issues

Sixty-four percent of the providers specified other agencies with whom they have HIV-specific verbal agreements, commitment letters, letters of collaboration, binding agreements, or signed Memoranda of Understanding (MOUs) with other agencies in the area. The majority of the providers have MOUs with the organizations that function as the point of entry into care (i.e. case management).

Ten providers indicated specific methods of tracking referrals.

Five providers who indicated that they sometimes have a waiting list, described their methods of tracking people the list.

Eight providers specified ways in which the CARE Council could help their agencies better coordinate services with other providers in the area. These suggestions included details related to the following themes:

- Facilitate Outreach and Networking
- Increase Funding for Private Providers
- Ensure Seamless System of Care

Nine organizations said they are planning to provide additional services to PLWHA, including the following:

- “We are currently, as a pilot, opening some of our clinics for half a day on Saturday. If this proves successful, we will expand to include HIV services. In the past, clients didn't utilize the evening hours (many years ago).”
- “Expanding to provide more services by hiring another physician; would like to have funding for an in-office case manager.”
- “Exploring funding for increased capacity.”
- “Yes, as our Agency identifies more individuals meeting TOPWA's criteria (women who are pregnant).”
- “FoundCare is providing more medical care to people living with HIV/AIDS.”
- “We want to expand our services for newly infected individuals looking for services or individuals that have been out of care for more than six months.”
- “We have just launched a Pharmaceutical Assistance and Drug Access Program (MEDNet).”
- “If funding provided, agency will want to expand case management and supportive services.”
- “Adding a part-time social worker.”

Highlights Regarding Trends in Service Utilization, Gaps, and Barriers (2000-2010)

Needs assessments were conducted in 2000, 2003, 2007 and 2010. In addition to data analyses for each year's needs assessment, analyses were conducted to identify trends from 2000 through 2010. Service categories used to analyze utilization, gaps, and barriers have varied slightly in the four 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 in the 2010 needs assessment. The list of service categories in the 2010 data collection instrument includes only the services in the current continuum of care that were prioritized and funded by the CARE Council in 2010. In some cases, this resulted in nonconsecutive rankings of services across time.

Note: The findings in this section are based on survey responses only and do not necessarily reflect actual utilization patterns or availability of services.

Utilization

Although rates of utilization have changed for the following services, they have *remained highly utilized* (by more than 50% of respondents) from 2000 through 2010.

- Primary Medical Care
- Laboratory Diagnostic Testing
- Medical Specialist
- Oral/Dental Health
- Case Management

The following services *significantly increased in utilization* from 2000 through 2010.

- Medications
- Primary Medical Care
- Medical Specialist
- Transportation

The following services *significantly decreased in utilization* from 2000 through 2010.

- Case Management
- Food Bank/Home Delivered Meals
- Health Education/Risk Reduction
- Counseling (if this means Early Intervention, etc.)
- Substance Abuse Residential
- Substance Abuse Outpatient
- Hospice

Gaps

The following categories had gaps that generally remained somewhat consistent over time:

- Case Management
- Mental Health Services
- Food Bank/Home Delivered Meals
- Transportation
- Emergency Financial Assistance

Gaps in the following service categories for generally decreased over time:

- Medications

- Oral/Dental Health
- Health Insurance
- Early Intervention Services
- Home Health Care
- Hospice

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 the following populations of special concern:

1. Men who Have Sex with Men (MSM)
2. Haitian Men and Women
3. African American Women
4. Men Recently Released from Incarceration
5. Latin/Hispanic Men and Women
6. Women Who Used Drugs Illegally During the Past 12 Months

For this Needs Assessment, focus groups were conducted with PLWHA from each of the first five 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.

Highlights Regarding 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.¹

Service Gaps

The 2010 Needs Assessment included 90 respondents who identified themselves as MSM. 79% of these were in care, 43% were at or below 100% of the federal poverty level, and about half had been unemployed during the past 12 months.

Out of Care MSM Respondents

When out of care MSM were asked to describe their situation, 63% said they had been recently diagnosed and had not entered primary care, compared to 45% among all out of care respondents. The rate of MSM who had not been recently diagnosed but had never been in care was about the same rate as among all out of care respondents (26% and 23% respectively). When out of care MSM were asked to identify the reasons that they are not

¹Florida 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.*

in primary 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 MSM, the second most frequently mentioned reason was “I did not know where to go” (53%) while this response given at half that rate (26%) by all out of care respondents. When out of care MSM respondents were asked to identify the services, other than medical care and medications, that they need in order to get into primary medical care, the four most frequently selected services were the same as those selected by all out of care respondents (financial assistance, food, housing, and case management). Compared to all out of care respondents, a higher percentage of MSM selected financial assistance and labs.

In Care MSM Respondents

MSM respondents in care most frequently identified service gaps (“need but can’t get”) in case management, food bank/home delivered meals, oral/dental health, transportation, and emergency financial assistance. As with all in care respondents, emergency financial assistance was the most frequently mentioned service that in care MSM “needed but didn’t know about”(service barrier). The next most frequently mentioned services in this category were mental health services, nutrition counseling, legal services/permanency, oral/dental health, and food bank/home delivered meals.

MSM Focus Group Findings

Respondents identified the following reasons for not being in primary care: lack of knowledge about appropriate care and treatment services; depression and stress; lack of information about treatment and availability of services; adverse reactions to medications; high cost of medication; having to take time off from work to pick up medications every month instead of every three months due to cutbacks in ADAP funding; drug and alcohol abuse/addiction; difficulties qualifying for services due to means testing; and stigma/embarrassment. When asked what would help MSM get back into care or stay in care, respondents identified facing a life or death illness; billboards; case management; support groups; learning to make taking care of oneself a priority; reducing or eliminating alcohol and drugs; exercise; having sympathetic and caring physicians; developing coping skills; psychotherapy; and concern for others. Participants said they were receiving the services they need (especially case management, medical care, medications, lab tests, and mental health counseling) and were generally very satisfied with those services. Some identified service gaps and barriers were the difficult and time-consuming eligibility process; ineligibility for food stamps and need for a food bank; the ADAP waiting list and change in medication distribution from every three months to every month; and unmet needs or difficulty accessing emergency financial assistance, dental health care, legal services (especially regarding immigration status), and transportation.

Additional Data Highlights Related to MSM Survey Respondents

- 24.7% (90) of all respondents identified themselves as MSM.
- 19 (21.1%) are out of care and 71 (78.9%) are in care.
- 82 (91.1%) identified English and 6 (6.7%) identified Spanish as their primary language.
- 17.2% identified themselves as Hispanic/Latino.

- 39 (43.3%) are at or below 100% of the federal poverty level.
- 47 (52.2%) had been unemployed during the past 12 months.
- 7 (7.8%) traded sex for money or drugs within the past 12 months.
- 4 used injection drugs, 2 used methamphetamines, and 30 used other street drugs.
- 26.6% (20) traded sex for money or drugs within the past 12 months.
- 37.3% (28) utilize private doctors for most of their medical care.

Highlights Regarding 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.²

Additional challenges arise from immigration status. In Florida, only people with an AIDS-defining 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.³

Service Gaps

The 2010 Needs Assessment survey included 67 Haitian respondents. 72% of the respondents were out of care and 28% were in care. Almost one-half were unemployed, about one-quarter had either no schooling or an education level of grade 8 or less, and 82% lived at or below the poverty level. Almost all (97%) indicated they were heterosexual.

²Miami-Dade HIV/AIDS Partnership (2009). *Comprehensive Plan for HIV/AIDS 2009-2011*.

³Miami-Dade HIV/AIDS Partnership (2009). *Comprehensive Plan for HIV/AIDS 2009-2011*.

Out of Care Haitian Respondents

Among survey respondents, the rate of Haitian out of care respondents was higher than the out of care rate of all respondents (28% compared to 19%). The rate of Haitian out of care respondents who have never been in care was nearly twice the rate of all out of care respondents (42% compared to 23%). When asked why they did not get HIV/AIDS related medical care during the past year, 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 was depressed; and I missed my appointment. Overall, the services, other than medical care and medication, that Haitian out of care respondents indicated they need to get into primary medical care were very similar to those needed by all out of care respondents. Respondents in both groups most frequently mentioned the same five services (financial assistance, food, housing, case management, and transportation), although larger percentages of Haitian out of care respondents indicated that they needed the services.

In Care Haitian Respondents

Like all in care respondents, Haitian respondents who are in care most frequently mentioned gaps in services (“need but can’t get”) were for Emergency Financial Assistance, Food Bank/Home Delivery Meals, and Rehabilitation Services. Unlike all in care respondents, Haitian in care respondents also indicated gaps in Linguistic Services and Support Services. Like all respondents in care, Haitian in care respondents most frequently reported barriers (“needed but didn’t know about”) in regard to Support Services rather than to Core Services. The services most frequently mentioned by Haitian respondents in care that they needed but didn’t know about were Rehabilitation Services, Legal Services/Permanency, Emergency Financial Assistance, and Health Education/Risk Reduction.

Haitian Focus Group Findings

Recurrent themes of continued reliance on case management, medical care, medications, and transportation were discussed throughout the group session. Participants also expressed their ongoing fears and anxieties regarding immigration status and financial and housing insecurities exacerbated by HIV. When asked about what it would take to persuade PLWH/A who are not in care to get back into care, respondents again expressed the need to help people overcome fear. When asked what helped them to get into care and stay in care, participants noted the importance of case management. When asked about what services are needed to help get back in care, participants expressed the inextricable link between clinical and support services. When asked about services they need but can’t get, the only specific services mentioned was financial assistance for housing. However, participants expressed their need for continued help with services.

Additional Data Highlights Related to Haitian Survey Respondents:

- 67 (18.4% of all respondents) indicated they were Haitian.
- 97% said they are straight (heterosexual)
- 28.4% are in care, compared to 81.1% of all respondents.
- 71.6% are out of care, compared to 18.9% of all respondents.

- 97% said Creole is their primary language.
- 26.9% of Haitian respondents had either no schooling or an education level of 8th grade less compared to 12.9% of all respondents.
- 44.8% described their work situation in the past year as “unemployed” compared to 64.7% of all respondents.
- 82.1% were living at or below 100% FPL compared to 70.7% of all respondents.

Highlights Regarding African American Women

Unique Challenges

African-American women face many barriers to care and experience many factors that complicate their care. Poverty, limited education, lack of health insurance, immigration status, and lack of transportation continue to be significant problems for these women. Many African-American PLWH/A women feel disempowered in their relationships with men, 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. There are high rates of reported stigma attached to HIV/AIDS, creating a culture of denial that results in low-income African-American women not learning they are HIV positive until they become pregnant. 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. Many African-American women 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. Additional factors such as partner domestic violence compound safety, security, and preventive health behaviors.⁴

Service Gaps

The 2010 Needs Assessment survey included 128 African American female respondents. 86% reported they were in care. 17% had either no schooling or an education level of 8th grade less, almost three-fourths were unemployed, and 82% were living at or below the poverty level. 89% indicated they were heterosexual.

Out of Care African-American Women Respondents

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 African American females was, “I have recently been diagnosed with HIV, and have not entered primary care.” The second most frequently described situation for African American females was “I have not been recently diagnosed but have never been in care.” Respondents were asked to identify the reasons for being out of care. In each group (all out of care respondents and African American female out of care respondents), the most frequently cited reason in was, “I am afraid of being identified as HIV-positive.” When asked what services they needed to get into primary medical care, out of care respondents as a whole and African- American female out of care respondents mentioned the same top service categories (financial assistance, food, housing, case management, and transportation) as all out of care respondents. In nearly every category (except

⁴ Miami-Dade HIV/AIDS Partnership (2009). *Comprehensive Plan for HIV/AIDS 2009-2011*.

financial assistance), a larger percentage of African American females indicated the need for the services.

In Care African-American Women Respondents

African American female in care respondents and all in care respondents most frequently identified the leading service gaps (“need but can’t get”) to be Food Bank/Home Delivered Meals, Emergency Financial Assistance, Transportation, Health Insurance, and Legal Services. African American females also reported a gap in Oral/Dental Health. All in care respondents and African American female respondents reported similarly low levels of barriers to services (“needed but didn’t know about”). The barriers most frequently cited by African American females were Rehabilitative Services and Legal Services/Permanency Planning.

African-American Women Focus Group Findings

When participants were asked why they or others they knew were out of care, their discussion focused on various combinations of fear, lack of knowledge about the disease and available treatment, denial, addiction, and barriers to accessing care due to lack of knowledge or financial resources. Participants discussed what they think it would take to persuade a person to get into care for the first time or to return to care after being out of care. Their responses focused on providing support and education. There was extensive discussion among participants regarding the importance of assuring their access to medical care, especially prescription medications. Several participants discussed fear and worry regarding funding cuts, wait lists, and barriers. As participants discussed the complex maze of access to prescription medications, they mentioned a wide assortment of funding jargon and resources. In addition to issues related to access, participants also discussed complications with medications and problems with side-effects.

Additional Data Highlights Regarding African American Women Respondents:

- 128 (35% of all respondents) indicated they were African American women.
- 89.1% said they are straight (heterosexual)
- 85.9% are in care, compared to 81.1% of all respondents.
- 14.1% are out of care, compared to 18.9% of all respondents.
- 21.4% said Creole is their primary language.
- 16.7% of African American female respondents had either no schooling or an education level of 8th grade less compared to 12.9% of all respondents.
- 72.2% described their work situation in the past year as “unemployed” compared to 64.7% of all respondents.
- 81.7% were living at or below 100% FPL compared to 70.7% of all respondents.

Highlights Regarding Men Recently Released from Incarceration *Recently Released Former Prisoners*

In 2009, 3% of PLWH/A in Palm Beach County had been released from state corrections facilities within the past 3 years, compared to 0.2% of the county’s general population.

Thus, the rate of recent state incarceration among the PLWH/A population is 15 times the rate in the general population

The Florida corrections system has two types of incarceration facilities: prisons, which are funded and operated by the state Department of Corrections, and jails, which are operated and funded by local county governments.⁵ The above figures pertain to the prisons; analogous data for jails and for Federal facilities are not available at this time.

The average length of stay in prisons is three to five years, and the prisons are mandated to test each inmate for HIV within 60 days of release. The average length of stay in jails is 23 to 46 days and the jails are not required to test inmates for HIV unless they have been convicted of a sex crime.⁶ In 2009, 3,235 jail inmates in Palm Beach County were tested for HIV and 0.4% of these tested positive.⁷

In 2008 (latest date available), the average daily population in Palm Beach County jails was 3,006.⁸ Applying the above HIV-positive jail rate (0.4%), it can be estimated that there are approximately 12 PLWHAs in Palm Beach County jails on an average day. Since the average jail stay is less than two months, all of these individuals would be released back into the community within a year's period.

The Florida Department of Health operates a Pre-Release Planning Program in all the state prisons. The program is responsible for offering pre-release services to all known HIV-positive prisoners. Four pre-release planners cover the entire state. The pre-release planners provide services directly to the inmate within six months of their release date to determine the community to which the inmate is returning and what type of services he/she will need. The pre-release planner contacts at least one or two social service agencies or medical providers to connect the client to the care system prior to their release. Upon release, the clients are given a copy of their medical records (if requested) and a 30-day supply of medication. Pre-release planners follow up with the ex-offender and/or provider after one month to determine if the initial medical or social service appointment was kept. Additionally, the Florida Department of Health operates a jail linkage program in Palm Beach County to implement transitional services in the local jails. This program includes counseling and testing for HIV/AIDS, tuberculosis, hepatitis, and STIs; prevention education; pre-release planning; and follow-up services.⁹ In 2009, 68 PLWHA inmates in Palm Beach County were linked to services, and 96% of them kept their initial appointment.¹⁰

⁵ Florida Department of Health, Bureau of HIV/AIDS (2010). *Florida Corrections Programs*.

⁶ Ibid.

⁷ Florida Department of Health, Bureau of HIV/AIDS (2010). *Florida's Corrections Programs: 2009 Annual Report*.

⁸ Florida Department of Corrections (2009). *Jail Populations and Incarceration Rates by County*.

⁹ Florida Department of Health, Bureau of HIV/AIDS (2010). *Florida Corrections Programs: 2009 Annual Report*.

¹⁰ Florida Department of Health, Bureau of HIV/AIDS (2010). *Florida Corrections Programs: 2009 Annual Report*.

In 2010, the Palm Beach County's HIV CARE Council conducted a survey of 117 PLWH/As who had been released from jail or prison within the past 12 months. 17 of these were currently out of care. The most frequently cited reasons for being out of care were lack of insurance or money to pay for care (65%); using drugs or alcohol (65%); lack of transportation (42%); not being ready to deal with one's HIV status (35%); and homelessness (29%). The recently incarcerated out of care respondents most frequently cited financial assistance (89%); food and transportation (83% each); housing (72%); and substance abuse treatment (61%) as their most needed services.¹¹ In a focus group of recently incarcerated male PLWHA in care, respondents indicated that the linkage program had helped them get into care. They expressed 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.¹² Clearly, recently released former prisoners add to the cost and complexity of the service delivery system, particularly in regard to enhancing follow-through to help them remain in care upon release.

Unique Challenges

Because, 26 (96.3%) of the men who had been released within the past 12 months were African American, the following narrative focuses on their unique challenges.

HIV/AIDS service provision to the African-American community is complicated; the documented "down low" phenomenon among African-American men that contributes to increased STI and HIV infections in the community for both men and women. The economic and social ramifications of poverty in this community contribute to high levels of substance abuse, diagnosis at a later stage of illness, and other collateral problems. Stigma and lack of insurance are additional complicating factors that often result in late entry into care. African-Americans are also significantly more likely to drop out of care than other racial/ethnic groups.¹³ Further, unique challenges to service delivery for recently incarcerated African-American men include substance abuse, lack of transportation, not being ready to deal with one's HIV status, and homelessness.¹⁴

Service Gaps

The 2010 Needs Assessment survey included 27 men who had been incarcerated in the past 12 months. 10 of these were out of care, and 23 lived at or below 100% of the federal poverty level.

Out of Care Incarcerated Men Respondents

The ten respondents who are out of care were asked to describe their situation. As among all out of care respondents, out of care respondents who were recently incarcerated most frequently mentioned, "I had been receiving medical care for HIV, but I stopped more than 12 months ago." Like all out of care respondents, the most frequently cited reasons

¹¹ Treasure Coast Health Council (2010). *PLWH/A Released from Jail/Prison in last 12 months*.

¹² Treasure Coast Health Council (2007). *Comprehensive Needs Assessment 2007-2010*.

¹³ Miami-Dade HIV/AIDS Partnership (2009). *Comprehensive Plan for HIV/AIDS 2009-2011*.

¹⁴ Treasure Coast Health Council (2010). *PLWH/A Released from Jail/Prison in last 12 months*.

for being out of care were “I did not feel sick” and “I did not want people to know that I have HIV.” As all out of care respondents, recently incarcerated out of care respondents most frequently cited food, financial assistance, transportation, and housing as the most needed services.

In Care Incarcerated Men Respondents

Recently incarcerated in care men and all in care respondents most frequently reported a service gap (“need but can’t get) regarding food/home delivered meals. Respondents in this special population mentioned transportation just as frequently as they mentioned food, followed by primary medical care. Generally, this population reported gaps regarding a fewer number of services, but at higher rates than among all in care respondents. The most frequently mentioned barriers (“needed but didn’t know about”) reported by recently incarcerated men were for food bank/home delivered meals and transportation.

Recently Incarcerated Men Focus Group Findings

Recently incarcerated men identified depression, stigma, and dislike of medication as barriers to care. They identified service gaps in housing, food, and ADAP (i.e. the recently-instituted waiting list). In regard to what helped them get into care, the respondents mentioned case management and having a support system.

Additional Data Regarding Recently Incarcerated Men Survey Respondents

Of all survey respondents, 38 (10.4% of all respondents) indicated they had been in jail or prison within the past twelve months. Of the 38, 27 were male and 11 were female. Of the 27 males who had been released from incarcerated during the past twelve months, 26 were African American and 1 was White. Of these 27 (71.1% of all 38 respondents):

- 17 are in care and 10 are out of care.
- 17 used other (than injection drugs or methamphetamines) street drugs
- 23 live at or below 100% of the federal poverty level.

Highlights Regarding Latin/Hispanic Men and Women

Unique Challenges

The challenges of serving Hispanic PLWH/A 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.¹⁵

Service Gaps

27 Hispanic respondents participated in the 2010 Needs Assessment survey. 18 of these were in care and 9 were out of care. The most frequently mentioned country of origin

¹⁵Miami-Dade HIV/AIDS Partnership (2009). *Comprehensive Plan for HIV/AIDS 2009-2011*.

was the United States (10) followed by Puerto Rico (6) and Mexico (6). Other countries of origin include the Dominican Republic, Columbia, and Nicaragua. Over one-half were not working during the past year, over one-third had less than a high school education, and nearly two-thirds lived at or below the poverty level.

Out of Care Hispanic Respondents

The most frequent circumstance cited by out of care Hispanic respondents was “I have recently been diagnosed with HIV, and have not entered primary care.” As with all out of care respondents, out of care Hispanics most frequently said that the reason they did not get HIV/AIDS medical care during the past year was because they “did not feel sick.” Both groups also cited financial barriers and not being “ready to deal with having HIV.” Hispanics were more than twice as likely as all out of care respondents to report not knowing where to go for care. When asked what services, other than medical services and medication, they need to get into primary medical care, Hispanic respondents, like all out of care respondents, most frequently mentioned financial assistance. Other services needed by both groups included housing, food, and transportation.

In Care Hispanic Respondents

As with all out of care respondents, Hispanic in care respondents reported service gaps (“need but can’t get”) in food bank/home delivered meals, transportation, and emergency financial assistance. Unlike all in care respondents, Hispanics also reported gaps in case management and mental health services. Like all in care respondents, Hispanics most frequently reported barriers regarding food bank/home delivered meals and emergency financial assistance. Hispanics also identified nutrition counseling, oral/dental health, and health education/risk reduction among the top five services they needed but didn’t know about.

Hispanic Focus Group Findings

Although all the Hispanic focus group participants said they were satisfied with their medical care and had access to medications, they complained about the pharmacy staff and about excessive waiting time and inconvenient hours of service at the pharmacy. Among the support the participant needed help accessing were financial assistance; transportation (gas cards, bus passes), food, housing, legal assistance, and work and job training.

Additional Data Regarding Latin/Hispanic Survey Respondents

- Among the 27 Hispanic/Latin survey respondents, 18 were in care and 9 were out of care.
- The most frequently mentioned country of origin was the United States (10) followed by Puerto Rico (6) and Mexico (6). Other countries of origin include the Dominican Republic, Columbia, and Nicaragua.
- 51.9% were not working during the past year.
- 37% have less than a high school education.
- 59.3% are at or below 100% of the federal poverty level.
- 25.9% used street drugs, other than injection drugs within the past 12 months.

- 18.5% reported being diagnosed with Hepatitis C during the past 12 months, compared to 13.4% of all respondents.

Highlights Regarding Women Who Used Drugs Illegally During the Past 12 Months

Note: Data in this section refer to women who used drugs other than those properly prescribed by a health care provider and taken as prescribed. The use or abuse of alcohol was not queried in the PLWHA survey and is therefore, not addressed in this section.

Question 17A. of the PLWHA survey asked the following:

“It is important that we try to meet the individual needs of all people living with HIV/AIDS. Please check any or all of the following that have applied to you at any time in the last 12 months.”

A total of 43 women (27.7% of all female respondents) indicated some type of drug use as follows:

- No women checked “Used illegal drugs through injection/needle”.
- 1 woman checked “Used methamphetamines” and did not indicate any other drug use.
- 42 women checked “Used other street drug (including marijuana)” only.
- 1 woman checked “Used methamphetamines” and “Used other street drug (including marijuana).”

Unique Challenges

The unique challenges of serving the population of women who use drugs illegally are complicated by other medical and psychosocial issues such as addiction, depression, anxiety, and other mental health issues.

Services Gaps

The 2010 Needs Assessment included 43 women who reported using drugs illegally within the previous 12 months. Of these, 79.1% are in care, and 92.5% were at or below 100% of the federal poverty level and had been unemployed during the past 12 months

Out of Care Women Who Had Used Drugs Illegally Respondents

When asked to describe their situation, 44.4% of women who had used drugs illegally said they have recently been diagnosed with HIV, about the same rate as all out of care respondents (44.9%). 44.9% said they had not been recently diagnosed but have never been in care, compared to 23.2% of all out of care respondents.

Out of care female respondents who had used drugs within the past 12 months most frequently identified similar reasons for being out of care as those identified by all out of care respondents. The reasons most frequently mentioned were, “I did not want people to know that I have HIV” (55.6%), “I did not feel sick” (55.6%), and “I was depressed” (44.4%).

The out of care female respondents who have used drugs within the past 12 months identified similar services they needed to get into care as all out of care respondents with one notable exception. While all out of care respondents most frequently identified financial assistance food, housing, and case management, and transportation, women who have used drugs indicated their need for substance abuse treatment at more than twice the rate as other respondents (55.6% compared to 21.7%).

In Care Women Who Used Drugs Illegally Respondents

Unlike other respondents, in care female respondents who have used drugs within the past 12 months reported almost no service utilization at all. Only one woman in this category identified case management as a service she needs and uses. When respondents were asked to identify services they need but can't get, in care female respondents who have used drugs within the past 12 months most frequently mentioned transportation followed by food bank/home delivered meals, and health insurance.

Focus Group of In Care Women Who Used Drugs Illegally Respondents

No focus group of this population was convened for this needs assessment.

Additional Findings Regarding Women Respondents Who Reported Drug Use During the Past 12 Months:

- Of the 155 women surveyed, 27.7% (43) reported using drugs during the previous 12 months.
- Of the 43 who had used drugs during the past 12 months
 - 30.9% (9) are out of care.
 - 79.1% (34) are in care.
 - 92.5% (37) are not employed.
 - 18.9% (10) are employed.
 - 41.9% (18) are on disability.
 - 92.5% (37) live at or below the federal poverty level.
 - 32.6% (14) have traded sex for money or drugs within the past 12 months.

II. INTRODUCTION

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 2011-2014 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:

- Lab work for CD4 count
- Lab work for viral load count
- Prescription for Anti-Retroviral Therapy (ART).”

This definition is an “operational” or working definition of being “in care” and uses information likely to be available in most states and EMAs. However, this definition is not intended to conform to the definition of “high quality care” that meets Public Health Service guidelines or to “standards of care” that guide clinical practice.

HIV/AIDS Epidemiology

Palm Beach County Demographics

The 2009 mid-year population estimate for Palm Beach County was 1,289,159. Of these, 48% were male and 52% female. The county is racially and ethnically diverse. In 2009, 64% of the population was White non-Hispanic, 16% was Black non-Hispanic, 18% was Hispanic, and 2% was other races/ethnicities. A large proportion of the county’s population is senior retirees. The 2009 age distribution in years was as follows: 0-12, 15%; 13-19, 8%; 20-24, 5%; 25-29, 6%; 30-39, 11%; 40-49, 13%; 50-59, 13%; 60+, 28%. (Florida Department of Health, Bureau of HIV/AIDS Surveillance Section (2010). *Epidemiological Profile, Palm Beach County.*)

HIV/AIDS Cases by Demographic Characteristics and Exposure Category

The data source for this section: Florida Department of Health, Bureau of HIV/AIDS Surveillance Section (2010), *Attachment 3: AIDS Incidence, AIDS Prevalence, and HIV (Not AIDS) Prevalence*.

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

As of December 31, 2009, the number of people living with HIV (not AIDS) (PLWH) in Palm Beach County was 2,959. This translates to an HIV prevalence rate of 230 per 100,000 ($100,000 \times 2,959/1,289,159$). 60% of these people were non-Hispanic Blacks, 26% were non-Hispanic Whites, and 13% were Hispanics. Over one-half (58%) were males. 97% were adults age 20+. A greater proportion (51%) were in the younger adult age group (20-44 years) than the older adult age group (age 45+; 46%). Among adults and adolescents, the most frequent exposure category was heterosexual (60%), followed by men having sex with men (MSM; 31%). Among the 28 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, 2009, the number of people living with AIDS (PLWA) in Palm Beach County was 4,589, representing an AIDS prevalence rate of 356 per 100,000 ($100,000 \times 4,589/1,289,159$). Approximately two-thirds (64%) of these people were non-Hispanic Blacks, 23% were non-Hispanic Whites, and 12% were Hispanics. About two-thirds (64%) were males, and 99% were adults age 20+. In contrast to the HIV (not AIDS) adult prevalence, a greater proportion of the people living with AIDS were older adults aged 45+ (62%) than younger adults age 20-44 (37%). The exposure categories are similar to those of people living with HIV. Among adults and adolescents, the most frequent exposure category was heterosexual (57%), followed by MSM (29%). All of the 15 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 2008 and 2009 was 648. 62% of these were non-Hispanic Blacks, 21% were non-Hispanic Whites, and 15% were Hispanics. 63% were males. Almost all (99%) of these cases were adults age 20+. 55% were age 20-44 and 44% were age 45+. Among adults and adolescents, the most frequent exposure category was heterosexual (65%), followed by MSM (27%). The one pediatric case (age 0-12) was 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.

Based on the data in the following table, the HIV/AIDS prevalence rate in the general population of Palm Beach County is 585 per 100,000 population ($100,000 \times 7,548/1,289,159$). The prevalence rates in the above table indicate that:

- Among non-Haitian Blacks, the HIV/AIDS prevalence rate is 3.6 times higher than among the general population.

- Among men who have sex with men (MSM), the HIV/AIDS prevalence rate is almost 12 times higher than among the general population.
- Among intravenous drug users (IDU), the HIV/AIDS prevalence rate is almost 25 times higher than among the general population.
- Among Haitian-born persons, the rate is 5 times higher than among the general population.

PLWH/A Subpopulations in Palm Beach County through 2009

PLWH/A Subpopulations	(A) Number of PLWH/A (N=7,548)*	(B) Percent of All PLWH/A (A/7,548)	(C) Number in Total County Population (N=1,289,159)	(D) Percent of Total County Population (C/1,289,159)	(E) HIV/AIDS Prevalence Rate per 100,000 (100,000XA/C)
Black (non-Haitian)	3,372	45%	160,913**	12%	2,096
Hispanic	899	12%	230,601***	18%	390
MSM Age 15+	2,220	29%	32,328***	3%	6,867
IDU	778	10%	5,400****	0.4%	14,407
Haitian Born	1,352	18%	45,780*****	4%	2,953

Sources:

*Florida Department of Health, Bureau of HIV/AIDS Surveillance Section (2010). *Section 2 – Table 1b: Background Data Used for the Calculations of AIDS Prevalence, and HIV (not AIDS) Prevalence.*

**Florida Department of Health, Bureau of HIV/AIDS Surveillance Section (2010). *Epidemiological Profile, Palm Beach County.*

***Estimate based on prevalence of 6.4% MSM among males, Kinsey Institute (2006). *Prevalence of Homosexuality.* Population data from U.S. Census (2009). *American Community Survey, 2008, Palm Beach County.*

****Florida Department of Health, Bureau of HIV/AIDS, Surveillance Section (2005). *HIV/AIDS among Intravenous Drug Users, Florida.*

*****U.S. Census (2009). *American Community Survey, 2008, Palm Beach County.*

Homeless

The 2009 point-in-time count of the homeless in Palm Beach County found 24 homeless PLWH/A and a total of 2,147 homeless in the county. These data suggest that the PLWH/A prevalence rate among the homeless is 1,118 per 100,000 population (24/2,147 X 100,000). Thus, HIV/AIDS is almost 2 times more prevalent among the homeless population than among the general population, a disproportionate impact.

Formerly Incarcerated Individuals

In 2009, 1,301 prison inmates were released to Palm Beach County by the Florida Department of Corrections; 66 of these were PLWH/A (Florida Department of Health, Bureau of HIV/AIDS Surveillance Section [2010]. *Co-Morbidities/Other Factors/Surrogate Markers.*)

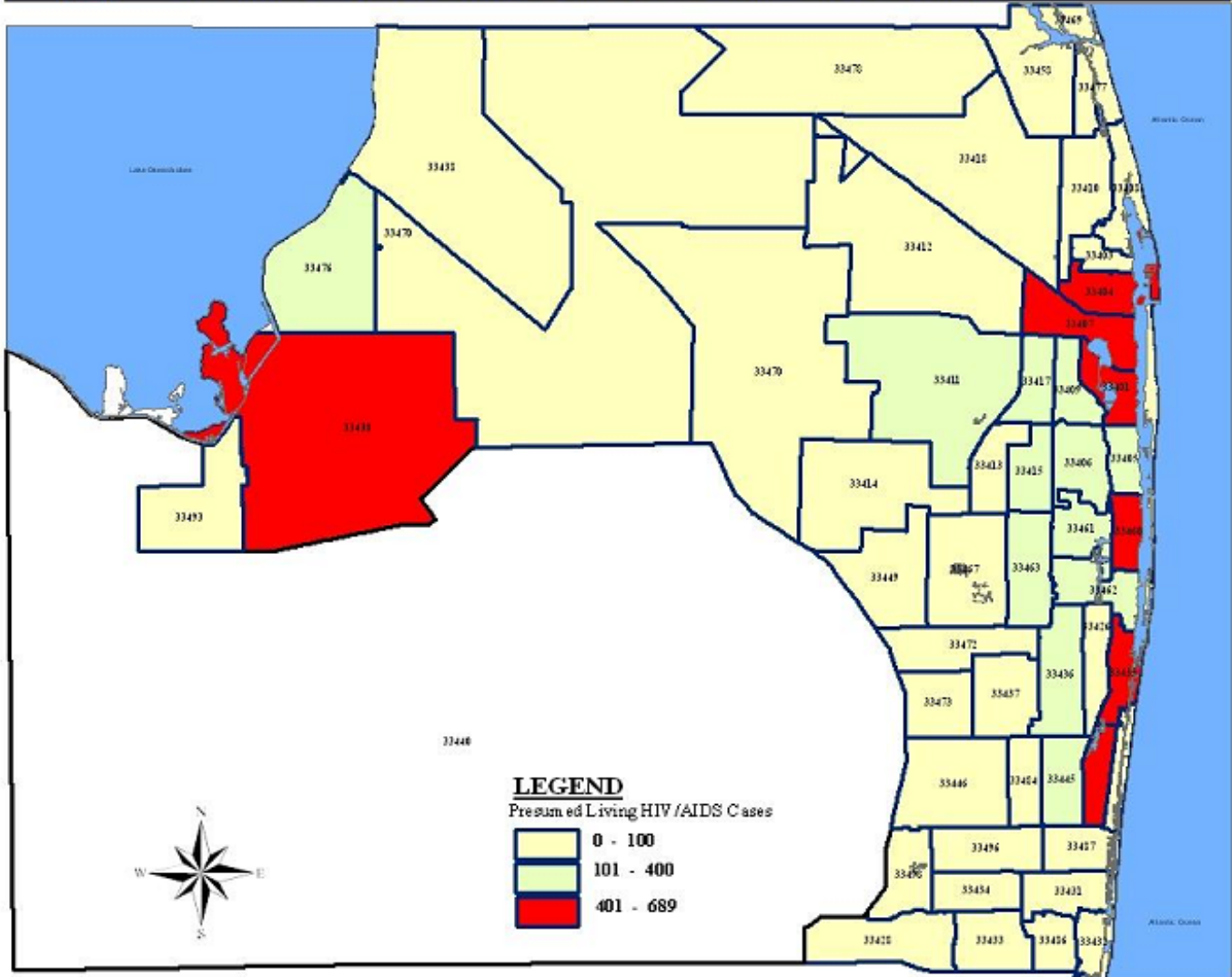
Thus, the PLWH/A prevalence rate among recently-released offenders in Palm Beach County is 5,073 per 100,000 ($66/1,301 \times 100,000$). Compared to the PLWH/A prevalence rate of 586 among the county's general population, the rate among the formerly incarcerated is almost 9 times higher. Thus the formerly incarcerated are clearly disproportionately impacted by HIV/AIDS.

Geographic Distribution

The following three 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 presumed living HIV/AIDS cases, PLWH/A who are not in medical care, and the location of Ryan White funded service providers (with bus routes). As shown on these three 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.



Presumed Living HIV/AIDS Cases 2009 - Palm Beach County, Florida

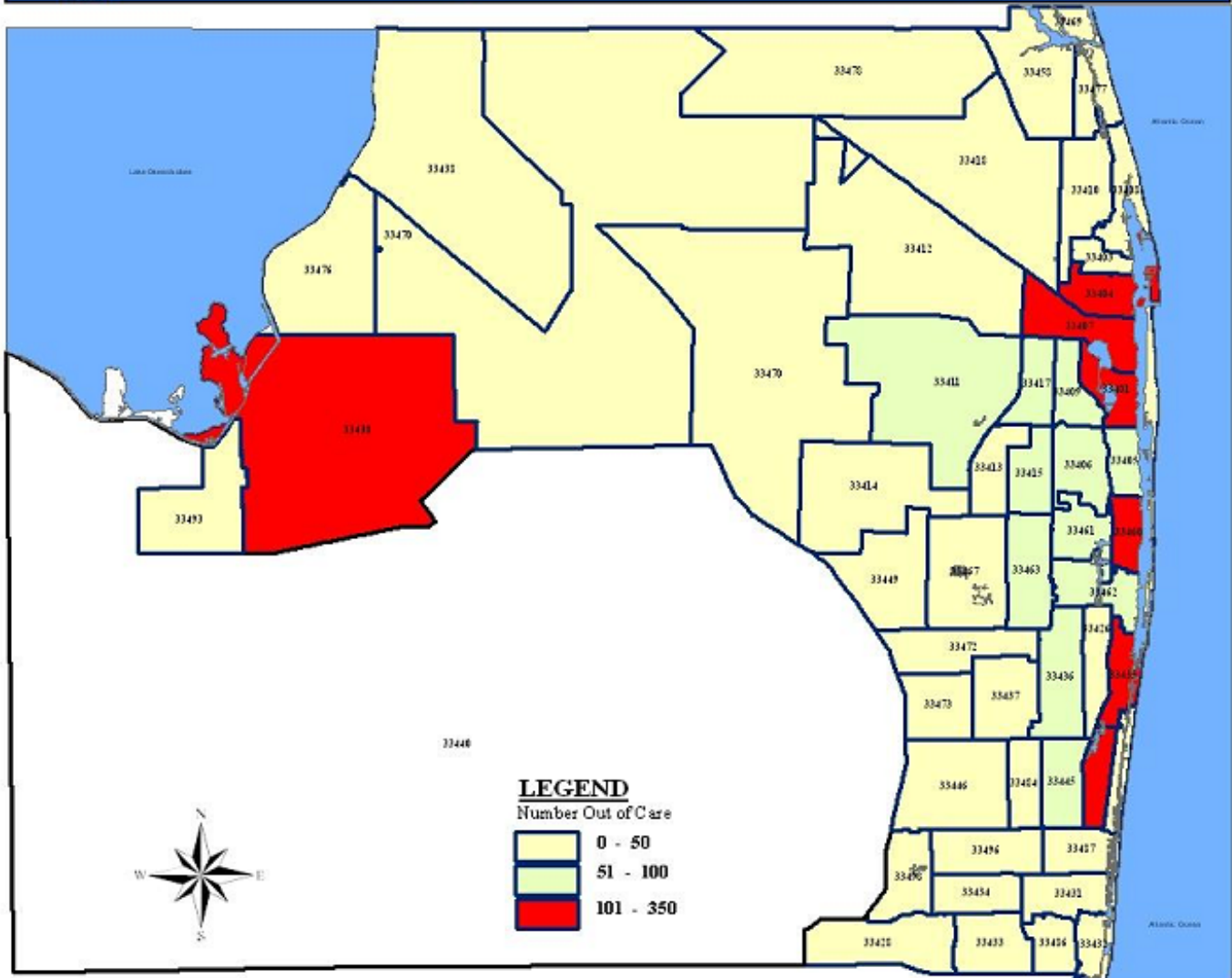


Palm Beach County, Florida Presumed Living HIV/AIDS Cases (PLWHA), 2009

Map of Palm Beach County, Florida with ZIP code boundaries. Waterways are included as a layer of information. Map indicates presumed living cases through 2009. Data presented complied with Florida HIV/AIDS Bureau policy. ZIP code of residence at time of diagnosis may not correspond to current ZIP code. Homeless count and non-Palm Beach County ZIP codes are not reflected on map. For further information contact Sonja Holbrook, Ryan White Program Manager at (561) 355-4730. Map and data are for planning purposes only. Printed September 28, 2010. Created by David Rafaidus (561) 355-4705.

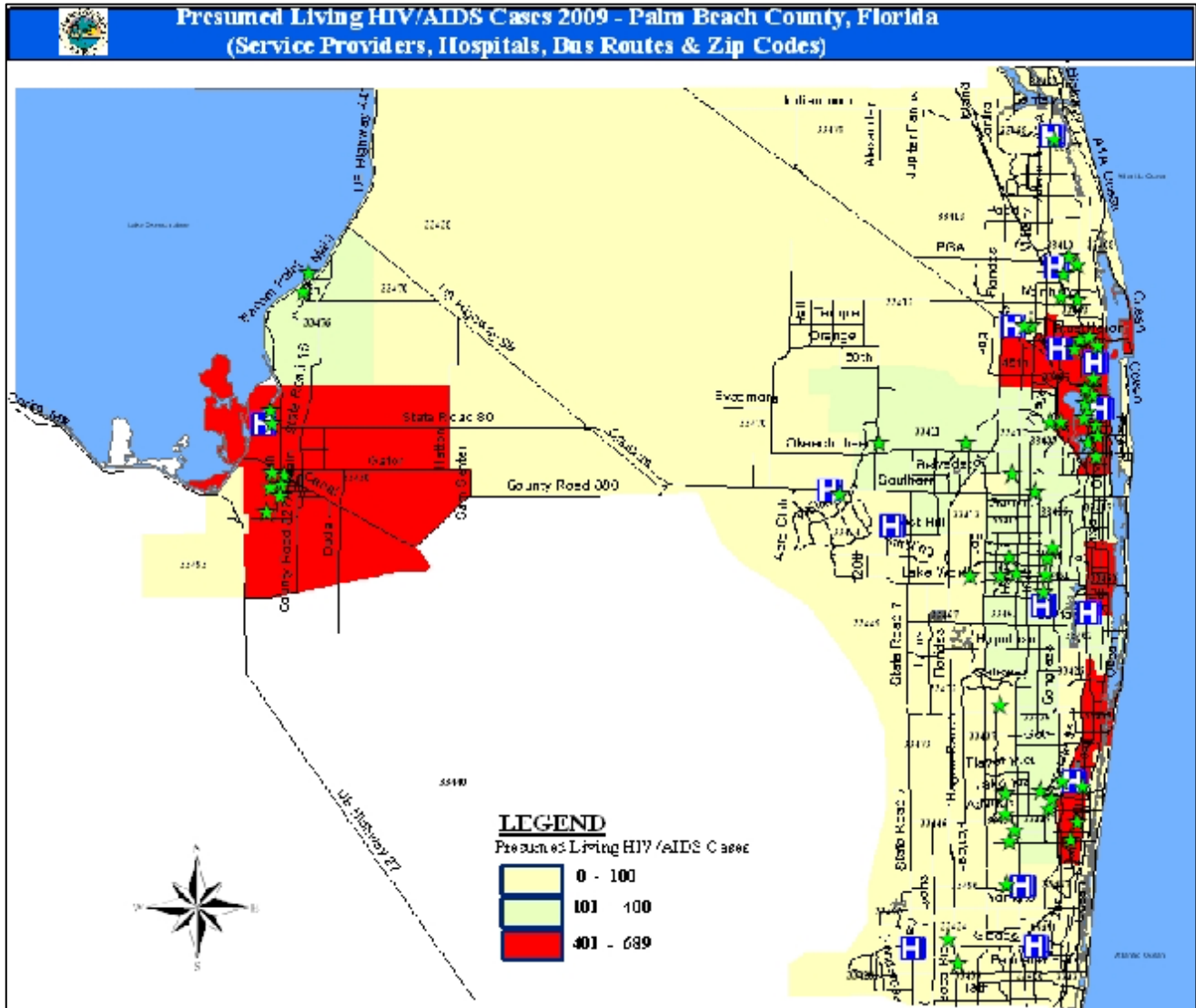


Palm Beach County, Florida - Number of PLWHA Not In Care



Palm Beach County, Florida Number of PLWHA Who Are Not in Care, 2009

Map of Palm Beach County, Florida with ZIP code boundaries. Waterways are included as a layer of information. Map indicates presumed living cases through 2009. Data presented complied with Florida HIV/AIDS Bureau policy. ZIP code of residence at time of diagnosis may not correspond to current zip code. Homeless count and non-Palm Beach County ZIP codes are not reflected on map. For further information contact Sonja Holbrook, Ryan White Program Manager at (561) 355-4730. Map and data are for planning purposes only. Printed September 28, 2010. Created by David Rafaidus (561) 355-4705.



**Palm Beach County, Florida
Presumed Living PLWHA, 2009
Service Providers, Hospitals, Bus Routes, and ZIP Codes**

Map of Palm Beach County, Florida with Service Providers, Hospitals, Major Roads, Bus Routes, Waterways and ZIP Codes included as a layer of information. Map indicates presumed living cases through 2009. Data presented complied with Florida HIV/AIDS Bureau policy. ZIP code of residence at time of diagnosis may not correspond to current ZIP code. Homeless count and non-Palm Beach County ZIP codes are not reflected on map. For further information contact Sonja Holbrook, Ryan White Program Manager at (561) 355-4730. Map and data are for planning purposes only. Printed September 28, 2010. Created by David Rafaidus (561) 355-4705.

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

The number of new AIDS cases reported in Palm Beach County in 2008 and 2009 was 648. 62% of these were non-Hispanic Blacks, 21% were non-Hispanic Whites, and 15% were Hispanics. 63% were males. Almost all (99%) of these cases were adults age 20+. 55% were age 20-44 and 44% were age 45+. Among adults and adolescents, the most frequent exposure category was heterosexual (65%), followed by MSM (27%). The one pediatric case (age 0-12) was exposed due to a mother with/at risk for HIV infection.

Populations Underrepresented in the Ryan White Program

Underrepresented populations may be identified by comparing demographic characteristics of the PLWH/A population in the county with the characteristics of PLWH/A served by the Ryan White Program-funded system in the county. The following table shows these comparisons in relation to race/ethnicity, gender, and age:

As seen in the table to the right, the demographic characteristics of the PLWH/A population in the county and the PLWH/A served by the Ryan White Program are very similar, with the possible exceptions of Whites, Blacks, males, and persons age 13-44. Whites comprise 25% of the PLWH/A population, but 19% of the PLWH/A served. Blacks comprise 62% of the PLWH/A population, but 57% of the PLWH/A served. Males comprise 61% of the PLWH/A population, but 58% of the PLWH/A served. Persons age 13-44 comprise 46% of the PLWH/A population, but 42% of the PLWH/A served. These figures suggest that these populations may be underserved.

In the *Characteristics of Survey Respondents* section of this report, a comparative analysis suggests that the sample of PLWHA survey respondents is similar to PLWHA Case Prevalence.

Comparison of all PLWH/A with PLWH/A Served, Palm Beach County, 2008

Populations	PLWH/A*	PLWH/A Served**
RACE/ETHNICITY		
White	25%	19%
Black	62%	57%
Hispanic	12%	13%
Asian/Pacific Islander	0%	0%
American Indian	0%	0%
Other/Unknown	1%	12%
GENDER		
Male	61%	58%
Female	39%	42%
AGE (years)		
0-12	1%	1%
13-44	46%	42%
45+	54%	57%
*Florida Department of Health, Bureau of HIV/AIDS Surveillance Section (2010). Attachment 3: AIDS Incidence, AIDS Prevalence, and HIV (not AIDS) Prevalence.		
**Treasure Coast Health Council (2010). RDR Summary Units & Clients Counts, 1/1/09-12/31/09.		

HIV case data represent the most recent trends of the HIV/AIDS epidemic. The total number of HIV cases in Palm Beach County continues to increase and, while the number and rate of new cases decreased between 1999 and 2008, in 2007 the number and rate started to increase again. The data in the table to the right summarizes the decrease in the number of new cases from a high of 695 in 1999 to 358 in 2006 as well as a decrease in the rate, from 62.8 to 27.7 per 100,000 population. By 2008, the rate was up to 40.7 per 100,000 population (Florida Department of Health, CHARTS Community Health Assessment Resource Tool Set).

Palm Beach County HIV Data			
Year	New Cases	Rate per 100,000	Total Population
1998	552	51.2	1,077,422
1999	695	62.8	1,107,053
2000	468	41.1	1,137,532
2001	457	39.4	1,160,977
2002	585	49.1	1,190,653
2003	543	44.6	1,218,508
2004	457	36.6	1,249,598
2005	397	31.2	1,272,335
2006	358	27.7	1,290,600
2007	415	32	1,295,586
2008	527	40.7	1,294,035

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 1996 to 2008, from 759, 74.3 per 100,000 to 339, 26.2 per 100,000 (Florida Department of Health, CHARTS Community Health Assessment Resource Tool Set).

Palm Beach County AIDS Data		
Year	New Cases	Rate per 100,000
1996	759	74.3
1997	559	53.2
1998	477	44.3
1999	432	39
2000	503	44.2
2001	453	39
2002	513	43.1
2003	444	36.4
2004	436	34.9
2005	360	28.3
2006	371	28.7
2007	284	21.9
2008	339	26.2

As with new HIV and new AIDS cases, the number of age adjusted HIV/AIDS deaths has dramatically decreased since 1996, dropping from 306 deaths in 1996 to 118 deaths in 2008 with a concomitant decrease in rates per 100,000 population from 32.2 to 9.4.

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 149.5 in 1996 to 40.3 in 2008 but this rate is still 12.6 times higher than the rate for Whites and 10.9 times higher than the rate for Hispanics (Florida Department of Health, CHARTS Community Health Assessment Resource Tool Set).

**Palm Beach County EMA
Total Deaths and Age Adjusted HIV/AIDS Death Rates
1996-2008**

Year	Number of Deaths	All Races/ Ethnicities Rate per 100,000	White Rate per 100,000	Black Rate per 100,000	Hispanic Rate per 100,000
1996	306	32.2	13.6	149.5	17.6
1997	191	19.1	6.0	106.1	15.3
1998	135	12.9	3.9	73.9	6.7
1999	138	13.2	5.6	59.7	8.3
2000	165	15.3	5.7	75.4	11.0
2001	147	13.3	3.7	73.2	5.5
2002	157	13.8	3.9	71.9	1.5
2003	156	13.4	4.2	68.0	6.5
2004	175	14.9	4.9	70.8	9.7
2005	149	12.4	3.7	50.0	7.6
2006	162	12.9	3.5	64.5	4.9
2007	118	9.7	3.2	41.8	1.9
2008	118	9.4	3.2	40.3	3.7

III. METHODOLOGY

The Comprehensive Needs Assessment 2011-2014 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, and 2007 Comprehensive Needs Assessments. With the guidance and approval of the Planning Committee, additional components were added regarding utilization of medical care and case management, as well as from where and from whom the respondents receive medical care and HIV information. 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 120-item survey was developed and implemented to collect information from PLWHA regarding service priorities and needs. The survey was translated into Spanish and Creole. 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?

Lab work for CD4 count?

Lab work for viral load count?

Prescription for Anti-Retroviral Therapy (ART)?”

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 lab work for CD4 or viral load, and no Antiretroviral Therapy).

Trained data collectors administered three hundred sixty-five (365) 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 January 2010. 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.

As noted in our 2002 study entitled “Speak Out Be Heard,”

“[Because] The target group is known to be relatively reticent about disclosing information relevant to the topic of HIV/AIDS (Denis, Wechsberg, McDermeita, Campbell & Raschc, 2001), clients were recruited using variants of convenience sampling (Carlson, Wang, Siegal, Falck, & Guo, 1994) combined with purposive sampling strategies.”

Provider Survey

Provider surveys were completed by the following organizations:

1. Compass
2. Comprehensive AIDS Program of Palm Beach County (CAP)
3. Families First of Palm Beach County
4. Florida Agency for Health Care Administration (AHCA)
5. Health Care District of Palm Beach County
6. Legal Aid Society of Palm Beach County
7. Minority Development & Empowerment
8. Palm Beach County Health Department (Children's Medical Services)
9. Palm Beach County Health Department (HIV/AIDS Program)
10. Palm Beach County Health Department (Perinatal Linkage)
11. The Oakwood Center of the Palm Beaches
12. Treasure Coast Health Council
13. Triple O Medical Services
14. United Deliverance Community Resource Center

PLWHA Focus Groups

Focus groups were conducted with all populations of special concern (except for Women who Used Drugs Illegally During the Previous 12 months):

- Men who Have Sex With Men (MSM)

- Haitian Men and Women
- African American Women
- African American Men Recently Released from Incarceration
- Latin/Hispanic Men and Women

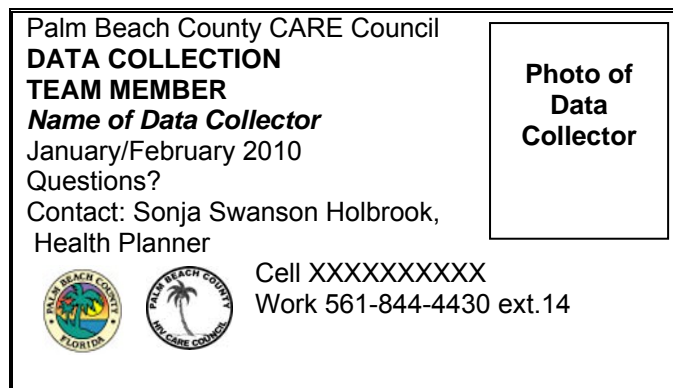
Focus group participants were recruited by focus group facilitators who were representative of or persons who work closely with the population of special concern. At the beginning of each focus group, the HRSA definition of being “in primary medical care” was reviewed, as were the HIV services that would 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 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.



IV. KEY FINDINGS

A. PLWHA AND PROVIDER SURVEY FINDINGS

1. CHARACTERISTICS OF PLWHA SURVEY RESPONDENTS

Throughout the surveying process, sampling was monitored and adjusted 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 Bureau of HIV/AIDS.

As shown in the following table, of the 365 survey respondents, 57.5% (210) were male compared to 61.1% (4,570) of the PLWHA in the area. Females were intentionally over-represented (42.5% [155] of survey respondents were female while only 38.9% [2,905] of the PLWHA in the area are female) to adjust for the increase in infection rates among the female population in Palm Beach County.

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

Gender	HIV/AIDS Case Prevalence Through 2008*		Survey Respondents	
	number	percent	number	percent

Male	4,570	61.1%	210	57.5%
Female	2,905	38.9%	155	42.5%
Total	7,475	100.0%	365	100.0%
*Source: Florida Department of Health, Bureau of HIV/AIDS, HIV/AIDS Reporting System				

Overall, Black not Hispanic survey respondents were somewhat over-represented at 70.1% (256) compared to Black not Hispanic PLWHA in the county (62.8%, 4,691). In contrast Hispanics were somewhat under-represented as 7.4% (27) of the survey respondents were Hispanic while 11.6% (866) of PLWHA in Palm Beach County are Hispanic. Likewise, White not Hispanic respondents were somewhat underrepresented at 18.9% (69) of the respondents compared to 24.4% (1,824) of PLWHA in Palm Beach County.

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

Race/Ethnicity	HIV/AIDS Case Prevalence Through 2008*		Survey Respondents	
	number	percent	number	percent
Black Not Hispanic	4,691	62.8%	256	70.1%
White Not Hispanic	1,824	24.4%	69	18.9%
Hispanic	866	11.6%	27	7.4%
Other/Unknown	94	1.3%	13	3.6%
Total	7,475	100.0%	365	100.0%
*Source: Florida Department of Health, Bureau of HIV/AIDS, HIV/AIDS Reporting System				

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 30-39, 40-44, and over 60 were somewhat underrepresented and ages 25-29, 45-49, and 50-59 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 2008*	Survey Respondents
-----	--	--------------------

	number	percent	number	percent
Below 24	342	4.6%	17	4.7%
25-29	379	5.1%	25	6.8%
30-39	1,517	20.3%	52	14.2%
40-44	1,225	16.4%	43	11.8%
45-49	1,423	19.0%	77	21.1%
50-59	1,777	23.8%	119	32.6%
60+	812	10.9%	31	8.5%
Unknown	n/a	n/a	1	0.3%
Total	7,475	100.0%	365	100.0%

*Source: Florida Department of Health, Bureau of HIV/AIDS, HIV/AIDS Reporting System

The survey sample was also similar to several special populations tracked by the Florida Department of Health, Bureau of HIV/AIDS, HIV/AIDS Reporting System. These special populations include heterosexuals, men who have sex with men (MSM), injection drug users (IDU), Haitian born persons, and women of child bearing age (WCBA).

The risk category “Heterosexual/Other” was somewhat overrepresented with 69.3% (253) of survey respondents compared to 59.7% (4,461) of the HIV/AIDS case prevalence. MSM were underrepresented with 24.7% (90) of the survey sample compared to 29.0% (2,166) of PLWHA in the county. IDUs were also underrepresented with 6.0% (22) of the respondents compared to 8.3% (618) of PLWHA in the county. Haitian Born persons were slightly overrepresented with 20.5% (75) of respondents compared with 18.0% (1,348) of PLWHA case prevalence in Palm Beach County. Women of childbearing age (15-44 years old) were also overrepresented with 31.8% (116) compared with 21.0% (1,570) PLWHA in Palm Beach County.

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

Special Population	HIV/AIDS Case Prevalence Through 2008* (N=7,475)		Survey Respondents (N=365)	
	number	percent	number	percent
Heterosexual/Other	4,461	59.7%	253	69.3%
MSM	2,166	29.0%	90	24.7%
IDU	618	8.3%	22	6.0%
Haitian Born	1,348	18.0%	75	20.5%
WCBA ¹	1,570	21.0%	116	31.8%

¹Women of Childbearing Age (15-44) White, Black, and Hispanic

*Source: Florida Department of Health, Bureau of HIV/AIDS, HIV/AIDS Reporting System

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 PLWH/A in the eastern and western areas of the county.

**Comparison of HIV/AIDS Case Prevalence in Palm Beach County with
Survey Respondents by Geographic Area**

Geographic Location	HIV/AIDS Cases Alive through 2008 EXCL DOC (N=7,475)		Survey Respondents (N=365)	
	number	percent	number	percent
East County	6,400	85.6%	273	74.8%
West County	999	13.4%	56	15.3%
Homeless	26	0.3%	21	5.8%
29 East County ZIP codes with <3 cases, and 4 West County ZIP codes with <3 cases	50	0.7%	6	1.6%
No response	n/a	n/a	9	2.5%
Total	7,475	100.0%	365	100.0%

Note: DOH case data excludes ZIP Codes with fewer than 3 cases.

Source: Florida Department of Health, Bureau of HIV/AIDS, HIV/AIDS Reporting System

Respondents were asked where they were living when they first tested positive for HIV. Of all respondents, 322 (88.2%) indicated they first tested positive in Florida (307, 84.1% in Palm Beach County and 15, 4.1% in another county in Florida). Respondents who said they were living in another state accounted for 9% (33) and 2 (.5%) 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 19A. Where were you living when you first tested positive for HIV? (check one only)			
Residence at Time of Diagnosis	Survey Respondents		
	number	percent of all respondents	percent of those who responded to this question
		(N=365)	(n=357)
In Palm Beach County	307	84.1%	86.0%
In another county in Florida	15	4.1%	4.2%
In another state	33	9.0%	9.2%
Outside of the United States	2	0.5%	0.6%
No response	8	2.2%	n/a
Total	365	100.0%	100.0%

As summarized in the following table, most of the PLWH/A in the EMA are in care as are the survey respondents (69.6% of PLWHA in EMA and 81.1% of survey respondents).

**Comparison of In Care and Out of Care Survey Respondents with
PLWH/A in Palm Beach County EMA**

PLWH/A	Palm Beach EMA		Survey Respondents	
	number	percent	number	percent
In care	5,276	69.6%	296	81.1%
Out of Care	2309	30.4%	69	18.9%
Total	7,585	100.0%	365	100.0%

Socioeconomic Characteristics of Survey Respondents

As summarized in the following tables, 40.5% (148) of respondents indicated a category that was less than a high school graduation level of education as follows:

- Less than high school graduation 101, 27.7%
- Eighth grade or less 32, 8.8%
- No formal schooling 15, 4.1%

High school or GED was the highest level of education reported by 31.8% (116) respondents.

Level of Education Completed

Survey Question 11A. What is the highest level of education that you have completed? (check only one)		
Level of Education	All Respondents (N=365)	
	number	percent
Less than high school graduation	101	27.7%
High school graduation	92	25.2%
Some college	60	16.4%
Eighth grade or less	32	8.8%
College graduate	27	7.4%
GED (high school equivalency)	24	6.6%
No formal schooling	15	4.1%
Technical/trade school	12	3.3%

No response	2	0.5%
Total	365	100.0%

When asked to indicate their work situation in the past year, 13.7% (50) indicated they were working a full-time job and 9.3% (34) said they were working a part-time job. “Not Working”, the most frequently reported situation, was reported by 64.7% (235) of all respondents.

Employment Situation in the Past Year

Survey Question 12A. What best describes your work situation in the past year? (check one only)		
Employment Status	All Respondents (N=365)	
	number	percent
Working full-time job	50	13.7%
Working part-time job	34	9.3%
Self employed	7	1.9%
Working off and on	32	8.8%
Not working	236	64.7%
Skipped Question	6	1.6%
Total	365	100.0%

Of the 292 respondents who cited a reason for not working, more than half (56.8%, 166) cited health reasons (45.5%, 133 on disability and 11.3%, 33 NOT on disability). More than a third (36.6%, 107) said they had been looking for a job.

Survey Question 13A. Why were you not working during the <i>past year?</i> (check one only)		
Reason for Not Working	Respondents (n=292)	
	number	percent
Student	1	0.3%
Looking for a job	107	36.6%
Attending job training	3	1.0%
For health reasons, on disability	133	45.5%
Retired	2	0.7%
For health reasons, NOT on disability	33	11.3%
Other, e.g., just got out of prison or jail not capable of finding a job Homeless laid off working off the books/ part time/ or sometimes	13	4.5%

Respondents were asked to identify what type of housing they live in now and where they lived six months ago. As shown in the table below, about half of all respondents reside(d) either in a an apartment/house that they rent(ed) or own(ed). A total of 190 (52.1%) currently reside in an apartment or house that they own or rent; six months ago, 179, 49.0% did so.

The next most frequently mentioned housing situation was, “At my parent’s /relative’s/ someone else’s apartment/ house (22.2% now, 21.4% six months ago).

The number of people who were homeless increased from 11 six months ago to 19, while the number of people who were residing in a homeless shelter decreased from 8 to 2.

As shown in the table below, most respondents currently reside in an apartment or house that they rent or own, with family or friends, in a room or boarding house, or are homeless.

Housing Situation				
Survey Question 83A. Place a ✓ in both of the columns that tell us where you live now and where you lived 6 months ago, even if it is the same.				
Housing Type	Now		6 months ago	
	(N=365)			
	number	percent	Number	percent
In an apartment/house that I own	35	9.6%	34	9.3%
In an apartment/house that I rent	155	42.5%	145	39.7%
At my parent’s /relative’s/ someone else’s apartment/ house	81	22.2%	78	21.4%
In a room or boarding house	47	12.9%	35	9.6%
In a “supportive living” facility (Assisted Living Facility)	3	0.8%	1	0.3%

In a half-way house, transitional housing, or treatment facility (drug or mental health)	2	0.5%	3	0.8%
Nursing home	1	0.3%	1	0.3%
Homeless (on street/in car/abandoned building)	19	5.2%	11	3.0%
Homeless shelter	2	0.5%	8	2.2%
Domestic violence shelter	0	0.0%	1	0.3%
Other housing provided by the city, county, or state (such as Section 8 voucher or Shelter+care)	16	4.4%	13	3.6%
In jail/prison	0	0.0%	28	7.7%
No response	4	1.1%	7	1.9%
Total	365	100.0%	365	100.0%

Of the 28 people who were in jail or prison six months ago, 21.5% (6) are now homeless. Nearly a third (9) 32.1% are living in an apartment or house they either rent or own. An equal number are living in a room or boarding house. An additional 14.3% (4) are living with a relative or someone else.

In Jail or Prison Six Months Ago. Now...		
Where I live now	(n=28)	
	number	percent
In an apartment/house that I own	1	3.6%
In an apartment/house that I rent	8	28.6%
At my parent's /relative's/ someone else's apartment/ house	4	14.3%
In a room or boarding house	9	32.1%
Homeless (on street/in car/abandoned building)	6	21.4%
Total	28	100.0%

The following matrix summarizes the housing situations of those who were homeless, in a homeless shelter, or incarcerated six months ago. Of 47 respondents who were in one of these situations six months ago, the most frequently cited current situations are “Homeless” (15, 31.9%), “In a room or boarding house” (23.4%), or with a family member or other person (10, 21.3%).

Comparison of Selected Survey Respondents' (n=47) Housing Situation Now Compared with Six Months Ago

Housing Situation	Now
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		In an apartment/ house that I own	In an apartment/ house that I rent	At my parent's/ relative's/ someone else's apartment/ house	In a room or boarding house	Homeless (on street/ in car/ abandoned building)	Homeless shelter	In jail/ prison	Total
Six Months Ago	Homeless (on street/ in car/ abandoned building)	n/a	n/a	4	n/a	7	n/a	n/a	11
	Homeless shelter	n/a	n/a	2	2	2	2	n/a	8
	In jail/ prison	1	8	4	9	6	n/a	n/a	28
	Total	1	8	10	11	15	2	n/a	47

Respondents were asked the following two questions in order to determine their federal poverty level, (Question 14A) “In 2008, how many family members (including yourself) lived in your household?” and (Question 15A) “In 2008, what was your annual family household income before taxes?”

Nearly three-fourths (70.7%, 258) of the respondents indicated they are living at or below 100% of the federal poverty level. Another 14.5% (53) were living at a rate between 101% and 150% poverty. See the table below for a summary of all responses.

Respondents by Federal Poverty Level

Federal Poverty Level	All Respondents (N=365)		Percent of those who answered this question (n=349)
	number	percent	
Below 100%	258	70.7%	73.9%
101% - 150%	53	14.5%	15.2%
151% - 200%	16	4.4%	4.6%
201% - 250%	11	3.0%	3.2%
251% - 300%	3	0.8%	0.9%
Over 300%	8	2.2%	2.3%
No response	16	4.4%	n/a
Total	365	100.0%	100.0%

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:

- Lab work for CD4 count
- Lab work for viral load count
- Prescription for Anti-Retroviral Therapy (ART).”

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:

- Lab work for CD4 count
- Lab work for viral load count
- Prescription for Anti-Retroviral Therapy (ART).”

As summarized in the following table, 69% (5276) of the PLWHA in the county are in care compared to 81.1% (296) of the survey respondents.

Comparison of In Care and Out of Care Survey Respondents with PLWH/A in Palm Beach County EMA

PLWH/A	Palm Beach EMA		Survey Respondents	
	number	percent	number	percent
In care	5,276	69.6%	296	81.1%
Out of Care	2309	30.4%	69	18.9%
Total	7,585	100.0%	365	100.0%

Source: Unmet need worksheet from Lorene Maddox DOH

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 365 respondents, 81.1% (296) were identified as being in primary medical care and 69 (18.9%).

In or Out of Care		
Survey Question 11B. Did you get HIV/AIDS related medical care OR a t-cell count OR a viral load test during the <u>past year</u>?		
In or Out of Care	Respondents (N=365)	
	number	percent
In Care	296	81.1%
Out of Care	69	18.9%
Total	365	100.0%

When asked to specify the type of primary medical care services they had received within the past 12 months, 96.6% (286) checked “Lab work of CD4 count”, 94.3% (279) checked “Lab work for viral load count”, and 80.7% (239) checked “Prescription for Anti-Retroviral Therapy (ART).

Survey Questions 21A, 22A, 23A. Have you received one of the following HIV-related primary medical care services within the past 12 months?		
Primary Medical Care Service	In Care Respondents (n=296)	
	number	percent
Lab work for CD4 count	286	96.6%
Lab work for viral load count	279	94.3%
Prescription for Anti-Retroviral Therapy (ART)	239	80.7%

As summarized in the table below, 79.7% (236) in-care respondents had received three of the services described in the table below, 14.2% (42) had received two, and 4.1% (12) had received only one type.

How Many Types of Primary Medical Care Services Received?		
How Many Types of Services Received	In Care Respondents (n=296)	
	number	percent

One	12	4.1%
Two	42	14.2%
Three	236	79.7%
No response	6	2.0%
Total	296	100.0%

Of the 296 respondents who are in care, 53% (157) stated that their case manager *always* encourages and helps them get regular medical care. An additional 16.2% (48 of 296) said that their case manager *sometimes* encourages and helps them get regular medical care. The table below summarizes all responses from the 296 respondents who are in care.

When asked whether or not a provider contacted them if they missed a medical appointment, 133 (44.9% of all in care respondents) said they never missed an appointment. As summarized in the table to the right, 50.9% (115) stated that someone always (16.9%, 50) or sometimes (22%, 50) contacts them to reschedule

How Often Case Manager Encourages Regular Medical Care

Survey Question 37A. How often does your case manager encourage and help you get regular medical care (CD4 test, or viral load test, or Antiretroviral Therapy) (check one only)?		
How often?	In Care Respondents (n=296)	
	number	percent
Always	157	53.0%
Sometimes	48	16.2%
Never	18	6.1%
I don't have a case manager	65	22.0%
No Response	8	2.7%
Total	296	100.0%

and/or follow up with them. Those who said they are never contacted accounted for 12.5% (37) of all in-care respondents.

Further analysis shows that of those 152 in-care respondents who indicated they have missed an appointment, a total of three-fourths (75.5% 115) said that someone contacts them always (32.9%, 50) or sometimes (42.8%, 65). Nearly a fourth (24.3%, 37) said they are never contacted.

Contact after Missed Medical Appointment

Survey Question 38A. When you have missed a medical appointment, has someone (case manager, clinic staff person, mental health counselor, treatment adherence counselor, etc.) contacted you and tried to reschedule and/or find out why you did not come and if they could help you get to the next appointment? (check only one)				
How often?	In-Care Respondents (n=296)		In-Care Respondents Who Have Missed an Appointment (n=152)	
	number	percent	number	percent
I have never missed a medical appointment	133	44.9%	n/a	n/a
Always	50	16.9%	50	32.9%
Sometimes	65	22.0%	65	42.8%
Never	37	12.5%	37	24.3%
No response	11	3.7%	0	0.0%
Total	296	100.0%	152	100.0%

When asked to specify the clinic/organization/facility that contacted them after a missed medical appointment, 29.9% (29) mentioned a case management provider and 60.8% (57) mentioned a clinical provider. A summary of the 97 responses of those who missed a medical appointment and answered this question are summarized in the following table.

Survey Question 39A. If someone has contacted you, please specify the clinic/organization/facility where they work.		
Contacted by whom?	In Care Respondents Who Missed a Medical Appointment (n=97)	
	number	percent
Case Management Organization	21	21.6%
Case Manager at Clinic	8	8.2%
Clinic Clerk/ Nurse/ Other Staff	37	38.1%
Doctor/Dentist Office	12	12.4%
Health Department	10	10.3%
Veteran's Administration	3	3.1%
Other	6	6.2%

Total	97	100.0%
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When asked about taking their medications as prescribed, 258 of all in-care respondents responded. Of all 296 in-care respondents, 203 (68.6%) said they always take their HIV medications as prescribed; another 43 (14.5%) said they take them most of the time.

Further analysis showed that of those who have been prescribed medication, 78.7% said they always take their medications as prescribed and another 16.7% said they take their medications as prescribed most of the time. A total of nearly 6% said they take their meds as prescribed only some of the time (3.5%) or never (1.2%).

Survey Question 46A. How often do you take your medications to treat your HIV/AIDS just as the doctor said you should? (check one only)				
How Often?	In Care Respondents (n=296)		In Care Respondents Who Have Been Prescribed HIV Medications (n=258)	
	number	percent	number	percent
This does not apply to me. I have not been prescribed HIV medications.	33	11.1%	n/a	n/a
Always	203	68.6%	203	78.7%
Most of the time	43	14.5%	43	16.7%
Some of the time	9	3.0%	9	3.5%
Never	3	1.0%	3	1.2%
I do not know what the directions are.	0	0.0%	0	0.0%
No response	5	1.7%	0	0%
Total	296	100.0%	258	100.0%

Of the 273 in-care respondents who answered this question, 225 (82.8%) said this question does not apply to them because they have not been prescribed medications or they always take their medications on time. Among the 23.1% (63) who cited reasons for missing medications to treat HIV/AIDS, the most frequently mentioned reasons cited were as follows:

- I do not like taking medications (49.2%, 31).
- They make me feel really bad (44.4%, 28).
- I cannot afford the cost (12.7%, 8).
- I have trouble understanding how to take my medications (7.9%, 5).
- Other, e.g. forgetfulness, stress, I don't want people to know (28.6%, 18)

Reasons for Not Taking HIV/AIDS Medications as Prescribed

Survey Question 47A. Why do you sometimes miss taking medications to treat your HIV/AIDS? (check any or all that apply)

Reasons for Not Taking HIV/AIDS Medications as Prescribed	In Care Respondents Who Answered this Question (n=273)		Percent of In-care Respondents who cited reasons why they don't take Meds as prescribed (n=63)
	number	percent	
This does not apply to me. I have not been prescribed HIV medications or I always take my HIV medications as prescribed.	226	82.8%	n/a
I do not know where to get them.	0	0.0%	0.0%
I cannot afford the cost.	8	2.9%	12.7%
They make me feel really bad.	28	10.3%	44.4%
I am on a 'Drug Holiday' directed by my doctor.	0	0.0%	0.0%
I am on a 'Drug Holiday' directed by myself.	1	0.4%	1.6%
I do not like taking medications.	31	11.4%	49.2%
These medications are not a priority for me.	2	0.7%	3.2%
I have trouble understanding how to take my medications.	5	1.8%	7.9%
My doctor wanted to treat another medical problem first.	2	0.7%	3.2%
Religious/Cultural beliefs.	0	0.0%	0.0%
I have an abusive spouse or partner.	1	0.4%	1.6%
Other (e.g. I don't want people to know; I forget.)	18	6.6%	28.6%

Note: Columns total more than 100% because, as summarized in the following table, 28 respondents mentioned more than one reason for not taking medications as prescribed.

Of the 63 in-care respondents who cited one or more reasons for not taking HIV/AIDS medications as prescribed, 34 (54.0%) cited one reason, 24 (38.1%) cited two reasons and 5 (7.9%) cited three reasons.

Number of Reasons for Not Taking HIV/AIDS Medications as Prescribed

Number of Reasons	In-Care Respondents Who Cited One or More Reasons (n=63)	
	number	percent
one reason	34	54.0%
two reasons	24	38.1%
three reasons	5	7.9%
Total	63	100.0%

Female respondents in care (n=132) were asked if they had received a pelvic exam (pap smear) in the last 12 months. Annual pelvic exams ensure early detection and treatment of sexually transmitted human papilloma virus (HPV), associated with increased risk of cervical cancer. As summarized in the table to the right, fewer than three-fourths (73.5%, 97) said yes. Nearly a fourth said no (20.5%, 27) or did not respond to this question at all (6.1%, 8).

**Pelvic Exams for
In-Care Female Respondents**

Survey Question 98A. Have you received a pelvic exam (pap smear) in the last 12 months (check only one)?		
Pelvic exam in the last 12 months?	In-Care Female Respondents n= (132)	
	number	percent
Yes	97	73.5%
No	27	20.5%
No Response	8	6.1%
Total	132	100.0%

**Pregnancy Among
Female Respondents In Care**

Survey Question 98A. Have you been pregnant in the last 12 months (check only one)?		
Pregnant in the last 12 months?	In-Care Female Respondents (n=132)	
	number	percent
Yes	5	3.8%
No	94	71.2%
No Response	33	25.0%
Total	132	100.0%

Of all female respondents in care who were asked if they had been pregnant in the last 12 months, 3.84% (5) said, “Yes”. The table to the left summarizes all responses to this question.

Access to Health Care and Information

In-care respondents were asked to indicate if they were enrolled in specific programs. Of the 287 respondents who answered this question, 23.4% (67 of 287) receive Ryan White funded services. The following table summarizes the number and percentages of respondents enrolled in other programs.

Enrollment in Government Programs

Survey Question 93A. Are you enrolled in any of these programs? (check any or all that apply)?

Government Program Enrollment	In-Care Respondents (n=296)		In-Care Respondents Who Answered this Question (n=287)
	number	percent	percent
Food Stamps	143	48.3%	49.8%
Medicaid	110	37.2%	38.3%
Social Security Disability	100	33.8%	34.8%
Healthcare District	94	31.8%	32.8%
ADAP	65	22.0%	22.6%
Medicare	62	20.9%	21.6%
Ryan White A (CSN form)	53	17.9%	18.5%
Ryan White B (notice of eligibility)	14	4.7%	4.9%
Housing Opportunities for Person with AIDS	12	4.1%	4.2%
Medically Needy	9	3.0%	3.1%
Veteran's Administration	7	2.4%	2.4%
Insurance Continuation	3	1.0%	1.0%
TANF	1	0.3%	0.3%
WIC	1	0.3%	0.3%
Compassionate Use (Medications)	0	0.0%	0.0%
Other (SSI)	31	10.5%	10.8%
No response	9	3.0%	0%

Respondents were asked if they have private health insurance. As shown in the following table, only 18.2% (54) said they had health insurance.

Survey Question 45A. Do you have private health insurance?		
Enrolled in Private Insurance	In-Care Respondent (n=296)	
	number	percent
Yes	54	18.2%
No	235	79.4%

No Response	7	2.4%
Total	296	100.0%

Out-of-pocket health care expenditures for more than half (52.45%, 155) of all in care respondents and more than two-thirds (68.9%, 155) of in care respondents who answered this question was less than \$100.00.

Out of Pocket Healthcare Cost for In Care Respondents

Survey Question 94A. What is the estimated amount that you have spent out of pocket (i.e. health insurance, deductibles, co-payments, premiums, etc.) on your personal healthcare needs over the past 12 months? (check only one)				
Estimated Out-of-Pocket Expenditures	In Care Respondents (n=296)		In Care Respondents Who Answered this Question (n=225)	
	number	percent	number	percent
Under \$100	155	52.4%	155	68.9%
\$101 - \$500	48	16.2%	48	21.3%
\$501 - \$1000	14	4.7%	14	6.2%
\$1001 - \$2500	8	2.7%	8	3.6%
More than \$2500	0	0.0%	0	0.0%
No response	71	24.0%	n/a	n/a
Total	296	100.0%	225	100.0%

Most of the respondents who are in care indicated that they receive *most* of their medical care at either the health department (57.1%, 144 out of 252) or a private doctor's office (29.4%, 74 out of 252).

Medical Care Provider

Survey Question 40A. Where did you regularly receive your HIV/AIDS medical care during the past year? (check one only)		
Medical Care Provider	In Care Respondents (n=296)	In Care Respondents Who Answered this Question (n=269)

	number	percent	number	percent
Walk-In Emergency Clinic	0	0.0%	0	0.0%
Doctor's Office	67	22.6%	67	24.9%
Hospital Emergency Room	1	0.3%	1	0.4%
Veteran's Administration	8	2.7%	8	3.0%
Public Clinic/Health Department	184	62.2%	184	68.4%
HIV Specialty Clinic	9	3.0%	9	3.3%
no response	27	9.1%	n/a	n/a
Total	296	100.0%	269	100.0%

When in-care respondents were asked, “In which county did you get your HIV/AIDS-related medical care this year?” nearly all (262, 98.9% of the 265 who responded) mentioned Palm Beach County, 3 mentioned Broward, and one said both “Palm Beach and Indian River”.

As shown in the following table, 31 (10.5%) of all in-care respondents reported being hospitalized and 49 (16.6%) received emergency room services for an HIV/AIDS related condition during the past year.

Survey Questions 43A., 44A. Have you been hospitalized or to the Emergency Room in the last 12 months for an HIV/AIDS related condition?		
Hospital and Emergency Room Utilization in the last 12 months?	In Care Respondents (n=296)	
	number	percent
Hospitalized	31	10.5%
To the Emergency Room	49	16.6%

The most frequently mentioned sources of HIV/AIDS information among in-care respondents were their clinic/doctor’s office (161, 54.5%), the Health Department (159, 53.7%), and case manager (110, 37.2%). The following table summarizes all responses.

HIV/AIDS Service Information

Survey Question 76A. Where do you get most of your information about HIV/AIDS services in your area? (check all that apply)?		
Source of HIV/AIDS Information	In Care Respondents (n=296)	In Care Respondents Who Answered this Question (n=266)

	number	percent	number	percent
Clinic/doctor's office	161	54.4%	161	60.5%
Health Department	159	53.7%	159	59.8%
Case manager	110	37.2%	110	41.4%
Community health fair	28	9.5%	28	10.5%
Community based organizations	28	9.5%	28	10.5%
AIDS organization/advocacy group	75	25.3%	75	28.2%
Place of worship	10	3.4%	10	3.8%
Friends/family	40	13.5%	40	15.0%
Internet/Newspaper/Radio/TV	35	11.8%	35	13.2%
Other: VA, street, hospital, support groups, outreach, own research, Pal Program	13	4.4%	13	4.9%

All 296 respondents who are in care were asked to identify problems they have had trying to get needed services. The 148 (50%) who responded that they had problems trying to access needed services most frequently mentioned the following:

- Didn't know how to apply (44.6%, 66)
- Didn't know where to apply (30.4%, 45)
- Transportation problems (24.3%, 36)
- Turned down/not eligible (18.2%, 27)
- I don't want people to know I have HIV (17.6%, 26)
- Cost of service is too high (16.9%, 25)
- Application process is too complicated (16.9%, 25)
- On waiting list (15.5%, 23)

The following table summarizes all responses to this question.

Problems While Trying to Get Needed Services

Survey Question 95A. 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=296)		In Care Respondents who Indicated One or More Problems (n=148)	
	number	percent	number	percent
Did not have any problems trying to get needed services	114	38.5%	n/a	n/a
Didn't know how to apply	66	22.3%	66	44.6%
Didn't know where to apply	45	15.2%	45	30.4%

Transportation problems	36	12.2%	36	24.3%
Turned down/not eligible	27	9.1%	27	18.2%
I don't want people to know I have HIV	26	8.8%	26	17.6%
Cost of service is too high	25	8.4%	25	16.9%
Application process too complicated	25	8.4%	25	16.9%
On waiting list	23	7.8%	23	15.5%
Had to wait too long for service	16	5.4%	16	10.8%
Trouble communicating	15	5.1%	15	10.1%
Drug or alcohol addiction	15	5.1%	15	10.1%
Service sites located too far away	13	4.4%	13	8.8%
Needed evening appointment	7	2.4%	7	4.7%
Needed weekend appointment	6	2.0%	6	4.1%
Other health problems	4	1.4%	4	2.7%
Too busy taking care of partner	1	0.3%	1	0.7%
Too busy taking care of child	0	0.0%	0	0.0%
Other (please specify)	14	4.7%	14	9.5%
Not available funds Criminal record Social Security Disability is pending Housing HOPWA Not sure, don't speak English well Not sure why Bad case manager Cannot find all paperwork to get driver license Not sure why I were told but did not find the place because did ask no one to take me Did not need no help at time No income Never ask for help I taught I won't get any Services!				

More than half (54.1%, 80) 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.

**Number of Problems
While Trying to Get Needed Services**

Number of Problems	In Care Respondents who Answered this Question (n=148)	
	number	percent
One	68	45.9%

Two to Four	62	41.9%
More than Four	18	12.2%
Total	148	100.0%

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

Out of Care within the Past 5 Years

Survey Question 29A. During the past five years has there been a period of at least 12 months when you were *not* receiving HIV-related primary medical care (no lab work for CD4 or no viral load count or no Antiretroviral Therapy)?

The 296 respondents who are currently in care were asked if there had been a period during the last 5 years during which they had been out of care for more than twelve months. Of the 296 respondents in care, 16.6% (49) responded in the affirmative. The table to the right summarizes all responses to this question.

Out of Care within the Past 5 Years?	In Care Respondents (n=296)	
	number	percent
Yes	49	16.6%
No	244	82.4%
No Response	3	1.0%
Total	296	100.0%

The 49 respondents who had been out of care were asked to describe their circumstances during that time. The most frequently reported situation was “I had been receiving medical care for HIV, but I decided to stop” (63.3%, 31) followed by “drug use/addiction” (10.2%, 5). The table below summarizes all responses to this question.

Out of Care Circumstances

Survey Question 31A. What best describes your situation during that period? (check one only)		
Out of Care Situation	In Care Respondents Who Were Out of Care (n=49)	
	number	percent
I had recently been diagnosed with HIV, and had not entered primary care.	4	8.2%
I had been receiving medical care for HIV, but I decided to stop.	31	63.3%
Other		
depression	2	4.1%
drug use/addiction	5	10.2%
didn't care/did not seek care	2	4.1%
Got upset with the system and decided to stop	1	2.0%
before I went back to jail	1	2.0%
No Response	3	6.1%
Total	49	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 seven most frequently mentioned reasons are as follows:

- I did not have medical insurance and could not afford care (36.7%, 18).
- I was using alcohol or drugs (30.6%, 15).
- I was afraid of being identified as HIV-positive (26.5%, 13).
- I knew where to go but I did not want to go there (24.5%, 12)
- I had heard bad things about the medications and their side effects (22.4%, 11)
- I did not have transportation (18.4%, 9)

- I was homeless (18.4%, 9)

Out of Care Reasons

Survey Question 33A. Why were you not receiving primary medical care during that period? (check any or all that apply)		
Reasons for Not Receiving Primary Medical Care	In Care Respondents Who Had Been Out of Care and Returned to Care (n=49)	
	number	percent
I did not have medical insurance and could not afford care.	18	36.7%
I did not know where to go.	4	8.2%
I had heard bad things about the medications and their side effects.	11	22.4%
I knew where to go but I did not want to go there.	12	24.5%
I was not ready to deal with my HIV status.	6	12.2%
I was afraid of being identified as HIV-positive.	13	26.5%
I did not have transportation.	9	18.4%
I was homeless.	9	18.4%
I was using drugs or alcohol.	15	30.6%
I had mental health problems.	2	4.1%
I could not get an appointment.	0	0.0%
The wait was too long at the clinic/office/hospital.	2	4.1%
I did not think it would help.	8	16.3%
I was scared of immigration or other legal issues.	4	8.2%
Other (please specify)	8	16.3%
Upset with system.		
Then I started back 3 years ago.		
I just stop.		
I just found out and I don't need med.		
Lost husband, did not want to deal with it.		
Came to Palm Beach County, I did not know my way around.		
The doctor did not decide yet.		
Job said I could keep taking off.		

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=49)

The table to the right summarizes the number of reasons respondents identified for having been out of primary medical care. Nearly a third (32.7%, 16) cited only one reason, while more than two-thirds (61.2%) 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	percent
1	16	32.7%
2 to 4	23	46.9%
5 to 8	5	10.2%
no response	5	10.2%
Total	49	100.0%

The forty-nine in care respondents who had been out of care for more than 12 months within the past five years were asked what services, other than medical care and medications, did they need but not get while they were out of care. The three most frequently identified services were food (63.3%, 31), financial assistance (51%, 25), housing (42.9%, 21), transportation (36.7%, 18), case management (34.7%, 17), substance abuse treatment (22.4%, 11), legal services (22.4%, 11), and labs (22.4%, 11). The table to the right displays all responses to this question.

The table below displays the number of services that the respondents identified. More than three-fourths (75.5%, 37) 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=49)	
	number	percent
1	5	10.2%
2 to 4	24	49.0%
More than 4	13	26.5%
None/No Response	7	14.3%
Total	49	100.0%

Services Needed When Out of Care

Services Needed When Out of Care	In Care Respondents Who Were Out of Care (n=49)	
	number	percent
Food	31	63.3%
Financial assistance	25	51.0%
Housing	21	42.9%
Transportation	18	36.7%
Case management	17	34.7%
Substance abuse treatment	11	22.4%
Legal services	11	22.4%
Labs	11	22.4%
Dental care	10	20.4%
Treatment Adherence	7	14.3%
Other (please specify)	6	12.2%
Mental health services	7	14.3%
None/No response	7	14.3%

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

- I got sick and knew I needed care (59.2%, 29).
- I was ready to deal with my illness (32.7%, 16).

- I got a referral to get into care (20.4%, 10).
- An outreach worker found me and helped me get into care (20.4%, 10).

The following table summarizes all the responses to this question.

Reasons for Returning to Care

Survey Question 35A. What are the reasons that caused you to return to primary 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=49)	
	number	percent
I got sick and knew I needed care.	29	59.2%
I was ready to deal with my illness.	16	32.7%
I got a referral to get into care.	10	20.4%
An outreach worker found me and helped me get into care.	10	20.4%
I was able to deal with other problems in my life that kept me out of care.	7	14.3%
A family member or friend helped me get into care.	4	8.2%
Someone else with HIV/AIDS reached out to me.	3	6.1%
I got transportation to go to a doctor or clinic.	3	6.1%
I found a doctor or clinic where I do not have to wait very long in the waiting room.	3	6.1%
I found a doctor or medical facility that I like and who accepts me.	1	2.0%
Someone arranged to have my care paid for.	1	2.0%
I found a doctor or medical facility that ensured my confidentiality.	0	0.0%
Other, for example:	8	16.3%
I have to take of me. I learned that.		
Pregnancy		
I need and want to live.		
Went back to jail		
Father's death		
Being in jail		
I called the Clinic for appointment.		
I was waiting for lab result.		

Nearly two-thirds (61.2%, 30) 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.

**Number of Reasons for
Returning to Care**

Number of Reasons	In Care Respondents Who Had Been Out of Care and Returned to Care (n=49)	
	number	percent
1	14	28.6%
2 to 4	28	57.1%
5 to 8	2	4.1%
No Response	5	10.2%
Total	49	100.0%

When respondents were asked if someone had been involved in their care or if an outreach worker helped get them back into care, 44.9% (22 of the 49) responded in the affirmative and cited the following source of assistance:

- Compass (7)
- Health Department Clinic/Case Manager or Outreach Worker (6)
- United Deliverance (3)
- Comprehensive AIDS Program (2)
- Case Manager (1)
- TOPWA (1)
- Myself (1)
- Farmworker (1)

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:

- viral load count
- CD4 lab work
- antiretroviral therapy within the last 12 months

As summarized in the following table, 30.4% of PLWHA in Palm Beach County are out of care compared 18.9% of survey respondents.

Comparison of In Care and Out of Care Survey Respondents with PLWH/A in Palm Beach County EMA

PLWH/A	Palm Beach EMA		Survey Respondents	
	number	percent	number	percent
In care	5,276	69.6%	296	81.1%
Out of care	2309	30.4%	69	18.9%
Total	7,585	100.0%	365	100.0%

The following table summarizes some of the demographic and risk exposure categories and geographic region of the 69 respondents who were not in care.

Characteristics of Respondents

Who are Out of Primary Medical Care (n=69)

Race/Ethnicity	number	percent
Black	52	75.40%
White	8	11.60%
Mixed/More than One Race	8	11.60%
Other	1	1.40%
Ethnicity	number	percent
Hispanic/Latino/a	9	13.00%
Not Hispanic/Latino/a	41	59.40%
Haitian	19	27.50%
Gender	number	percent
Male	46	66.70%
Female	23	33.30%
Transgender	0	0.00%
Age	number	percent
Under 18	0	0.00%
18-24	8	11.60%
25-29	8	11.60%
30-39	13	18.80%
40-44	9	13.00%
45-49	12	17.40%
50-59	14	20.30%
60-69	4	5.80%
70+	0	0.00%
No response	1	1.40%
Special Populations	number	percent
MSM	19	27.50%
IDU	5	7.20%
Haitian	19	27.50%
WCBA	6	8.70%
Heterosexual	45	65.20%
Geographic Region	number	percent
East County	52	75.40%
West County	12	17.40%
No response	2	2.90%

Respondents were asked what best describes their situation regarding being out of care. Of the 69 respondents who were out of care, (68.1%,47) reported that they had never been in care including 44.9% (31) who had recently been diagnosed with HIV and had not entered primary care and 23.2% (16) who had not been recently diagnosed but had

never been in care. More than a quarter (26.12%, 18) had been receiving care for HIV but had stopped more than 12 months ago.

Out of Care Situation

Question 24A. What best describes your situation? (check only one)		
Out of Care Situation	Out of Care Respondents (n=69)	
	number	percent
I have recently been diagnosed with HIV, and have not entered primary care.	31	44.9%
I have <u>not</u> been recently diagnosed but have never been in care.	16	23.2%
I had been receiving medical care for HIV, but I stopped more than 12 months ago.	18	26.1%
Other (specify)		
I found people I know will tell about me.	2	2.9%
Don't want to be bothered.		
Skipped Question	2	2.9%
Total	69	100.0%

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

- I did not feel sick. (47.8%, 33)
- I did not want people to know that I have HIV. (42.0%, 29)

- I could not pay for services. (36.2%, 25)
- I was depressed. (36.2%, 25)
- I was not ready to deal with having HIV. (31.9%, 22)
- I did not know where to go. (31.9%, 18)
- I could not get transportation. (18.8%, 13)

The following table summarizes all responses to this question.

Reasons for Not Getting Medical Care		
Survey Question 25A. Why did you not get HIV/AIDS related medical care during the <u>past year</u>? (check any or all that apply)		
Reasons for Not Getting Medical Care	Out of Care Respondents (n=69)	
	number	percent
I did not feel sick.	33	47.8%
I did not want people to know that I have HIV.	29	42.0%
I could not pay for services.	25	36.2%
I was depressed.	25	36.2%
I was not ready to deal with having HIV.	22	31.9%
I did not know where to go.	18	26.1%
I could not get transportation.	13	18.8%
I could not get time off work.	8	11.6%
I missed my appointment(s).	8	11.6%
I had a bad experience with the medical staff.	6	8.7%
I could not get an appointment.	4	5.8%
I was too busy taking care of my partner.	2	2.9%
I could not get childcare.	0	0.0%
There are not enough doctors in my area.	0	0.0%
Other (please specify)		
Did not go for help		
Drugs		
I taught life was over for me, no job!	6	8.7%
In process		
No insurance		
Recently diagnosed		
No Response	8	11.6%

As summarized in the following table, 82.6%, (57) identified more than one reason for being out of care.

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

Number of Reasons	Out of Care Respondents (n=69)	
	number	percent
1	10	14.5%
2	22	31.9%
3	9	13.0%
4	16	23.2%
5	4	5.8%
6	3	4.3%
7	1	1.4%
8	1	1.4%
9	1	1.4%
No Response	2	2.9%
Total	69	100.0%

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 25A/12B4. Why did you not get HIV/AIDS related medical care during the <u>past year</u> ? (check any or all that apply)				
Provider Survey Question 26. 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	Out of Care Respondents (n=69)		Provider Respondents (N=14)	
	number	percent	number	percent
I did not feel sick.	33	47.8%	8	57.1%
I did not want people to know that I have HIV.	29	42.0%	10	71.4%
I could not pay for services.	25	36.2%	5	35.7%
I was depressed.	25	36.2%	6	42.9%
I was not ready to deal with having HIV.	22	31.9%	10	71.4%
I did not know where to go.	18	26.1%	5	35.7%
I could not get transportation.	13	18.8%	7	50.0%
I could not get time off work.	8	11.6%	2	14.3%
I missed my appointment(s).	8	11.6%	6	42.9%
I had a bad experience with the medical staff.	6	8.7%	4	28.6%
I could not get an appointment.	4	5.8%	1	7.1%
I was too busy taking care of my partner.	2	2.9%	0	0.0%
I could not get childcare.	0	0.0%	7	50.0%
There are not enough doctors in my area.	0	0.0%	2	14.3%
Other (please specify)				
Did not go for help				
Drugs				
I taught life was over for me, no job!				
In process	7	10.1%	3	21.4%
No insurance				
Recently diagnosed				
Per Providers: substance abuse, socio-psychological barriers; unsure				
No Response	8	11.6%	1	7.1%

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 42% of out of care respondents cited “I did not want people to know that I have HIV”, 71.4% 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 (n=69)		Provider Respondents (N=14)	
	number	percent	number	percent
I did not want people to know that I have HIV.	29	42.0%	10	71.4%
I was not ready to deal with having HIV.	22	31.9%	10	71.4%
I did not know where to go.	18	26.1%	5	35.7%
I could not get transportation.	13	18.8%	7	50.0%
I missed my appointment(s).	8	11.6%	6	42.9%

When respondents who are not in primary medical care were asked what services, other than medical care and medication, they needed to get into primary medical care, the three

most frequently chosen responses were financial assistance, food and housing. The table below summarizes all responses to this question.

Services Needed to Get Into Primary Medical Care

Survey Question 27A. What services, other than medical care and medications, do you need to get into primary medical care? (check any or all that apply)		
Services Needed	Out of Care Respondents (n=69)	
	number	percent
Financial assistance	34	49.3%
Food	32	46.4%
Housing	31	44.9%
Case management	28	40.6%
Transportation	25	36.2%
Substance abuse treatment	15	21.7%
Mental health services	12	17.4%
Legal services	11	15.9%
Labs	11	15.9%
Dental care	6	8.7%
Treatment Adherence	5	7.2%
None	3	4.3%
Not sure	2	2.9%
Other (e.g. job, late appointments, might need mental health services later)	3	4.3%

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, 21.7% (15) said they needed only one service. Of all out of care respondents, 94.2% (65) said they needed at least one service to get into care and 72.5% (50) said they needed more than one.

**Number of Services Needed
to Get Into Medical Care**

Number of Services Needed	Out of Care Respondents (n=69)	
	number	percent
None	3	4.3%
1	15	21.7%
2	13	18.8%
3	14	20.3%
4	6	8.7%
5	6	8.7%
6	2	2.9%
7	3	4.3%
8	4	5.8%
9	2	2.9%
No Response	1	1.4%
Total	69	100.0%

Providers were asked the same question regarding services, other than medical care and medications 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, 64.3% of provider respondents indicated that PLWHA need mental health services to get into care, while only 17.4% of out of care respondents did. Likewise, 50.0% of providers indicated that PLWHA need substance abuse treatment, compared to only 21.7% 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 27A. What services, other than medical care and medications, do you need to get into primary medical care? (check any or all that apply)				
Provider Question 27. 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	Out of Care Respondents (n=69)		Provider Respondents (N=14)	
	number	percent	number	percent
Financial assistance	34	49.3%	6	42.9%
Food	32	46.4%	7	50.0%
Housing	31	44.9%	8	57.1%
Case management	28	40.6%	7	50.0%
Transportation	25	36.2%	7	50.0%
Substance abuse treatment	15	21.7%	7	50.0%
Mental health services	12	17.4%	9	64.3%
Legal services	11	15.9%	4	28.6%
Labs	11	15.9%	6	42.9%
Dental care	6	8.7%	4	28.6%
Other (e.g. job, late appointments, might need mental health services later)	3	4.3%	0	0.0%

Respondents who are out of care were asked what would be some reasons they would enter primary medical care. The most frequently cited reasons were:

- When I get sick and know I need care. 65.2% (45)
- When I am ready to deal with my illness. 29% (20)
- Someone else with HIV/AIDS reaches out to me. 26.1% (18)
- I get transportation to go to a doctor or clinic. 26.1% (18)
- Someone arranges to have my care paid for. 26.1% (18)

The following table summarizes all responses to this question.

Reasons to Enter Primary Medical Care

Survey Question 28A. What would be some reasons you enter primary medical care? (check any or all that apply)		
Reasons	Out of Care Respondents (n=69)	
	number	percent
I get sick and know I need care.	45	65.2%
I am ready to deal with my illness.	20	29.0%
Someone else with HIV/AIDS reaches out to me.	18	26.1%
I get transportation to go to a doctor or clinic.	18	26.1%
Someone arranges to have my care paid for.	18	26.1%
I find a doctor or medical facility that ensures my confidentiality.	16	23.2%
I find a doctor or clinic where I do not have to wait very long in the waiting room.	10	14.5%
I get a referral to get into care.	7	10.1%
I am able to deal with other problems in my life that keep me out of care.	7	10.1%
I find a doctor or medical facility that I like and who accepts me.	6	8.7%
An outreach worker finds me and helps me get into care.	6	8.7%
I find a medical facility that has evening or weekend hours.	6	8.7%
A family member or friend helps me get into care.	4	5.8%
Other (Explain)	1	1.4%
Insurance		
Skipped question	1	1.4%

Most respondents who are not in care (72.5%, 50) 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 to Get Into
Medical Care**

Number of Reasons Cited	Out of Care Respondents (n=69)	
	number	percent
1	18	26.1%
2	18	26.1%
3	14	20.3%
4	9	13.0%
5	5	7.2%
6	3	4.3%
7	1	1.4%
8	0	0.0%
9		0.0%
No Response	1	1.4%
Total	69	100.0%

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 28A. What would be some reasons you enter primary medical care? (check any or all that apply)				
Provider Survey 28. What would be some reasons people living with HIV/AIDS would enter primary medical care? (check all that apply)				
Reasons	Out of Care Respondents (n=69)		Provider Respondents (N=14)	
	number	percent	number	percent
I get sick and know I need care.	45	65.2%	12	85.7%
I am ready to deal with my illness.	20	29.0%	9	64.3%
Someone else with HIV/AIDS reaches out to me.	18	26.1%	6	42.9%
I get transportation to go to a doctor or clinic.	18	26.1%	9	64.3%
Someone arranges to have my care paid for.	18	26.1%	6	42.9%
I find a doctor or medical facility that ensures my confidentiality.	16	23.2%	8	57.1%
I find a doctor or clinic where I do not have to wait very long in the waiting room.	10	14.5%	7	50.0%
I get a referral to get into care.	7	10.1%	6	42.9%
I am able to deal with other problems in my life that keep me out of care.	7	10.1%	8	57.1%
I find a doctor or medical facility that I like and who accepts me.	6	8.7%	6	42.9%
An outreach worker finds me and helps me get into care.	6	8.7%	9	64.3%
I find a medical facility that has evening or weekend hours.	6	8.7%	4	28.6%
A family member or friend helps me get into care.	4	5.8%	6	42.9%
Other (Explain)				
Insurance; per providers, someone they know dies of AIDS.	1	1.4%	1	7.1%
Skipped question	1	1.4%	2	14.3%

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.

Comparison of Highest Level of Education Completed

Survey Question 11A. What is the highest level of education that you have completed? (check only one)						
Level of Education	All Respondents (N=365)		In Care Respondents (n=296)		Out of Care Respondents (n=69)	
	number	percent	number	percent	number	percent
Less than high school graduation	101	27.7%	82	27.7%	19	27.5%
High school graduation	92	25.2%	68	23.0%	24	34.8%
Some college	60	16.4%	56	18.9%	4	5.8%
Eighth grade or less	32	8.8%	25	8.4%	7	10.1%
College graduate	27	7.4%	25	8.4%	2	2.9%
GED (high school equivalency)	24	6.6%	20	6.8%	4	5.8%
No formal schooling	15	4.1%	9	3.0%	6	8.7%
Technical/trade school	12	3.3%	10	3.4%	2	2.9%
No response	2	0.5%	1	0.3%	1	1.4%
Total	365	100.0%	296	100.0%	69	100.0%

The overall pattern of employment of respondents who are in care is similar to those who are out of care; in both groups, nearly two-thirds of respondents said they are not working.

A higher percentage of respondents who are in care indicated that they were unemployed compared to those who are out of care (65.5% in care compared to 60.9% out of care). Among respondents in both groups, “working full-time” was the second most frequently mentioned status (13.2% in care compared to 15.9% out of care).

Comparison of Work Situation in the Past Year

Survey Question 12A. What best describes your work situation in the past year? (check one only)						
Employment Status	All Respondents (N=365)		In Care Respondents (n=296)		Out of Care Respondents (n=69)	
	number	percent	number	percent	number	percent
Working full-time job	50	13.7%	39	13.2%	11	15.9%
Working part-time job	34	9.3%	28	9.5%	6	8.7%
Self employed	7	1.9%	5	1.7%	2	2.9%
Working off and on	32	8.8%	26	8.8%	6	8.7%
Not working	236	64.7%	194	65.5%	42	60.9%
Skipped Question	6	1.6%	4	1.4%	2	2.9%
Total	365	100.0%	296	100.0%	69	100.0%

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 24.6% of in care respondents.

The reason most frequently cited by in care respondents was “for health reasons, on disability” (54.3%) while only 11.3% 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”.

Comparison of Reasons for Not Working

Survey Question 13A/8B. Why were you not working during the <i>past year</i> ? (check one only)						
Reason for Not Working	Respondents who answered this Question (n=292)		In Care Respondents who answered this Question (n=232)		Out of Care Respondents who answered this Question (n=53)	
	number	percent	number	percent	number	percent
Student	1	0.3%	0	0.0%	1	1.9%
Looking for a job	107	36.6%	57	24.6%	33	62.3%
Attending job training	3	1.0%	1	0.4%	0	0.0%
For health reasons, on disability	133	45.5%	126	54.3%	6	11.3%
Retired	2	0.7%	2	0.9%	0	0.0%
For health reasons, NOT on disability	33	11.3%	21	9.1%	5	9.4%
*Other	13	4.5%	25	10.8%	8	15.1%
Total	292	100.0%	232	100.0%	53	100.0%

***Other includes reasons such as the following:**

All Respondents	In Care Respondents	Out of Care Respondents
Just got out of prison or jail.	Jail.	Homeless.
Not capable of finding a job.	I can't find work.	Hard to find job.
Homeless.	Laid off. Sometimes too sick.	Too difficult to find full-time job.
Laid off. Sometimes too sick.	Caregiver for person that died.	
Working off the books/ part time/ sometimes.	Working off the books/ part time/ sometimes.	

When respondents were asked to describe their housing situation, those who are in care reported housing situations very different from those who are not in care as follows:

- Only 1.4% of out of care respondents reside in an apartment or house that they own, compared to 11.5% of respondents who are in care.
- In care respondents reside in an apartment or house that they rent at more than twice the rate as out of care respondents (47% compared to 23.2%).
- Out of care respondents indicated that they are living at the home of family or someone else at a higher rate than in care respondents, 30.4% and 20.33%, respectively.
- Out of care respondents live in a room or boarding house at more than twice the rate as in care respondents (24.6% compared to 10.1%) and are homeless at more than three times the rate of in care respondents (11.6% compared to 3.7%).

The following table summarizes all responses to this question.

Comparison of Current Housing Situation

Housing Type	All Respondents (N=365)		In Care Respondents (n=296)		Out of Care Respondents (n=69)	
	number	percent	number	percent	number	percent
In an apartment/house that I own	35	9.6%	34	11.5%	1	1.4%
In an apartment/house that I rent	155	42.5%	139	47.0%	16	23.2%
At my parent's /relative's/ someone else's apartment/ house	81	22.2%	60	20.3%	21	30.4%
In a room or boarding house	47	12.9%	30	10.1%	17	24.6%
In a "supportive living" facility (Assisted Living Facility)	3	0.8%	3	1.0%	0	0.0%
In a half-way house, transitional housing, or treatment facility (drug or mental health)	2	0.5%	2	0.7%	0	0.0%
Nursing home	1	0.3%	1	0.3%	0	0.0%
Homeless (on street/in car/ abandoned building)	19	5.2%	11	3.7%	8	11.6%
Homeless shelter	2	0.5%	1	0.3%	1	1.4%
Domestic violence shelter	0	0.0%	0	0.0%	0	0.0%
Other housing provided by the city, county, or state (such as Section 8 voucher or Shelter+care)	16	4.4%	13	4.4%	3	4.3%
In jail/prison	0	0.0%	0	0.0%	0	0.0%
No response	4	1.1%	2	0.7%	2	2.9%
Total	365	100.0%	296	100.0%	69	100.0%

Respondents' 2008 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, 82.6% and 67.9%, respectively.

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

Federal Poverty Level	All Respondents (N=365)		In Care Respondents (n=296)		Out of Care Respondents (n=69)	
	number	percent	number	percent	number	percent
Below 100%	258	70.7%	201	67.9%	57	82.6%
101% - 150%	53	14.5%	48	16.2%	5	7.2%
151% - 200%	16	4.4%	14	4.7%	2	2.9%
201% - 250%	11	3.0%	11	3.7%	0	0.0%
251% - 300%	3	0.8%	3	1.0%	0	0.0%
Over 300%	8	2.2%	7	2.4%	1	1.4%
No response	16	4.4%	12	4.1%	4	5.8%
Total	365	100.0%	296	100.0%	69	100.0%

Respondents were asked if, during the past 12 months, they traded sex for money or drugs. Respondents who are out of care responded affirmatively at more than twice the rate as respondents who are in care (13.0% compared to 6.1%).

Comparison of Respondents who Traded Sex for Money or Drugs

Traded Sex for Money or Drugs	All Respondents (N=365)		In Care Respondents (n=296)		Out of Care Respondents (n=69)	
	number	percent	number	percent	number	percent
Yes	27	7.4%	18	6.1%	9	13.0%
No response	338	92.6%	278	93.9%	60	87.0%
Total	365	100.0%	296	100.0%	69	100.0%

6. PRIORITIZATION OF SERVICE CATEGORIES

Respondents who are in care were asked 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 (73.6%, 218)
- Laboratory Diagnostic Testing (62.8%, 186)
- Medications (58.4%, 173)
- Case Management (57.4%, 170)
- Medical Specialist (41.6%, 123)

Five Most Important Services

Survey Question 77A. Which five services do you think are most important for people with HIV/AIDS?		
Service Category	In Care Respondents (n=296)	
	number	percent
Primary Medical Care	218	73.6%
Laboratory Diagnostic Testing	186	62.8%
Medications	173	58.4%
*Case Management	170	57.4%
Medical Specialist	123	41.6%
*Case management functions as the EMA's single point of entry, providing primary access to the EMA's continuum of care. Clients' initial eligibility must be determined by case managers, necessitating high utilization and prioritization of case management services. Once eligibility is established, case managers assist clients in navigating the continuum of care, or clients may choose to access some services (e.g. primary medical care) independently.		

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

Survey Question 77A. Which five services do you think are most important for people with HIV/AIDS?				
Provider Survey Question 29. If we have limited funding, what are the five (5) most important services?				
Service Category	In Care Respondents (n=296)		Provider Respondents (N=14)	
	#	%	#	%
Primary Medical Care	218	73.6%	14	100.0%
Laboratory Diagnostic Testing	186	62.8%	9	64.3%
Medications	173	58.4%	11	78.6%
Case Management	170	57.4%	9	64.3%
Medical Specialist	123	41.6%	1	7.1%
Oral/Dental Health	74	25.0%	2	14.3%
Food Bank/Home Delivered Meals	64	21.6%	0	0.0%
Health Insurance	52	17.6%	5	35.7%
Transportation	40	13.5%	1	7.1%
Nurse Care Coordination	38	12.8%	4	28.6%
Emergency Financial Assistance	35	11.8%	0	0.0%
Mental Health Services	20	6.8%	3	21.4%
Support groups	18	6.1%	1	7.1%
Legal Services/Permanency	14	4.7%	2	14.3%
Substance Abuse Residential	13	4.4%	2	14.3%
Nutrition Counseling	13	4.4%	0	0.0%
Early Intervention Services	8	2.7%	3	21.4%
Outreach	7	2.4%	3	21.4%
Home Health Care	6	2.0%	0	0.0%
Health Education/Risk Reduction	4	1.4%	2	14.3%
Rehabilitation Services	3	1.0%	0	0.0%
Linguistics Services	3	1.0%	1	7.1%
Substance Abuse Outpatient	1	0.3%	0	0.0%
Hospice	1	0.3%	0	0.0%
Treatment Adherence	1	0.3%	1	7.1%
Other (e.g. Need all the services; Housing; Meeting people my age with HIV; app't. reminders)	5	1.7%	0	0.0%
No response	22	7.4%	0	0.0%
Total In Care Respondents/Provider Respondents	296	100.0%	14	100.0%

All providers and 73.6% of PLWHA identified Primary Medical Care as the most important service. Notable differences between PLWHA and providers include the following:

- Providers cited Medications as the second most important service, while PLWHA ranked Laboratory Diagnostic Testing as the second.
- 41.6% of PLWA cited Medical Specialists one of the five most important services compared to 7.1% of providers who mentioned this service category
- Providers mentioned Nurse Care Coordination at more than twice the rate of PLWA (28.6% compared to 12.8%).
- Food was mentioned by 21.6% of PLWHA but by 0% of providers.

7. SERVICE UTILIZATION, GAPS, AND BARRIERS

Survey respondents in care were asked to describe their level of utilization of the twenty-six service categories prioritized by the planning council. The 296 respondents in care described their utilization of each survey categories as one of the following:

- “Need and Use” if they utilize the service
- “Need But Can’t Get” to show possible gaps in services
- “Needed But Didn’t Know about Service” to show barriers to service utilization
- “Don’t Need” if they do not utilize the service

Utilization: “Need and Use”

The five most frequently utilized, “Need and Use” services:

Medications 76.4%, 226
Primary Medical Care 76%, 225
Laboratory Diagnostic Testing 75.7%, 224
Medical Specialist 61.1%, 181
Oral/Dental Health, 59.5%, 176

Gaps: “Need But Can’t Get”

The five top ranked “Need But Can’t Get” services:

Food Bank/Home Delivered Meals 26.4%, 78
Emergency Financial Assistance 21.3%, 63
Transportation 14.2%, 42
Health Insurance 11.1%, 33
Legal Services/Permanency 8.1%, 24
Rehabilitation Services 8.1%, 24

In the Out of Care section of this report, data from respondents who are out of care report similar service gaps. When asked what supportive services the respondents who are out of care need in order to enter primary medical care, the most frequently named services included financial assistance (i.e., emergency financial services), food, housing, case management, and transportation.

Barriers: “Needed But Didn’t Know About Service”

The top five ranked services in this category were:

Emergency Financial Services 11.1%, 33
Legal Services/Permanency 11.1%, 33
Food Bank/Home Delivered Meals 9.5%, 28
Support Groups 7.4%, 22
Outreach 7.1%, 21
Transportation, 6.4%, 19
Health Education/Risk Reduction, 6.4%, 19

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

Service Utilization, Gaps, and Barriers

Service Categories	Utilization			Gaps			Barriers			Don't Need		
	Need and Use			Need But Can't Get			Needed But Didn't Know About Service					
	Rank	#	%	Rank	#	%	Rank	#	%	Rank	#	%
CORE SERVICES												
Medical Care												
Primary Medical Care	2	225	76.0%		11	3.7%		3	1.0%		13	4.4%
Laboratory Diagnostic Testing	3	224	75.7%		12	4.1%		5	1.7%		10	3.4%
Medical Specialist	4	181	61.1%		16	5.4%		7	2.4%		32	10.8%
Nurse Care Coordination		56	18.9%		6	2.0%		9	3.0%		132	44.6%
Case Management		171	57.8%		22	7.4%		11	3.7%		29	9.8%
Medications	1	226	76.4%		9	3.0%		3	1.0%		27	9.1%
Oral/Dental Health	5	176	59.5%		25	8.4%		18	6.1%		41	13.9%
Health Insurance		102	34.5%	4	33	11.1%		15	5.1%		106	35.8%
Mental Health Services		88	29.7%		21	7.1%		19	6.4%		134	45.3%
Substance Abuse Treatment												
Substance Abuse Residential		33	11.1%		11	3.7%		10	3.4%	4	198	66.9%
Substance Abuse Outpatient		28	9.5%		11	3.7%		7	2.4%	4	189	63.9%
Nutrition Counseling		94	31.8%		21	7.1%		17	5.7%		123	41.6%
Early Intervention Services (HIV testing & counseling, medical evaluation)		52	17.6%		11	3.7%		5	1.7%	5	189	63.9%
Home Health Care		24	8.1%		11	3.7%		12	4.1%	2	206	69.6%
Hospice		14	4.7%		9	3.0%		10	3.4%	1	222	75.0%
SUPPORT SERVICES												
Food Bank/Home Delivered Meals		99	33.4%	1	78	26.4%	2	28	9.5%		68	23.0%
Transportation		119	40.2%	3	42	14.2%	5	19	6.4%		92	31.1%
Outreach		47	15.9%		9	3.0%	4	21	7.1%		184	62.2%
Health Education/Risk Reduction		96	32.4%		14	4.7%	5	19	6.4%		132	44.6%
Treatment Adherence		96	32.4%		10	3.4%		15	5.1%		137	46.3%
Legal Services/Permanency		82	27.7%	5	24	8.1%	1	33	11.1%		118	39.9%
Rehabilitation Services		33	11.1%	5	24	8.1%		17	5.7%	5	186	62.8%
Emergency Financial Assistance (help paying for utilities, appliances, etc.)		60	20.3%	2	63	21.3%	1	33	11.1%		103	34.8%
Linguistics Services (interpretation & translation services)		26	8.8%		19	6.4%		7	2.4%	3	201	67.9%
Support groups		89	30.1%		22	7.4%	3	22	7.4%		13	4.4%
Other (housing, app't. reminders)					5	1.7%						

8. FINDINGS FROM PROVIDER SURVEYS

The fourteen providers who completed a 30-item on-line survey represented a broad range of types of organizations and agencies that provide services to PLWH/A in Palm Beach County as follows:

Provider Survey Respondents		
Type of Organization or Agency	Number	Percent
AIDS service organization	2	14.3%
Health clinic	1	7.1%
Community-based organization (not AIDS-specific)	2	14.3%
Multi-service agency that includes HIV/AIDS services	2	14.3%
Substance abuse treatment facility	1	7.1%
Public Health Department	2	14.3%
Other (please specify)	4	28.6%
Pharmacy Services	1	7.1%
Medicaid Program Office	1	7.1%
Community Health Planning Agency	1	7.1%
Legal Services	1	7.1%

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?"

- Support group for HIV positive black men who have sex with men to promote HIV positive prevention, HIV positive treatment and medications.
- Palm Beach County Health Department is bi-lingual, has staff to interpret Spanish, covers all of PBC helping clients access medical and support services, home visits
- Diverse providers and clinical staff
- Provider education
- Participating in health fairs and outreaches to target populations
- Collaborating with the community organizations and STD service providers
- Monthly client education luncheons

- Health Care District and Department of Children and Families staff co-located in clinics
- Partner with other organizations to provide maximum services that are available to patients.
- Outreach/services rendered in communities.
- Providing legal services to address disparities.
- Working with other collaborative such as Mama Bear Coalition.
- CAP reaches out to all populations living with HIV/AIDS and works hard to link them to primary medical care and support services. This is done with a multi-cultural, multi-lingual staff, and through 4 service centers located in the highest incidence areas of the county.
- HIV prevention department targets African American and Latinos including MSM. The case management department has a multiracial team, two African American, two Latinos, and one White. Also four case managers are multilingual, including Spanish, Creole and French.
- We work closely with the Grantee and CARE Council to find cost effective quality care for all who seek it.
- Outreach program works closely with case management and medical providers to ensure access and retention in care. Case Management emphasizes adherence to treatment and prescribed medications. HIV Counseling and Testing seeks to identify early those who are HIV positive but are not aware of their status.

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 Ensure clients have somewhere to live and to receive medical care within 3 day. (1)
 - o Ensure access to affordable housing (2)
- Medication
 - o Improve access to affordable medication(2)
 - o The ADAP crisis should find a solution as soon as possible. Thousands of individuals will remain without treatment due to the complexity of the Prescription Assistance Programs.
- Uniform access to health care
- Ensure access to education and clinical care
- Add mental health services to clinics
- Higher fee schedule for Medicaid services (to increase access to additional providers and reduce dependence on Ryan White funding)

Promote Client Empowerment

- Patients need to strengthen their position in the management of their HIV health and not look at Ryan White as an entitlement, rather as one tool in their arsenal of weapons in fighting the disease and managing their health.

Improve Systematic Approach to Change

- A major systems approach to reducing poverty, food insecurity, housing instability, and lack of transportation. Many people living with HIV/AIDS do not access medical services because they lack food, housing, and transportation.

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
 - Complex and cumbersome contracting process.
 - Long delays and unfair placement of burden of financing services while the HRSA/Grantee contracting process produces long delays in obtaining initial reimbursement each year.
 - Single year contracts, rather than contracts that can easily be renewed.
- Funding
 - State & Federal funding cuts
 - There is no funding to help with rental assistance

Service Capacity & Availability

- Case Management
 - Access to case manager
 - HIV providers do not have enough case managers
 - Case loads too large
 - specialized housing resources for people living with HIV
- Medication
 - Access to medication
 - Medications Assistance Programs and ADAP & AICP wait list
- Mental Health and Substance Abuse
 - Access to qualified mental health provider
 - More local facilities that offer residential substance abuse treatment of HIV+ pregnant women in hospital setting like Plantation General in Broward
- Housing
 - Lack of housing options/resources
 - Specialized housing resources for people living with HIV
- Transportation
 - Lack of transportation to get to appointments;
- Basic resources

- o Clients' lack of basic resources (i.e. \$\$) prevents them from seeking medical services

Psychological and Cultural Issues

- Fear and Denial
 - o Sense of hopelessness, general distrust of government and/or organizations, lacking belief that medicine can help you.
 - o Denial of the disease- women don't believe they are positive
 - o Denial that they are sick or at risk due to the disease
 - o Confidentiality
 - Fear of others finding out their status
- Treatment Adherence
 - o Clients not taking responsibility for their own care (no shows for appointments, not picking up medications on time, not following through with specialty medical appointments or social service visits). This is referring to clients who have access to transportation, don't have mental health or substance abuse issues and speak English.
 - o Non-compliance
 - o Lack of applicants who want treatment
- Language barriers

Sixty-four percent (9) of the providers specified other agencies with whom they have HIV-specific verbal agreements, commitment letters, letters of collaboration, binding agreements, or signed Memoranda of Understanding (MOUs) with other agencies in the area. The majority of the providers have MOUs with the organizations that function as the point of entry into care (i.e. case management).

Ten providers indicated the following methods of tracking referrals:

- We have a tracking log that we update daily.
- PLN follows up on appointments and services.
- Informal, for specialty medical appointments staff calls for follow-up.
- Electronic medical records.
- Through CAREWare.
- Contacting referral source if release signed. Verification from client.
- Case managers follow-up with client to assure service was received, especially if it is a part of the care plan.
- The case manager follows up with the client and if possible with the institution to which it was referred.
- Phone follow-up with referral source.
- We keep records of assessments.

The five providers who indicated that they sometimes have a waiting list described their methods of tracking people on a waiting list as follows:

- When necessary we utilize a waiting list.
- Contacting referral list if release signed. Verification from client.

- In the few instances when we've had a wait list, we have contacted clients as spaces are available to assure that they get the services.
- We use a excel sheet with the client name, the date of contact, the main issue and the date of the intake.
- Continued communication.

Eight 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

- Meetings of Introduction
- Coordinate outreach to providers in the community, educate on issues and needs of the HIV community
- Facilitate networking and coordination of opportunities with other providers in this field.
- Establish a networking system for sharing/making available resources to all clients

Increase Funding for Private Providers

- Funding for case managers to assist with private providers, dental, and mental healthcare.

Ensure a Seamless System of Care

- Making sure individuals access HIV/AIDS services regardless of the agency where they receive the services.
- Continue to and further focus on a SYSTEM of Care where each spoke affects the other. Look at the whole picture.
- Coordinate baby cloths, Carnation Good Start Formula, diaper, baby donations for our clients

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

- We are currently, as a pilot, opening some of our clinics for half a day on Saturday. If this proves successful, we will expand to include HIV services. In the past, clients didn't utilize the evening hours (many years ago).
- Expanding to provide more services by hiring another physician; would like to have funding for an in-office case manager.
- Exploring funding for increased capacity.
- Yes, as our Agency identifies more individuals meeting TOPWA's criteria (women who are pregnant).
- FoundCare is providing more medical care to people living with HIV/AIDS.
- We want to expand our services for newly infected individuals looking for services or individuals that have been out of care for more than six months.
- We have just launched a Pharmaceutical Assistance and Drug Access Program (MEDNet)

- If funding provided, agency will want to expand case management and supportive services.
- Adding a part-time social worker.

Other Comments

- Housing services are not accessed equally among agencies. What we can do make sure we can improve our access to HOPWA and STRMU.
- We believe the program should evolve to a point where there is heavy assistance early on after entry into care, then the PT should be responsible for maintaining his/her health over the long run, with RW re-entering the picture at points where there is severe health crisis, and at the end of the disease cycle.

B. TRENDS IN SERVICE UTILIZATION, GAPS, AND BARRIERS (2000-2010)

Needs assessments were conducted in 2000, 2003, 2007 and 2010. 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 2010. Service categories used to analyze utilization, gaps, and barriers have varied slightly in the four 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 in the 2010 needs assessment. The list of service categories in the 2010 data collection instrument includes only the services in the current continuum of care that were prioritized and funded by the CARE Council in 2010. In some cases, this has resulted in nonconsecutive rankings in the tables below.

Utilization: "Need and Use"

Although rates of utilization have changed for the following services, they have *remained highly utilized* (by more than 50% of respondents) from 2000 through 2010. The following table lists the services from the highest to lowest rates of utilization in 2010.

Service Categories that Remain Highly Utilized Since 2000

Service Categories	2000		2003		2007		2010		
	(n=271)		(n=400)		(n=252)		(n=296)		
	rank	%	rank	%	rank	%	rank	#	%
Primary Medical Care	3	59%	8	52.8%	4	56.3%	2	225	76.0%
Laboratory Diagnostic Testing	1	75%	2	72.0%	2	71.0%	3	224	75.7%
Medical Specialist	n/a	n/a	n/a	n/a	8	40.0%	4	181	61.1%
Oral/Dental Health	6	58%	5	61.5%	3	57.5%	5	176	59.5%
Case Management	2	68%	1	73.5%	1	74.6%	6	171	57.8%

The following services *significantly increased in utilization* from 2000 through 2010. The following table lists the services from the highest to lowest rankings of utilization in 2010.

Service Categories that Significantly Increased in Utilization Since 2000

Service Categories	2000		2003		2007		2010		
	(n=271)		(n=400)		(n=252)		(n=296)		
	rank	%	rank	%	rank	%	rank	#	%
Medications*	8	53.0%	7	56.3%	17	31.0%	1	226	76.4%
Primary Medical Care	3	59.0%	8	52.8%	4	56.3%	2	225	76.0%
Medical Specialist	n/a	n/a	n/a	n/a	8	40.1%	4	181	61.1%
Transportation	24	27.0%	15	44.8%	6	45.6%	7	119	40.2%

*No category "Medications" prior to 2010; most closely resembled "Drug Reimbursement" in 2007.

The following services (listed from the highest to lowest rankings of utilization in 2010) *significantly decreased in utilization* from 2000 through 2010.

Service Categories that Significantly Decreased in Utilization Since 2000

Service Categories	2000		2003		2007		2010		
	(n=271)		(n=400)		(n=252)		(n=296)		
	rank	%	rank	%	rank	%	rank	#	%
Case Management	2	68.0%	1	73.5%	1	74.0%	6	171	57.8%
Food Bank/Home Delivered Meals	11	43.0%	15	45.0%	10	37.7%	9	99	33.4%
Health Education/Risk Reduction	13	43.0%	6	59.0%	5	51.6%	10	96	32.4%
Counseling (if this means Early Intervention, etc.)	27	23.0%	21	29.8%	5	51.6%	17	52	17.6%
Substance Abuse Residential	n/a	n/a	24	22.8%	24	15.1%	19	33	11.1%
Substance Abuse Outpatient	n/a	n/a	24	22.8%	23	15.1%	20	28	9.5%
Hospice	35	11.0%	41	5.8%	27	5.6%	23	14	4.7%

The following table summarizes all utilization data from the current and past four needs assessments. The top five categories for each year are highlighted for emphasis.

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

Service Categories	2000		2003		2007		2010		
	(n=271)		(n=400)		(n=252)		(n=296)		
	rank	%	rank	%	rank	%	rank	#	%
CORE SERVICES									
Medical Care									
Primary Medical Care	3	59%	8	52.8%	4	56.3%	2	225	76.0%
Laboratory Diagnostic Testing	1	75%	2	72.0%	2	71.0%	3	224	75.7%
Medical Specialist	n/a	n/a	n/a	n/a	8	40.0%	4	181	61.1%
Nurse Care Coordination	n/a	n/a	43	5.0%	24	13.1%	16	56	18.9%
Case Management	2	68%	1	73.5%	1	74.6%	6	171	57.8%
Medications*	8	53%	7	56.3%	17	31.0%	1	226	76.4%
Oral/Dental Health	6	58%	5	61.5%	3	57.5%	5	176	59.5%
Health Insurance	23	27%	25	22.3%	14	34.9%	8	102	34.5%
Mental Health Services	16	35%	23	27.0%	9	38.1%	13	88	29.7%
Substance Abuse Treatment									
Substance Abuse Residential	n/a	n/a	24	22.8%	24	15.1%	19	33	11.1%
Substance Abuse Outpatient	n/a	n/a	24	22.8%	23	15.1%	20	28	9.5%
Nutrition Counseling	n/a	n/a	n/a	n/a	n/a	n/a	11	94	31.8%
Early Intervention Services	27	23%	21	29.8%	5	51.6%	17	52	17.6%
Home Health Care	45	6%	42	5.5%	22	15.9%	22	24	8.1%
Hospice	35	11%	41	5.8%	27	5.6%	23	14	4.7%
SUPPORT SERVICES									
Food Bank/Home Delivered Meals	11	43%	15	44.8%	10	37.7%	9	99	33.4%
Transportation	24	27%	15	44.8%	6	45.6%	7	119	40.2%
Outreach	n/a	n/a	n/a	n/a	11	36.1%	18	47	15.9%
Health Education/Risk Reduction**	n/a	n/a	n/a	n/a	n/a	n/a	10	96	32.4%
Treatment Adherence	n/a	n/a	n/a	n/a	12	35.7%	10	96	32.4%
Legal Services/Permanency	17	33%	20	34.3%	12	34.9%	14	82	27.7%
Rehabilitation Services*	n/a	n/a	n/a	n/a	n/a	n/a	19	33	11.1%
Emergency Financial Assistance	25	25%	18	36.5%	13	57.5%	15	60	20.3%
Linguistics Services	40	10%	29	17.3%	26	12.3%	21	26	8.8%
Support groups	n/a	n/a	n/a	n/a	n/a	n/a	12	89	30.1%
*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.									

Service Gaps: “Need, Can’t Get”

This section includes data from the 2000, 2003, 2007, and 2010 needs assessments regarding services which respondents indicated they “need, can’t get”. The table below lists the service gaps that *remained somewhat consistent* from 2000 through 2010. The top five categories that remained somewhat consistent for each year are highlighted for emphasis.

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

Service Categories	2000		2003		2007		2010	
	(n=271)		(n=400)		(n=252)		(n=296)	
	rank	%	rank	%	rank	%	rank	%
CORE SERVICES								
Medical Care								
Primary Medical Care	21	6.0%	26	9.5%	25	6.3%	13	3.7%
Laboratory Diagnostic Testing	24	2.0%	31	7.8%	22	9.1%	12	4.1%
Case Management	19	9.0%	24	10.0%	21	10.7%	7	7.4%
Mental Health Services	19	9.0%	23	10.8%	15	13.9%	8	7.1%
SUPPORT SERVICES								
Food Bank/Home Delivered Meals	12	19.0%	3	27.0%	3	32.1%	1	26.4%
Transportation	10	21.0%	17	13.5%	9	21.4%	3	14.2%
Health Education/Risk Reduction*	n/a	n/a	n/a	n/a		n/a	11	4.7%
Emergency Financial Assistance	2	34.0%	5	26.3%	2	32.5%	2	21.3%
Linguistics Services	23	4.0%	33	6.8%	19	11.5%	9	6.4%
*Only HRSA service categories and “Support groups” were used in the 2010 survey. Therefore, the category “HIV Prevention” was not used (as in previous years) and “Health Education/Risk Reduction” was added to the 2010 survey.								

The following table displays the service categories for which gaps significantly decreased from 2000 through 2010

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

Service Categories	2000		2003		2007		2010	
	(n=271)		(n=400)		(n=252)		(n=296)	
	rank	%	rank	%	rank	%	rank	%
CORE SERVICES								
Nurse Care Coordination	n/a	n/a	25	9.8%	18	12.3%	16	2.0%
Medications*	17	11.0%	20	11.5%	5	26.6%	15	3.0%
Oral/Dental Health	12	19.0%	9	20.0%	7	23.8%	6	8.4%
Health Insurance	9	22.0%	7	23.8%	8	21.4%	4	11.1%
Substance Abuse Treatment								
Substance Abuse Residential	n/a	n/a	28	9.0%	24	7.1%	13	3.7%
Substance Abuse Outpatient	n/a	n/a	28	9.0%	23	8.1%	13	3.7%
Early Intervention Services	18	10.0%	18	12.8%	11	19.0%	13	3.7%
Home Health Care	23	4.0%	29	8.8%	12	16.3%	13	3.7%
Hospice	23	4.0%	21	11.8%	18	12.3%	15	3.0%
SUPPORT SERVICES								
Outreach	n/a	n/a	n/a	n/a	14	14.7%	15	3.0%
Treatment Adherence	n/a	n/a	n/a	n/a	14	14.3%	14	3.4%
Rehabilitation Services*	n/a	n/a	n/a	n/a	n/a	n/a	5	8.1%
*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 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 four needs assessments. The five most highly ranked gaps for each year are highlighted for emphasis.

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

Service Categories	2000		2003		2007		2010		
	(n=271)		(n=400)		(n=252)		(n=296)		
	rank	%	rank	%	rank	%	rank	#	%
CORE SERVICES									
Medical Care									
Primary Medical Care	21	6.0%	26	9.5%	25	6.3%	13	11	3.7%
Laboratory Diagnostic Testing	24	2.0%	31	7.8%	22	9.1%	12	12	4.1%
Medical Specialist	n/a	n/a	n/a	n/a	19	11.1%	10	16	5.4%
Nurse Care Coordination	n/a	n/a	25	9.8%	18	12.3%	16	6	2.0%
Case Management	19	9.0%	24	10.0%	21	10.7%	7	22	7.4%
Medications*	17	11.0%	20	11.5%	5	26.6%	15	9	3.0%
Oral/Dental Health	12	19.0%	9	20.0%	7	23.8%	6	25	8.4%
Health Insurance	9	22.0%	7	23.8%	8	21.4%	4	33	11.1%
Mental Health Services	19	9.0%	23	10.8%	15	13.9%	8	21	7.1%
Substance Abuse Treatment									
Substance Abuse Residential	n/a	n/a	28	9.0%	24	7.1%	13	11	3.7%
Substance Abuse Outpatient	n/a	n/a	28	9.0%	23	8.1%	13	11	3.7%
Nutrition Counseling	n/a	n/a	n/a	n/a	n/a	n/a	8	21	7.1%
Early Intervention Services	18	10.0%	18	12.8%	11	19.0%	13	11	3.7%
Home Health Care	23	4.0%	29	8.8%	12	16.3%	13	11	3.7%
Hospice	23	4.0%	21	11.8%	18	12.3%	15	9	3.0%
SUPPORT SERVICES									
Food Bank/Home Delivered Meals	12	19.0%	3	27.0%	3	32.1%	1	78	26.4%
Transportation	10	21.0%	17	13.5%	9	21.4%	3	42	14.2%
Outreach	n/a	n/a	n/a	n/a	14	14.7%	15	9	3.0%
Health Education/Risk Reduction**	n/a	n/a	n/a	n/a	n/a	n/a%	11	14	4.7%
Treatment Adherence	n/a	n/a	n/a	n/a	14	14.3%	14	10	3.4%
Legal Services/Permanency	11	20.0%	19	23.3%	17	13.1%	5	24	8.1%
Rehabilitation Services**	n/a	n/a	n/a	n/a	n/a	n/a	5	24	8.1%
Emergency Financial Assistance	2	34.0%	5	26.3%	2	32.5%	2	63	21.3%
Interpretation & translation services	23	4.0%	33	6.8%	19	11.5%	9	19	6.4%
Support groups	n/a	n/a	n/a	n/a	n/a	n/a	7	22	7.4%
*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 and the data were not included (as in previous years) and "Health Education/Risk Reduction" and "Rehabilitation Services" were added to the 2010 survey.									

Barriers to Services: “Can Get, But Won’t Use” (2000, 2003, and 2007) and “Needed But Didn’t Know About Service” (2010)

With a few notable exceptions in 2010 (oral/dental health, health insurance, food bank, transportation, emergency financial assistance) the rates of respondents indicating barriers to particular services have *remained low and fairly consistent*. The following table summarizes data from the past four needs assessments with services having the highest rates of barriers highlighted for emphasis.

**Barriers to Service Categories Across the 2000, 2003, 2007, and 2010 Needs Assessments
(in 2000, 2003, and 2007, "Can Get, But Won't Use", in 2010, "Needed But Didn't Know About Service")**

Service Categories	2000		2003		2007		2010		
	(n=271)		(n=400)		(n=252)		(n=296)		
	rank	%	rank	%	rank	%	rank	#	%
CORE SERVICES									
Medical Care									
Primary Medical Care	13	1.0%	18	1.0%	9	2.8%	13	11	3.7%
Laboratory Diagnostic Testing	12	2.0%	19	0.8%	10	2.4%	12	12	4.1%
Medical Specialist	n/a	n/a	n/a	n/a	2	6.7%	10	16	5.4%
Nurse Care Coordination	n/a	n/a	11	2.8%	5	4.8%	16	6	2.0%
Case Management	9	3.0%	15	1.8%	9	2.8%	7	22	7.4%
Medications*	8	4.0%	10	3.0%	9	2.8%	15	9	3.0%
Oral/Dental Health	4	6.0%	14	2.0%	9	2.8%	5	25	8.4%
Health Insurance	9	3.0%	17	1.3%	6	4.0%	4	33	11.1%
Mental Health Services	5	5.0%	13	2.3%	7	3.6%	8	21	7.1%
Substance Abuse Treatment									
Substance Abuse Residential	1	7.0%	9	3.3%	3	6.0%	13	11	3.7%
Substance Abuse Outpatient	1	7.0%	9	3.3%	5	4.8%	13	11	3.7%
Nutrition Counseling	n/a	n/a	n/a	n/a	n/a	n/a	8	21	7.1%
Early Intervention Services	3	6.0%	15	1.8%	8	3.2%	13	11	3.7%
Home Health Care	6	4.0%	16	1.5%	10	2.4%	13	11	3.7%
Hospice	10	3.0%	14	2.0%	7	3.6%	15	9	3.0%
SUPPORT SERVICES									
Food Bank/Home Delivered Meals	8	4.0%	16	1.5%	9	2.8%	1	78	26.4%
Transportation	13	1.0%	20	1.0%	12	1.6%	3	42	14.2%
Outreach	n/a	n/a	n/a	n/a	5	4.8%	15	9	3.0%
Health Education/Risk Reduction**	n/a	n/a	n/a	n/a	7	n/a	11	14	4.7%
Treatment Adherence	n/a	n/a	n/a	n/a	11	2.0%	14	10	3.4%
Legal Services/Permanency	10	3.0%	15	1.8%	6	4.0%	6	24	8.1%
Rehabilitation Services**	n/a	n/a	n/a	n/a	n/a	n/a	6	24	8.1%
Emergency Financial Assistance	11	3.0%	17	1.3%	11	2.0%	2	63	21.3%
Linguistics Services	12	2.0%	18	1.0%	5	4.8%	9	19	6.4%
Support groups	n/a	n/a	n/a	n/a	n/a	n/a	6	22	7.4%

*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.

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. Men who Have Sex with Men (MSM)
2. Haitian Men and Women
3. African American Women
4. Men Recently Released from Incarceration
5. Latin/Hispanic Men and Women
6. Women Who Used Drugs Illegally During the Past 12 Months

For this Needs Assessment, focus groups were conducted with PLWHA from each of the first five 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 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.¹⁶

Service Gaps

The 2010 Needs Assessment included 90 respondents who identified themselves as MSM. 79% of these were in care, 43% were at or below 100% of the federal poverty level, and about half had been unemployed during the past 12 months.

Out of Care MSM Respondents

When out of care MSM were asked to describe their situation, 63% said they had been recently diagnosed and had not entered primary care, compared to 45% among all out of care respondents. The rate of MSM who had not been recently diagnosed but had never been in care was about the same rate as among all out of care respondents (26% and 23% respectively). When out of care MSM were asked to identify the reasons that they are not in primary 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 MSM, the second most frequently mentioned reason was "I did not know where to go" (53%) while this response given at half that rate (26%) by all out of care respondents. When out of care MSM respondents were asked to identify the services, other than medical care and medications, that they need in order to get into primary medical care, the four most frequently selected services were the same as those selected by all out of care respondents (financial assistance, food, housing, and case management). Compared to all out of care respondents, a higher percentage of MSM selected financial assistance and labs.

In Care MSM Respondents

MSM respondents in care most frequently identified service gaps ("need but can't get") in case management, food bank/home delivered meals, oral/dental health, transportation, and emergency financial assistance. As with all in care respondents, emergency financial assistance was the most frequently mentioned service that in care MSM "needed but didn't know about"(service barrier). The next most frequently mentioned services in this category were mental health services, nutrition counseling, legal services/permanency, oral/dental health, and food bank/home delivered meals.

¹⁶Florida 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.*

MSM Focus Group Findings

Respondents identified the following reasons for not being in primary care: lack of knowledge about appropriate care and treatment services; depression and stress; lack of information about treatment and availability of services; adverse reactions to medications; high cost of medication; having to take time off from work to pick up medications every month instead of every three months due to cutbacks in ADAP funding; drug and alcohol abuse/addiction; difficulties qualifying for services due to means testing; and stigma/embarrassment. When asked what would help MSM get back into care or stay in care, respondents identified facing a life or death illness; billboards; case management; support groups; learning to make taking care of oneself a priority; reducing or eliminating alcohol and drugs; exercise; having sympathetic and caring physicians; developing coping skills; psychotherapy; and concern for others. Participants said they were receiving the services they need (especially case management, medical care, medications, lab tests, and mental health counseling) and were generally very satisfied with those services. Some identified service gaps and barriers were the difficult and time-consuming eligibility process; ineligibility for food stamps and need for a food bank; the ADAP waiting list and change in medication distribution from every three months to every month; and unmet needs or difficulty accessing emergency financial assistance, dental health care, legal services (especially regarding immigration status), and transportation.

Data Highlights Related to MSM Survey Respondents

- 24.7% (90) of all respondents identified themselves as MSM.
- 19 (21.1%) are out of care and 71 (78.9%) are in care.
- 82 (91.1%) identified English and 6 (6.7%) identified Spanish as their primary language.
- 17.2% identified themselves as Hispanic/Latino.
- 39 (43.3%) are at or below 100% of the federal poverty level.
- 47 (52.2%) had been unemployed during the past 12 months.
- 7 (7.8%) traded sex for money or drugs within the past 12 months.
- 4 used injection drugs, 2 used methamphetamines, and 30 used other street drugs.
- 26.6% (20) traded sex for money or drugs within the past 12 months.
- 37.3% (28) utilize private doctors for most of their medical care.

Please see the following pages for additional data and analysis.

When out of care MSM were asked to describe their situation, 63.2% said they had been recently diagnosed and had not entered primary care, compared to 44.9% among all out of care respondents. The rate of MSM who had not been recently diagnosed but had never been in care was about the same rate as among all out of care respondents (26.3% and 23.2% respectively). Out of care MSM who had been receiving medical care for HIV but had stopped more than 12 months ago accounted for only 10.5% of all out of care MSM respondents. This category accounted for 26.1% of all out of care respondents.

The following table displays all responses to this survey question.

Out of Care Circumstances

Survey Question 24A. What best describes your situation (check one only)				
Out of Care Situation	All Out of Care Respondents (n=69)		MSM Out of Care Respondents (n=19)	
	number	percent	number	percent
I have recently been diagnosed with HIV, and have not entered primary care.	31	44.9%	12	63.2%
I have <u>not</u> been recently diagnosed but have never been in care.	16	23.2%	5	26.3%
I had been receiving medical care for HIV, but I stopped more than 12 months ago.	18	26.1%	2	10.5%
Other	2	2.9%	0	0.0%
No Response	2	2.9%	0	0.0%
Total	69	100.0%	19	100.0%

When out of care MSM were asked to identify the reasons that they are not in primary 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 MSM, the second most frequently mentioned reason was “I did not know where to go” (52.6%) while this response given at half the rate (26.1%) than 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”, “I could not pay for services”, and “I was not ready to deal with having HIV”.

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

Survey Question 25A. Why did you not get HIV/AIDS related medical care the past year? (check any or all that apply)				
Reasons for Not Getting Medical Care	All Out of Care Respondents		MSM Out of Care Respondents	
	(n=69)		(n=19)	
	number	percent	number	percent
I did not know where to go.	18	26.1%	10	52.6%
I could not get an appointment.	4	5.8%	4	21.1%
I could not get transportation.	13	18.8%	6	31.6%
I could not get childcare.	0	0.0%	0	0.0%
I was too busy taking care of my partner.	2	2.9%	0	0.0%
I could not pay for services.	26	37.7%	8	42.1%
I did not want people to know that I have HIV.	29	42.0%	8	42.1%
I was not ready to deal with having HIV.	22	31.9%	8	42.1%
I did not feel sick.	33	47.8%	14	73.7%
There are not enough doctors in my area.	0	0.0%	0	0.0%
I could not get time off work.	8	11.6%	7	36.8%
I was depressed.	25	36.2%	5	26.3%
I missed my appointment(s).	8	11.6%	1	5.3%
I had a bad experience with the medical staff.	6	8.7%	2	10.5%
Other (e.g. drugs; recently diagnosed; in process)	6	8.7%	1	5.3%

When out of care MSM respondents were asked to identify the services, other than medical care and medications, that they need in order to get into primary medical care, the four 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 financial assistance and labs.

The following table summarizes all responses to this survey question.

Services Needed to Get Into Primary Medical Care

Survey Question 27A. What services, other than medical care and medications, do you need to get into primary medical care? (check all that apply)				
Services	All Out of Care Respondents (n=69)		MSM Out of Care Respondents (n=19)	
	number	percent	number	percent
Financial assistance	34	49.3%	11	57.9%
Food	32	46.4%	6	31.6%
Housing	31	44.9%	6	31.6%
Case management	28	40.6%	7	36.8%
Transportation	25	36.2%	3	15.8%
Substance abuse treatment	15	21.7%	3	15.8%
Mental health services	12	17.4%	2	10.5%
Legal services	11	15.9%	3	15.8%
Labs	11	15.9%	4	21.1%
Dental care	6	8.7%	1	5.3%
Treatment Adherence	5	7.2%	0	0.0%
Other (e.g. job, late appointments, might need mental health services later)	3	4.3%	2	10.5%

When out of care MSM respondents were asked to identify reasons they would enter care, the most frequently mentioned factor was “Someone else with HIV/AIDS reaches out to me”. Out of care MSM mentioned this reason more than twice as often as all out of care respondents (68.4% and 26.1% 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.

Reasons to Enter Primary Medical Care

Survey Question 28A. What would be some reasons you enter primary medical care? (check any or all that apply)				
Reasons to Enter Primary Medical Care	Out of Care Respondents (n=69)		MSM Out of Care Respondents (n=19)	
	number	percent	number	percent
I get sick and know I need care.	45	65.2%	10	52.6%
I am ready to deal with my illness.	20	29.0%	1	5.3%
Someone else with HIV/AIDS reaches out to me.	18	26.1%	13	68.4%
I get transportation to go to a doctor or clinic.	18	26.1%	5	26.3%
Someone arranges to have my care paid for.	18	26.1%	8	42.1%
I find a doctor or medical facility that ensures my confidentiality.	16	23.2%	5	26.3%
I find a doctor or clinic where I do not have to wait very long in the waiting room.	10	14.5%	4	21.1%
I get a referral to get into care.	7	10.1%	6	31.6%
I am able to deal with other problems in my life that keep me out of care.	7	10.1%	3	15.8%
I find a doctor or medical facility that I like and who accepts me.	6	8.7%	3	15.8%
An outreach worker finds me and helps me get into care.	6	8.7%	1	5.3%
I find a medical facility that has evening or weekend hours.	6	8.7%	5	26.3%
A family member or friend helps me get into care.	4	5.8%	2	10.5%
Other (insurance)	1	1.4%	1	5.3%

When asked to rate the five most important services, in care MSM rated medications, case management, primary medical care, laboratory diagnostic testing, and oral/dental health as the top five. This prioritization is similar that of all in care respondents, but in different order. For example, 78.7% of in care MSM said medications were one of the most important services, but only 58.4% of all in care respondents did so. Although 41.6% of all in care respondents said medical specialists were one of the five most important services, only 21.1% of in care MSM agreed.

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

Five Most Important Services

Survey Question 77A. Which five services do you think are most important for people with HIV/AIDS?				
Service Category	In Care Respondents (n=296)		MSM In Care Respondents (n=71)	
	number	percent	number	percent
Primary Medical Care	218	73.6%	39	54.9%
Laboratory Diagnostic Testing	186	62.8%	31	43.7%
Medications	173	58.4%	56	78.9%
Case Management*	170	57.4%	40	56.3%
Medical Specialist	123	41.6%	15	21.1%
Oral/Dental Health	74	25.0%	27	38.0%

*Case management functions as the EMA’s single point of entry, providing primary access to the EMA’s continuum of care. Clients’ initial eligibility must be determined by case managers, necessitating high utilization and prioritization of case management services. Once eligibility is established, case managers assist clients in navigating the continuum of care, or clients may choose to access some services (e.g. primary medical care) independently.

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

Five Most Important Services

Survey Question 77A. Which five services do you think are most important for people with HIV/AIDS?				
Service Category	In Care Respondents (n=296)		MSM In Care Respondents (n=71)	
	number	percent	number	percent
Primary Medical Care	218	73.6%	39	54.9%
Laboratory Diagnostic Testing	186	62.8%	31	43.7%
Medications	173	58.4%	56	78.9%
Case Management	170	57.4%	40	56.3%
Medical Specialist	123	41.6%	15	21.1%
Oral/Dental Health	74	25.0%	27	38.0%
Food Bank/Home Delivered Meals	64	21.6%	14	19.7%
Health Insurance	52	17.6%	23	32.4%
Transportation	40	13.5%	8	11.3%
Nurse Care Coordination	38	12.8%	2	2.8%
Emergency Financial Assistance (help paying for utilities, appliances, etc.)	35	11.8%	10	14.1%
Mental Health Services	20	6.8%	10	14.1%
Support groups	18	6.1%	5	7.0%
Legal Services/Permanency	14	4.7%	7	9.9%
Substance Abuse Residential	13	4.4%	1	1.4%
Nutrition Counseling	13	4.4%	5	7.0%
Early Intervention Services (HIV testing & counseling, medical evaluation)	8	2.7%	4	5.6%
Outreach	7	2.4%	3	4.2%
Home Health Care	6	2.0%	3	4.2%
Health Education/Risk Reduction	4	1.4%	0	0.0%
Rehabilitation Services	3	1.0%	3	4.2%
Linguistics Services (interpretation & translation services)	3	1.0%	1	1.4%
Substance Abuse Outpatient	1	0.3%	1	1.4%
Hospice	1	0.3%	0	0.0%
Treatment Adherence	1	0.3%	0	0.0%
Other (e.g. need all the services, housing, meeting people my age with HIV, app't. reminders)	6	2.0%	3	4.2%
No response	22	7.4%	4	5.6%
Total In Care Respondents	296	100.0%	71	100.0%

Service Needs and Utilization

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

- “need and use” if they utilize the service
- “do not need” if they do not utilize the service
- “need, can’t get” to show possible gaps in services
- “can get, won’t use” to show barriers in service utilization

Utilization: “Need and Use”

Among MSM respondents in care, primary medical care and laboratory diagnostic testing were the most highly utilized services (by 84.4% of in care MSM) followed by medications (81.7%), medical specialist (66.2%) and case management (59.2%).

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.

Comparison of Service Utilization "Need and Use"

Utilized Service Categories	All in Care Respondents (n=296)			MSM in Care Respondents (n=71)		
	rank	number	percent	rank	number	percent
CORE SERVICES						
Medical Care						
Primary Medical Care	2	225	76.0%	1	60	84.5%
Laboratory Diagnostic Testing	3	224	75.7%	1	60	84.5%
Medical Specialist	4	181	61.1%	3	47	66.2%
Case Management	6	171	57.8%	4	42	59.2%
Medications	1	226	76.4%	2	58	81.7%
Oral/Dental Health	5	176	59.5%	6	41	57.7%

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

Comparison of Service Utilization "Need and Use"

Utilized Service Categories	All in Care Respondents (n=296)			MSM in Care Respondents (n=71)		
	rank	number	percent	rank	number	percent
CORE SERVICES						
Medical Care						
Primary Medical Care	2	225	76.0%	1	60	84.5%
Laboratory Diagnostic Testing	3	224	75.7%	1	60	84.5%
Medical Specialist	4	181	61.1%	3	47	66.2%
Nurse Care Coordination		56	18.9%		10	14.1%
Case Management		171	57.8%	4	42	59.2%
Medications	1	226	76.4%	2	58	81.7%
Oral/Dental Health	5	176	59.5%		41	57.7%
Health Insurance		102	34.5%		39	54.9%
Mental Health Services		88	29.7%		18	25.4%
Substance Abuse Treatment						
Substance Abuse Residential		33	11.1%		2	2.8%
Substance Abuse Outpatient		28	9.5%		3	4.2%
Nutrition Counseling		94	31.8%		19	26.8%
Early Intervention Services		52	17.6%		9	12.7%
Home Health Care		24	8.1%		1	1.4%
Hospice		14	4.7%		3	4.2%
SUPPORT SERVICES						
Food Bank/Home Delivered Meals		99	33.4%		26	36.6%
Transportation		119	40.2%		25	35.2%
Outreach		47	15.9%		7	9.9%
Health Education/Risk Reduction		96	32.4%		18	25.4%
Treatment Adherence		96	32.4%		19	26.8%
Legal Services/Permanency		82	27.7%		24	33.8%
Rehabilitation Services		33	11.1%		8	11.3%
Emergency Financial Assistance		60	20.3%		14	19.7%
Linguistics Services		26	8.8%		2	2.8%
Support groups		89	30.1%		19	26.8%

Service Gaps: “Need, Can’t Get”

Some MSM respondents in care identified service gaps in case management, food bank/home delivered meals, oral/dental health, transportation, and emergency financial assistance.

The following table highlights the most frequently reported service gaps.

Comparison of Gaps "Need But Can't Get"

Service Categories	All in Care Respondents (n=296)			MSM in Care Respondents (n=71)		
	rank	number	percent	rank	number	percent
CORE SERVICES						
Medical Care						
Primary Medical Care		11	3.7%		4	5.6%
Laboratory Diagnostic Testing		12	4.1%		4	5.6%
Medical Specialist		16	5.4%		4	5.6%
Nurse Care Coordination		6	2.0%		2	2.8%
Case Management		22	7.4%	1	10	14.1%
Medications		9	3.0%		2	2.8%
Oral/Dental Health		25	8.4%	3	8	11.3%
Health Insurance	4	33	11.1%		1	1.4%
Mental Health Services		21	7.1%		6	8.5%
Substance Abuse Treatment						
Substance Abuse Residential		11	3.7%		2	2.8%
Substance Abuse Outpatient		11	3.7%		3	4.2%
Nutrition Counseling		21	7.1%		5	7.0%
Early Intervention Services		11	3.7%		2	2.8%
Home Health Care		11	3.7%		2	2.8%
Hospice		9	3.0%		2	2.8%
SUPPORT SERVICES						
Food Bank/Home Delivered Meals	1	78	26.4%	2	9	12.7%
Transportation	3	42	14.2%	4	7	9.9%
Outreach		9	3.0%		2	2.8%
Health Education/Risk Reduction		14	4.7%		4	5.6%
Treatment Adherence		10	3.4%		1	1.4%
Legal Services/Permanency	5	24	8.1%		5	7.0%
Rehabilitation Services	5	24	8.1%		5	7.0%
Emergency Financial Assistance	2	63	21.3%	4	7	9.9%
Linguistics Services		19	6.4%		4	5.6%
Support groups		22	7.4%		5	7.0%
Other (housing, app't. reminders)		5	1.7%		3	4.2%

Barriers to Services: “Needed But Didn’t Know About Services”

As with all in care respondents, emergency financial assistance was the most frequently mentioned service that in care MSM “needed but didn’t know about”. The next most frequently mentioned services in this category were mental health services, nutrition counseling, legal services/permanency, oral/dental health, and food bank/home delivered meals. The most frequently responses to this survey item are highlighted in the following table.

Comparison of Barriers "Needed But Didn't Know About Services"

Service Categories	All in Care Respondents (n=296)			MSM in Care Respondents (n=71)		
	rank	number	percent	rank	number	percent
CORE SERVICES						
Medical Care						
Primary Medical Care		3	1.0%		1	1.4%
Laboratory Diagnostic Testing		5	1.7%		1	1.4%
Medical Specialist		7	2.4%		3	4.2%
Nurse Care Coordination		9	3.0%		3	4.2%
Case Management		11	3.7%		3	4.2%
Medications		3	1.0%		1	1.4%
Oral/Dental Health		18	6.1%	4	7	9.9%
Health Insurance		15	5.1%		2	2.8%
Mental Health Services		19	6.4%	2	12	16.9%
Substance Abuse Treatment						
Substance Abuse Residential		10	3.4%		3	4.2%
Substance Abuse Outpatient		7	2.4%		3	4.2%
Nutrition Counseling		17	5.7%	3	8	11.3%
Early Intervention Services		5	1.7%		1	1.4%
Home Health Care		12	4.1%		2	2.8%
Hospice		10	3.4%		2	2.8%
SUPPORT SERVICES						
Food Bank/Home Delivered Meals	2	28	9.5%	4	7	9.9%
Transportation	5	19	6.4%		4	5.6%
Outreach	4	21	7.1%		3	4.2%
Health Education/Risk Reduction	5	19	6.4%		4	5.6%
Treatment Adherence		15	5.1%		3	4.2%
Legal Services/Permanency	1	33	11.1%	3	8	11.3%
Rehabilitation Services		17	5.7%		3	4.2%
Emergency Financial Assistance	1	33	11.1%	1	15	21.1%
Linguistics Services		7	2.4%		1	1.4%
Support groups	3	22	7.4%		5	7.0%

Focus Group Findings: Themes and Notable Quotes

Reasons for not being in primary medical care

- Lack of knowledge about appropriate care and treatment services
“I have a guy have somebody that I know the guy is 20 some odd years old and he's in denial I was talking to him online and he was sick and I said well what are you doing oh I went to my doctor he test me and my T cells were like 50,000 way and is getting sick and sick and I said what you doing are you taking medicine he said no I said why he said the doctor said I didn't need it yet I said are you crazy go to these people go to the community in Fort Lauderdale and tell them I've had my doctor's appointment are you crazy you have your doctor your dying why haven't you taken your medicine he finally went there and started taking his medicine Broward house is pretty good.”
- Depression and stress
“The stress it can kill you”

“...once you're in it it's hard to get out”

“I want to be with my loving family around me. This is hard when you don't see your family, that's the depression...depression was bad for me.”
- Lack of information about treatment and availability of services. Several participants shared about the importance of the help they receive from their case manager. They advised others who were having problems to talk to their case managers, who can help them get anything they need.
- Adverse reactions to medications
- High cost of medications
- Having to take time off from work to pick up medications every month instead of every three months. Apparently this change is due to cutbacks in ADAP funding.
- Drug and alcohol abuse/addiction
- Difficulties qualifying for services due to means testing
e.g. qualifying for food stamps, “...they send me a letter saying no, you cannot have them because you're four dollars over...”
- Problems with treatment adherence
“I was on the meds but I wasn't taking them like I should...maybe they were working and I was resisting you know...”

- Stigma and embarrassment
“I have lost several friends from HIV for that very reason. You know they didn’t want somebody to even know or whatever there was quite a few reasons but it all boils down to Gay Pride”.

What will get people back into care and/or help people stay in care?

- “You have to talk to them and tell them it’s either living or die. Do you care if you get treatment? You live if you do. If you don’t you die within two years.”
- “When you have a rude awakening like I did. You get pneumonia. I almost died...that’s what really keeps you in treatment...”
- Billboards
- Persistent help and reminders by case managers about available services
“They may tell us the first day but then we forget.”
- Support groups
“I think the new people with HIV it would be good to hear from other people...”
“I just heard from them it’s good to hear that sleeping is good for your T cells...”

Learning to make taking care of oneself a priority:

“...Rest is your life, it’s your health.”

“Eating right, sleeping, eating healthy, exercising...”

“You need to get at least eight hours a day at least...”

- Reducing or eliminating alcohol and drugs
“No more coffee, no more pot, no more beer, no more wine, like no more alcohol”

“...I don't do any of that and my doctor said don't do any drugs the only thing you do is drink your water and your juices and take your medicines stay away from the Sodas and the caffeine but I love my sodas. I love my sodas like Coca-Cola I don’t eat healthy all the time but I do cheat because you know where Latin we like caffeine.”
- Exercise
“Now I walk everyday in the morning. I get up at six in the morning, I come back by seven...in the evening when the sun shines down I go all the way to Southern from Forest Hill...4 miles, 8 miles, walking, walking, walking.”
- Sympathetic and caring physicians
“What helps me stay in care is my doctor.”

“...If it wasn’t for him I probably would have gone down...”

- Developing coping skills
“I’ve been learning myself how to control my nerves because nothing you can do. You have to live your life...”
- Psychotherapy
“I’m getting mental health services. For me it’s excellent, it’s a way to talk to somebody else about so many things and get the help ...that I need.”
- Concern for others
“I love people and I don’t want to never think in my mind that I make people sick. That’s the last thing I fear myself, don’t want to make sick ...”

What services are you currently getting?

Participants said they were receiving the services they need (especially case management, medical care, medications, lab tests, and mental health counseling) and were generally very satisfied with those services. Some of the concerns voiced include the following:

- The eligibility process is difficult and time consuming.
- Some participants cannot get food stamps.
“We need a food bank.”
- The change in medication distribution (from once every three months to every month) is burdensome to some participants.
- There was a lot of discussion and confusion regarding reductions in ADAP funding and the onerous “wait list”.
- Some participants mentioned their unmet needs or difficulty accessing emergency financial assistance, dental health care, legal services (esp. regarding immigration status), and transportation.

2. 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.¹⁷

Additional challenges arise from immigration status. In Florida, only people with an AIDS-defining 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.¹⁸

Service Gaps

The 2010 Needs Assessment survey included 67 Haitian respondents. 72% of the respondents were out of care and 28% were in care. Almost one-half were unemployed, about one-quarter had either no schooling or an education level of grade 8 or less, and 82% lived at or below the poverty level. Almost all (97%) indicated they were heterosexual.

Out of Care Haitian Respondents

Among survey respondents, the rate of Haitian out of care respondents was higher than the out of care rate of all respondents (28% compared to 19%). The rate of Haitian out of care respondents who have never been in care was nearly twice the rate of all out of care respondents (42% compared to 23%). When asked why they did not get HIV/AIDS related medical care during the past year, 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 was depressed; and I missed my appointment. Overall, the services, other

¹⁷Miami-Dade HIV/AIDS Partnership (2009). *Comprehensive Plan for HIV/AIDS 2009-2011*.

¹⁸Miami-Dade HIV/AIDS Partnership (2009). *Comprehensive Plan for HIV/AIDS 2009-2011*.

than medical care and medication, that Haitian out of care respondents indicated they need to get into primary medical care were very similar to those needed by all out of care respondents. Respondents in both groups most frequently mentioned the same five services (financial assistance, food, housing, case management, and transportation), although larger percentages of Haitian out of care respondents indicated that they needed the services.

In Care Haitian Respondents

Like all in care respondents, Haitian respondents who are in care most frequently mentioned gaps in services (“need but can’t get”) were for Emergency Financial Assistance, Food Bank/Home Delivery Meals, and Rehabilitation Services. Unlike all in care respondents, Haitian in care respondents also indicated gaps in Linguistic Services and Support Services. Like all respondents in care, Haitian in care respondents most frequently reported barriers (“needed but didn’t know about”) in regard to Support Services rather than to Core Services. The services most frequently mentioned by Haitian respondents in care that they needed but didn’t know about were Rehabilitation Services, Legal Services/Permanency, Emergency Financial Assistance, and Health Education/Risk Reduction.

Haitian Focus Group Findings

Recurrent themes of continued reliance on case management, medical care, medications, and transportation were discussed throughout the group session. Participants also expressed their ongoing fears and anxieties regarding immigration status and financial and housing insecurities exacerbated by HIV. When asked about what it would take to persuade PLWH/A who are not in care to get back into care, respondents again expressed the need to help people overcome fear. When asked what helped them to get into care and stay in care, participants noted the importance of case management. When asked about what services are needed to help get back in care, participants expressed the inextricable link between clinical and support services. When asked about services they need but can’t get, the only specific services mentioned was financial assistance for housing. However, participants expressed their need for continued help with services.

Data highlights related to Haitian survey respondents:

- 67 (18.4% of all respondents) indicated they were Haitian.
- 97% said they are straight (heterosexual)
- 28.4% are in care, compared to 81.1% of all respondents.
- 71.6% are out of care, compared to 18.9% of all respondents.
- 97% said Creole is their primary language.
- 26.9% of Haitian respondents had either no schooling or an education level of 8th grade less compared to 12.9% of all respondents.
- 44.8% described their work situation in the past year as “unemployed” compared to 64.7% of all respondents.
- 82.1% were living at or below 100% FPL compared to 70.7% of all respondents.

Please see the following pages for additional data and analysis.

Findings regarding selected risk factors and co-morbidities are summarized in the table below and on the next page:

Comparison of Haitian Survey Respondents with All Respondents

Selected Demographic and Socioeconomic Variables	All Respondents		Haitian Respondents	
	(N=365)		(n=67)	
	Number	Percent	Number	Percent
Male	210	57.5%	35	52.2%
Female	155	42.5%	32	47.8%
Straight (heterosexual)	253	69.3%	65	97.0%
In care	296	81.1%	19	28.4%
Out of care	69	18.9%	48	71.6%
Primary Language				
English	275	75.3%	2	3.0%
Creole	66	18.1%	65	97.0%
Education Completed - none or 8th grade or less	47	12.9%	18	26.9%
Work situation in the past year - unemployed	236	64.7%	30	44.8%
Below 100% Federal Poverty Level	258	70.7%	55	82.1%

- More than a third (37.3%) of Haitian respondents are migrant or seasonal workers.
- 10.4% are women of childbearing age.
- 6% said they experienced mental illness and 4.5% said they used other (than IDU or methamphetamines) street drugs.
- 58.2% have been unable to find work during the previous 12 months.
- The rates of incarceration (1.5%), probation/parole (3%), street drug use (4.5%) and trading sex for money or drugs (0%) were much lower than among all respondents.
- 28.4% had been diagnosed with tuberculosis within the past 12 months compared to 6.8% of all respondents.

Comparison of Haitian Survey Respondents with All Respondents

Selected Risk Factors and Co-morbidities	All Respondents		Haitian Respondents	
	(N=365)		(n=67)	
	Number	Percent	Number	Percent
Survey Question 17A. During the past 12 months				
Migrant or seasonal worker	37	10.1%	25	37.3%
In jail or prison	38	10.4%	1	1.5%
on probation/parole	12	3.3%	2	3.0%
Used illegal drugs through injection/needle	8	2.2%	2	3.0%
Mental illness	26	7.1%	4	6.0%
Used methamphetamines	5	1.4%	0	0.0%
Used other street drug (including marijuana)	101	27.7%	3	4.5%
Traded sex for money or drugs	27	7.4%	0	0.0%
Woman of childbearing age (15-44 years old)	31	8.5%	7	10.4%
Domestic violence	8	2.2%	1	1.5%
Unable to find employment	95	26.0%	39	58.2%
Survey Question 21. Diagnosed in the past 12 months				
AIDS	75	20.5%	13	19.4%
Hepatitis A	9	2.5%	3	4.5%
Hepatitis B	27	7.4%	5	7.5%
Hepatitis C	49	13.4%	3	4.5%
Tuberculosis	25	6.8%	19	28.4%
Syphilis	27	7.4%	4	6.0%
Gonorrhea	13	3.6%	4	6.0%
Chlamydia	14	3.8%	2	3.0%
Other STD	16	4.4%	14	20.9%
Cancer	8	2.2%	0	0.0%
High Cholesterol	91	24.9%	23	34.3%
Liver Disease	28	7.7%	11	16.4%
Diabetes	27	7.4%	8	11.9%
Coronary Heart Disease	22	6.0%	5	7.5%

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 higher than the out of care rate of all respondents (28.4% compared to 18.9%).
- 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 (52.6% compared to 44.9%)
- The rate of Haitian out of care respondents who have not been recently diagnosed but have never been in care was nearly twice the rate of all out of care respondents (42.1% compared to 23.2%).
- While 26.1% of all out of care respondents had been receiving care but had stopped more than 12 months ago, none of the Haitian out of care respondents reported that situation.

Out of Care Circumstances

Survey Question 24A. What best describes your situation (check one only)				
Out of Care Situation	All Out of Care Respondents (n=69)		Haitian Out of Care Respondents (n=19)	
	number	percent	number	percent
I have recently been diagnosed with HIV, and have not entered primary care.	31	44.9%	10	52.6%
I have <u>not</u> been recently diagnosed but have never been in care.	16	23.2%	8	42.1%
I had been receiving medical care for HIV, but I stopped more than 12 months ago.	18	26.1%	0	0.0%
Other	2	2.9%	1	5.3%
No Response	2	2.9%	0	0.0%
Total	69	100.0%	19	100.0%

When asked why they did not get HIV/AIDS related medical care during the past year, out of care Haitian respondents most frequently mentioned “I was depressed” (63.2%, 12), I could not pay for services” (52.6%, 10) and “I missed my appointment (26.3%, 5).

The most frequently mentioned reasons among all respondents were “I did not feel sick” (47.8%, 33), “I did not know where to go” (26.1%, 18), and “I could not get transportation “18.8%, 13)

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 was depressed
- I missed my appointment

Survey Question 25A. Why did you not get HIV/AIDS related medical care the past year? (check any or all that apply)				
Out of Care Reasons	All Out of Care Respondents (n= 69)		Haitian Out of Care Respondents (n=19)	
	number	percent	number	percent
I did not know where to go.	18	26.1%	3	15.8%
I could not get an appointment.	4	5.8%	0	0.0%
I could not get transportation.	13	18.8%	2	10.5%
I could not get childcare.	0	0.0%	0	0.0%
I was too busy taking care of my partner.	2	2.9%	1	5.3%
I could not pay for services.	26	37.7%	10	52.6%
I did not want people to know that I have HIV.	29	42.0%	9	47.4%
I was not ready to deal with having HIV.	22	31.9%	6	31.6%
I did not feel sick.	33	47.8%	5	26.3%
There are not enough doctors in my area.	0	0.0%	0	0.0%
I could not get time off work.	8	11.6%	0	0.0%
I was depressed.	25	36.2%	12	63.2%
I missed my appointment(s).	8	11.6%	5	26.3%
I had a bad experience with the medical staff.	6	8.7%	0	0.0%
Other (e.g. drugs, recently diagnosed, in process)	6	8.7%	1	5.3%

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

- Financial assistance (All, 49.3%; Haitian, 68.4%)
- Food (All, 46.4%, Haitian 73.7%)
- Housing (All, 44.0%, Haitian, 63.2%)
- Case management (All, 40.6%; Haitian, 57.9%)
- Transportation (All, 36.2%, Haitian, 68.4%)

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

Services Needed to Get Into Primary Medical Care

Survey Question 27A. What services, other than medical care and medications, do you need to get into primary medical care? (check all that apply)				
Services	All Out Care Respondents (n=69)		Haitian Out Care Respondents (n=19)	
	number	percent	number	percent
Financial assistance	34	49.3%	13	68.4%
Food	32	46.4%	14	73.7%
Housing	31	44.9%	12	63.2%
Case management	28	40.6%	11	57.9%
Transportation	25	36.2%	13	68.4%
Substance abuse treatment	15	21.7%	2	10.5%
Mental health services	12	17.4%	5	26.3%
Legal services	11	15.9%	6	31.6%
Labs	11	15.9%	2	10.5%
Dental care	6	8.7%	3	15.8%
Treatment Adherence	5	7.2%	4	21.1%
Other (e.g. job, late appointments, might need mental health services later)	3	4.3%	3	15.8%

When asked “What would be some reasons you enter primary medical care?” the two most frequently cited reasons among all out of care and Haitian out of care respondents was “I get sick and know I need care” and “I am ready to deal with my illness”.

For Haitian out of care respondents, the next most important factors were “I get transportation to go to a doctor or clinic”, “I find a doctor or clinic where I do not have to wait very long in the waiting room”, “An outreach worker finds me and helps me get into care”, and “I find a medical facility that has evening or weekend hours.”

The table below summarizes all responses to this question.

Reasons to Enter Primary Medical Care

Survey Question 28A. What would be some reasons you enter primary medical care? (check any or all that apply)				
Reasons	Out of Care Respondents (n=69)		Haitian Out of Care Respondents (n=19)	
	number	percent	number	percent
I get sick and know I need care.	45	65.2%	9	47.4%
I am ready to deal with my illness.	20	29.0%	9	47.4%
Someone else with HIV/AIDS reaches out to me.	18	26.1%	1	5.3%
I get transportation to go to a doctor or clinic.	18	26.1%	6	31.6%
Someone arranges to have my care paid for.	18	26.1%	1	5.3%
I find a doctor or medical facility that ensures my confidentiality.	16	23.2%	4	21.1%
I find a doctor or clinic where I do not have to wait very long in the waiting room.	10	14.5%	6	31.6%
I get a referral to get into care.	7	10.1%	2	10.5%
I am able to deal with other problems in my life that keep me out of care.	7	10.1%	2	10.5%
I find a doctor or medical facility that I like and who accepts me.	6	8.7%	0	0.0%
An outreach worker finds me and helps me get into care.	6	8.7%	4	21.1%
I find a medical facility that has evening or weekend hours.	6	8.7%	4	21.1%
A family member or friend helps me get into care.	4	5.8%	1	5.3%
Other (insurance)	1	1.4%	0	0.0%

Prioritization of Service Categories

Haitian respondents who are in care, as well as all in care respondents selected Primary Medical Care and Laboratory Diagnostic Testing as the top two most important services. Both groups also included Case Management and Medical Specialist in their top five choices. Unlike all in care respondents, Haitian in care respondents did not identify Medications among the highest prioritized services and instead identified Nurse Care Coordination among the top five.

Five Most Important Services

Survey Question 77A. Which five services do you think are most important for people with HIV/AIDS?				
Service Category	All In Care Respondents (n=296)		Haitian In Care Respondents (n=48)	
	number	percent	number	percent
Primary Medical Care	218	73.6%	41	85.4%
Laboratory Diagnostic Testing	186	62.8%	39	81.3%
Medications	173	58.4%	7	14.6%
Case Management*	170	57.4%	36	75.0%
Medical Specialist	123	41.6%	38	79.2%
Oral/Dental Health	74	25.0%	1	2.1%
Food Bank/Home Delivered Meals	64	21.6%	2	4.2%
Health Insurance	52	17.6%	3	6.3%
Transportation	40	13.5%	1	2.1%
Nurse Care Coordination	38	12.8%	30	62.5%

*Case management functions as the EMA’s single point of entry, providing primary access to the EMA’s continuum of care. Clients’ initial eligibility must be determined by case managers, necessitating high utilization and prioritization of case management services. Once eligibility is established, case managers assist clients in navigating the continuum of care, or clients may choose to access some services (e.g. primary medical care) independently.

Service Needs and Utilization

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

- “need and use” if they utilize the service
- “do not need” if they do not utilize the service
- “need, can’t get” to show possible gaps in services
- “can get, won’t use” to show barriers in service utilization

Utilization: “Need and Use”

While there were differences in utilization patterns between all in care respondents and Haitian in care respondents, both groups cited medications and other core services as the most frequently utilized service categories. As highlighted in the following table, Haitian in care respondents also mentioned oral/dental health and nutritional counseling, mental health services, and health insurance.

Comparison of Service Utilization "Need and Use"

Utilized Service Categories	All in Care Respondents (n=296)			Haitian In Care Respondents (n=48)		
	rank	number	percent	rank	number	percent
CORE SERVICES						
Medical Care						
Primary Medical Care	2	225	76.0%		10	20.8%
Laboratory Diagnostic Testing	3	224	75.7%		10	20.8%
Medical Specialist	4	181	61.1%		9	18.8%
Nurse Care Coordination		56	18.9%		4	8.3%
Case Management		171	57.8%		5	10.4%
Medications	1	226	76.4%	1	37	77.1%
Oral/Dental Health	5	176	59.5%	2	35	72.9%
Health Insurance		102	34.5%	5	25	52.1%
Mental Health Services		88	29.7%	4	26	54.2%
Substance Abuse Treatment						
Substance Abuse Residential		33	11.1%		19	39.6%
Substance Abuse Outpatient		28	9.5%		13	27.1%
Nutrition Counseling		94	31.8%	3	28	58.3%

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

Comparison of Service Utilization "Need and Use"

Utilized Service Categories	All in Care Respondents (n=296)			Haitian In Care Respondents (n=48)		
	rank	number	percent	rank	number	percent
CORE SERVICES						
Medical Care						
Primary Medical Care	2	225	76.0%		10	20.8%
Laboratory Diagnostic Testing	3	224	75.7%		10	20.8%
Medical Specialist	4	181	61.1%		9	18.8%
Nurse Care Coordination		56	18.9%		4	8.3%
Case Management		171	57.8%		5	10.4%
Medications	1	226	76.4%	1	37	77.1%
Oral/Dental Health	5	176	59.5%	2	35	72.9%
Health Insurance		102	34.5%	5	25	52.1%
Mental Health Services		88	29.7%	4	26	54.2%
Substance Abuse Treatment						
Substance Abuse Residential		33	11.1%		19	39.6%
Substance Abuse Outpatient		28	9.5%		13	27.1%
Nutrition Counseling		94	31.8%	3	28	58.3%
Early Intervention Services		52	17.6%		24	50.0%
Home Health Care		24	8.1%		11	22.9%
Hospice		14	4.7%		10	20.8%
SUPPORT SERVICES						
Food Bank/Home Delivered Meals		99	33.4%		16	33.3%
Transportation		119	40.2%		21	43.8%
Outreach		47	15.9%		20	41.7%
Health Education/Risk Reduction		96	32.4%		22	45.8%
Treatment Adherence		96	32.4%		24	50.0%
Legal Services/Permanency		82	27.7%		19	39.6%
Rehabilitation Services		33	11.1%		9	18.8%
Emergency Financial Assistance		60	20.3%		7	14.6%
Linguistics Services		26	8.8%		19	39.6%
Support groups		89	30.1%		16	33.3%

Service Gaps: “Need, Can’t Get”

Like all in care respondents, Haitian respondents who are in care most frequently mentioned gaps in access to Emergency Financial Assistance, Food Bank/Home Delivery Meals, and Rehabilitation Services. Unlike all in care respondents, Haitian in care respondents also indicated gaps in Linguistic Services and Support Services.

Comparison of Gaps "Need But Can't Get"

Service Categories	All In Care Respondents (n=296)			Haitian In Care Respondents (n=48)		
	rank	number	percent	rank	number	percent
CORE SERVICES						
Medical Care						
Primary Medical Care		11	3.7%		2	4.2%
Laboratory Diagnostic Testing		12	4.1%		1	2.1%
Medical Specialist		16	5.4%		1	2.1%
Nurse Care Coordination		6	2.0%		0	0.0%
Case Management		22	7.4%		1	2.1%
Medications		9	3.0%		1	2.1%
Oral/Dental Health		25	8.4%		1	2.1%
Health Insurance	4	33	11.1%		8	16.7%
Mental Health Services		21	7.1%		6	12.5%
Substance Abuse Treatment						
Substance Abuse Residential		11	3.7%		3	6.3%
Substance Abuse Outpatient		11	3.7%		2	4.2%
Nutrition Counseling		21	7.1%		4	8.3%
Early Intervention Services		11	3.7%		2	4.2%
Home Health Care		11	3.7%		2	4.2%
Hospice		9	3.0%		3	6.3%
SUPPORT SERVICES						
Food Bank/Home Delivered Meals	1	78	26.4%	2	14	29.2%
Transportation	3	42	14.2%		7	14.6%
Outreach		9	3.0%		3	6.3%
Health Education/Risk Reduction		14	4.7%		4	8.3%
Treatment Adherence		10	3.4%		4	8.3%
Legal Services/Permanency	5	24	8.1%		4	8.3%
Rehabilitation Services	5	24	8.1%	4	10	20.8%
Emergency Financial Assistance	2	63	21.3%	1	21	43.8%
Linguistics Services		19	6.4%	3	11	22.9%
Support groups		22	7.4%	5	9	18.8%
Other (housing, app't. reminders)		5	1.7%		0	0.0%

Barriers to Services: “Needed But Didn’t Know About Services”

Like all respondents in care, Haitian in care respondents most frequently reported barriers to Support Services rather than to Core Services. The services most frequently mentioned by Haitian respondents in care include Rehabilitation Services, Legal Services/Permanency, Emergency Financial Assistance, and Health Education/Risk Reduction. The following table summarizes all responses to this question:

Comparison of Barriers "Needed But Didn't Know About Services"

Service Categories	All In Care Respondents (n=296)			Haitian In Care Respondents (n=48)		
	rank	number	percent	rank	number	percent
CORE SERVICES						
Medical Care						
Primary Medical Care		3	1.0%		0	0.0%
Laboratory Diagnostic Testing		5	1.7%		0	0.0%
Medical Specialist		7	2.4%		0	0.0%
Nurse Care Coordination		9	3.0%		0	0.0%
Case Management		11	3.7%		1	2.1%
Medications		3	1.0%		0	0.0%
Oral/Dental Health		18	6.1%		1	2.1%
Health Insurance		15	5.1%		3	6.3%
Mental Health Services		19	6.4%		2	4.2%
Substance Abuse Treatment						
Substance Abuse Residential		10	3.4%		1	2.1%
Substance Abuse Outpatient		7	2.4%		0	0.0%
Nutrition Counseling		17	5.7%		2	4.2%
Early Intervention Services		5	1.7%		1	2.1%
Home Health Care		12	4.1%	4	6	12.5%
Hospice		10	3.4%	4	6	12.5%
SUPPORT SERVICES						
Food Bank/Home Delivered Meals	2	28	9.5%		3	6.3%
Transportation	5	19	6.4%	5	5	10.4%
Outreach	4	21	7.1%	5	5	10.4%
Health Education/Risk Reduction	5	19	6.4%	3	7	14.6%
Treatment Adherence		15	5.1%		4	8.3%
Legal Services/Permanency	1	33	11.1%	2	9	18.8%
Rehabilitation Services		17	5.7%	1	11	22.9%
Emergency Financial Assistance	1	33	11.1%	3	7	14.6%
Linguistics Services		7	2.4%		2	4.2%
Support groups	3	22	7.4%		4	8.3%

Focus Group Findings: Themes and Notable Quotes

The focus group of Haitian PLWH/A was conducted with a Creole translator present in order to ensure accurate input from Creole speaking participants.

The focus group was convened in Belle Glade in the western, rural area of the county. The facilitator and the group members spoke in Creole. Excerpts of the discussion were translated into English for analysis.

Recurrent themes of continued reliance on case management, medical care, medications, and transportation were discussed throughout the group session. Participants also expressed their ongoing fears and anxieties regarding immigration status and financial and housing insecurities exacerbated by HIV.

“Some people don’t have (legal) status so they’re scared to go to the doctor. They are scared but refuse to go to the doctor you not to deport me to Haiti.”

When asked about what it would take to persuade PWHA/A who are not in care to get back into care, respondents again expressed the need to help people overcome fear.

“Maybe we make the outreach and a few people I speak to them I come here, they come here, I am scared.”

When asked what helped them to get into care and stay in care, participants noted the importance of case management.

“...because the medications are good and we have a good case manager. We would like to live more and we have family in Haiti.”

“Whenever we have a problem our case manager’s always there.”

“Very good, very good, here to help us.”

“Very good for me. I love them.”

When asked about what services are needed to help get back in care, participants expressed the inextricable link between clinical and support services.

“Bus passes very good. We need clinic very good. Very good always very good helping us... Very good at CAP people are helping us. Case Manager always calls...and speaks...”

“Very good very good system. Go to the doctor. Case manager is always there to help us. She will always help us.”

When asked about services they need but can't get, the only specific services mentioned was financial assistance for housing. However, participants expressed their need for continued help with services.

"I would like help paying my rent but I would like to live where I know people because I live in housing and I have found that they are helpful."

"Whatever we need we find it but we want it to continue nonstop yes."

"In Palm Beach County we have help. The help is here in this office so that we have Mr. Mario, Ms. Evelyn. These people are there they help us."

3. AFRICAN AMERICAN WOMEN

Unique Challenges

African-American women face many barriers to care and experience many factors that complicate their care. Poverty, limited education, lack of health insurance, immigration status, and lack of transportation continue to be significant problems for these women. Many African-American PLWH/A women feel disempowered in their relationships with men, 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. There are high rates of reported stigma attached to HIV/AIDS, creating a culture of denial that results in low-income African-American women not learning they are HIV positive until they become pregnant. 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. Many African-American women 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. Additional factors such as partner domestic violence compound safety, security, and preventive health behaviors.¹⁹

Service Gaps

The 2010 Needs Assessment survey included 128 African American female respondents. 86% reported they were in care. 17% had either no schooling or an education level of 8th grade less, almost three-fourths were unemployed, and 82% were living at or below the poverty level. 89% indicated they were heterosexual.

Out of Care African-American Women Respondents

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 African American females was, “I have recently been diagnosed with HIV, and have not entered primary care.” The second most frequently described situation for African American females was “I have not been recently diagnosed but have never been in care.” Respondents were asked to identify the reasons for being out of care. In each group (all out of care respondents and African American female out of care respondents), the most frequently cited reason in was, “I am afraid of being identified as HIV-positive.” When asked what services they needed to get into primary medical care, out of care respondents as a whole and African- American female out of care respondents mentioned the same top service categories (financial assistance, food, housing, case management, and transportation) as all out of care respondents. In nearly every category (except financial assistance), a larger percentage of African American females indicated the need for the services.

In Care African-American Women Respondents

African American female in care respondents and all in care respondents most frequently identified the leading service gaps (“need but can’t get”) to be Food Bank/Home

¹⁹ Miami-Dade HIV/AIDS Partnership (2009). *Comprehensive Plan for HIV/AIDS 2009-2011*.

Delivered Meals, Emergency Financial Assistance, Transportation, Health Insurance, and Legal Services. African American females also reported a gap in Oral/Dental Health. All in care respondents and African American female respondents reported similarly low levels of barriers to services (“needed but didn’t know about”). The barriers most frequently cited by African American females were Rehabilitative Services and Legal Services/Permanency Planning.

African-American Women Focus Group Findings

When participants were asked why they or others they knew were out of care, their discussion focused on various combinations of fear, lack of knowledge about the disease and available treatment, denial, addiction, and barriers to accessing care due to lack of knowledge or financial resources. Participants discussed what they think it would take to persuade a person to get into care for the first time or to return to care after being out of care. Their responses focused on providing support and education. There was extensive discussion among participants regarding the importance of assuring their access to medical care, especially prescription medications. Several participants discussed fear and worry regarding funding cuts, wait lists, and barriers. As participants discussed the complex maze of access to prescription medications, they mentioned a wide assortment of funding jargon and resources. In addition to issues related to access, participants also discussed complications with medications and problems with side-effects.

Data related to African American women respondents:

- 128 (35% of all respondents) indicated they were African American women.
- 89.1% said they are straight (heterosexual)
- 85.9% are in care, compared to 81.1% of all respondents.
- 14.1% are out of care, compared to 18.9% of all respondents.
- 21.4% said Creole is their primary language.
- 16.7% of African American female respondents had either no schooling or an education level of 8th grade less compared to 12.9% of all respondents.
- 72.2% described their work situation in the past year as “unemployed” compared to 64.7% of all respondents.
- 81.7% were living at or below 100% FPL compared to 70.7% of all respondents.

Please see the following pages for additional data and analysis.

Additional findings are summarized in the following table. Findings regarding selected risk factors and co-morbidities are summarized on the next page.

Comparison of African American Women Survey Respondents with All Respondents

Selected Demographic and Socioeconomic Variables	All Respondents		African American Women Respondents	
	(N=365)		(n=128)	
	Number	Percent	Number	Percent
Male	210	57.5%	0	0.0%
Female	155	42.5%	128	100.0%
Straight (heterosexual)	253	69.3%	114	89.1%
In care	296	81.1%	110	85.9%
Out of care	69	18.9%	18	14.1%
Primary Language				
English	275	75.3%	98	77.8%
Creole	66	18.1%	27	21.4%
Education Completed - none or 8th grade or less	47	12.9%	21	16.7%
Work situation in the past year - unemployed	236	64.7%	91	72.2%
Below 100% Federal Poverty Level	258	70.7%	103	81.7%

When asked about specific experiences during the past 12 months, African American female respondents reported the following:

- 7% said they were migrant or seasonal workers.
- 7% said they were in jail or prison; 3.1% were on probation/parole.
- 16.4% are women of childbearing age.
- 9.4% said they experienced mental illness and 28.9% said they used drugs other (than IDU or methamphetamines) than street drugs.
- 10.2% had traded sex for money or drugs compared to 7.4% of all respondents.
- 32% have been unable to find work during the previous 12 months.
- 6.3% had experienced domestic violence compared to 2.2% of all respondents.
- 5.5% had been diagnosed with tuberculosis within the past 12 months compared to 6.8% of all respondents.

The following table summarizes all responses to these questions.

Comparison of African American Women Respondents with All Respondents

Selected Risk Factors and Co-morbidities	All Respondents		African American Women Respondents	
	(N=365)		(n=128)	
	Number	Percent	Number	Percent
Survey Question 17A. During the past 12 months...				
Migrant or seasonal worker	37	10.1%	9	7.0%
In jail or prison	38	10.4%	9	7.0%
on probation/parole	12	3.3%	4	3.1%
Used illegal drugs through injection/needle	8	2.2%	0	0.0%
Mental illness	26	7.1%	12	9.4%
Used methamphetamines	5	1.4%	1	0.8%
Used other street drug (including marijuana)	101	27.7%	37	28.9%
Traded sex for money or drugs	27	7.4%	13	10.2%
Woman of childbearing age (15-44 years old)	31	8.5%	21	16.4%
Domestic violence	8	2.2%	8	6.3%
Unable to find employment	95	26.0%	41	32.0%
Survey Question 21. Diagnosed in the past 12 months...				
AIDS	75	20.5%	26	20.3%
Hepatitis A	9	2.5%	2	1.6%
Hepatitis B	27	7.4%	11	8.6%
Hepatitis C	49	13.4%	17	13.3%
Tuberculosis	25	6.8%	7	5.5%
Syphilis	27	7.4%	10	7.8%
Gonorrhea	13	3.6%	5	3.9%
Chlamydia	14	3.8%	8	6.3%
Other STD	16	4.4%	6	4.7%
Cancer	8	2.2%	1	0.8%
High Cholesterol	91	24.9%	33	25.8%
Liver Disease	28	7.7%	12	9.4%
Diabetes	27	7.4%	11	8.6%
Coronary Heart Disease	22	6.0%	10	7.8%

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 African American females was, “I have recently been diagnosed with HIV, and have not entered primary care. The second most frequently described situation for African American females was “I have not been recently diagnosed but have never been in care.”

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

Out of Care Circumstances

Survey Question 24A. What best describes your situation (check one only)				
Out of Care Situation	All Out of Care Respondents		African American Women Out of Care Respondents	
	(n=69)		(n=18)	
	number	percent	number	percent
I have recently been diagnosed with HIV, and have not entered primary care.	31	44.9%	9	50.0%
I had been receiving medical care for HIV, but I stopped more than 12 months ago.	18	26.1%	3	16.7%
I have <u>not</u> been recently diagnosed but have never been in care.	16	23.2%	4	22.2%
Other (e.g. Don't want to be bothered; I found people I know will tell about me.)	2	2.9%	2	11.1%
No Response	2	1.4%	0	0.0%
Total	69	100.0%	18	100.0%

Respondents were asked to identify the reasons for being out of care. In each group (all out of care respondents and African American female out of care respondents), responses were fairly evenly distributed among five reasons. The most frequently cited reason in both groups was, “I am afraid of being identified as HIV-positive.” The following table summarizes all responses to this question.

Survey Question 25A. Why did you not get HIV/AIDS related medical care the past year? (check any or all that apply)				
Out of Care Reasons	All Out of Care Respondents		African American Women Out of Care Respondents	
	(n=69)		(n=18)	
	number	percent	number	percent
I did not know where to go.	18	26.1%	4	22.2%
I could not get an appointment.	4	5.8%	0	0.0%
I could not get transportation.	13	18.8%	2	11.1%
I could not get childcare.	0	0.0%	0	0.0%
I was too busy taking care of my partner.	2	2.9%	1	5.6%
I could not pay for services.	26	37.7%	10	55.6%
I did not want people to know that I have HIV.	29	42.0%	9	50.0%
I was not ready to deal with having HIV.	22	31.9%	5	27.8%
I did not feel sick.	33	47.8%	7	38.9%
There are not enough doctors in my area.	0	0.0%	0	0.0%
I could not get time off work.	8	11.6%	0	0.0%
I was depressed.	25	36.2%	12	66.7%
I missed my appointment(s).	8	11.6%	2	11.1%
I had a bad experience with the medical staff.	6	8.7%	2	11.1%
Other (e.g. drugs; recently diagnosed; in process)	6	8.7%	1	5.6%

When asked what services they needed to get into primary medical care, out of care respondents as a whole and black heterosexual out of care respondents mentioned the same top five service categories as all out of care respondents. In nearly every category (except financial assistance and labs), a larger percentage of African American females indicated the need for specific services to get into care.

The table below displays all responses to this question.

Services Needed to Get Into Primary Medical Care

Survey Question 27A. What services, other than medical care and medications, do you need to get into primary medical care? (check all that apply)				
Services	All Out of Care Respondents (n=69)		African American Women Out of Care Respondents (n=18)	
	number	percent	number	percent
Financial assistance	34	49.3%	8	44.4%
Food	32	46.4%	11	61.1%
Housing	31	44.9%	10	55.6%
Case management	28	40.6%	10	55.6%
Transportation	25	36.2%	9	50.0%
Substance abuse treatment	15	21.7%	4	22.2%
Mental health services	12	17.4%	4	22.2%
Legal services	11	15.9%	3	16.7%
Labs	11	15.9%	2	11.1%
Dental care	6	8.7%	3	16.7%
Treatment Adherence	5	7.2%	3	16.7%
Other (e.g. job, late appointments, might need mental health services later)	3	4.3%	0	0.0%

The reasons cited by out of care African American females regarding why they would enter primary 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 Primary Medical Care

Survey Question 28A. What would be some reasons you enter primary medical care? (check any or all that apply)				
Reasons	Out of Care Respondents (n=69)		African American Women Out of Care Respondents (n=18)	
	number	percent	number	percent
I get sick and know I need care.	45	65.2%	10	55.6%
I am ready to deal with my illness.	20	29.0%	10	55.6%
Someone else with HIV/AIDS reaches out to me.	18	26.1%	3	16.7%
I get transportation to go to a doctor or clinic.	18	26.1%	4	22.2%
Someone arranges to have my care paid for.	18	26.1%	4	22.2%
I find a doctor or medical facility that ensures my confidentiality.	16	23.2%	6	33.3%
I find a doctor or clinic where I do not have to wait very long in the waiting room.	10	14.5%	4	22.2%
I get a referral to get into care.	7	10.1%	0	0.0%
I am able to deal with other problems in my life that keep me out of care.	7	10.1%	2	11.1%
I find a doctor or medical facility that I like and who accepts me.	6	8.7%	2	11.1%
An outreach worker finds me and helps me get into care.	6	8.7%	0	0.0%
I find a medical facility that has evening or weekend hours.	6	8.7%	0	0.0%
A family member or friend helps me get into care.	4	5.8%	0	0.0%
Other (insurance)	1	1.4%	0	0.0%

Prioritization of Service Categories

African American female in care respondents and all in care respondents selected the same five service categories as their top priorities. Both groups identified Primary Medical Care and Laboratory Diagnostic Testing as their two most important service categories. Notably, 60.9% of African American females ranked Medical Specialists as one of the most important services compared to 41.6% of all respondents.

Five Most Important Services

Survey Question 77A. Which five services do you think are most important for people with HIV/AIDS?				
Service Category	In Care Respondents (n=296)		African American Women In Care Respondents (n=110)	
	number	percent	number	percent
Primary Medical Care	218	73.6%	88	80.0%
Laboratory Diagnostic Testing	186	62.8%	76	69.1%
Medications	173	58.4%	58	52.7%
Case Management	170	57.4%	63	57.3%
Medical Specialist	123	41.6%	67	60.9%
Case management functions as the EMA’s single point of entry, providing primary access to the EMA’s continuum of care. Clients’ initial eligibility must be determined by case managers, necessitating high utilization and prioritization of case management services. Once eligibility is established, case managers assist clients in navigating the continuum of care, or clients may choose to access some services (e.g. primary medical care) independently.				

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

Five Most Important Services

Survey Question 77A. Which five services do you think are most important for people with HIV/AIDS?				
Service Category	In Care Respondents (n=296)		African American Women In Care Respondents (n=110)	
	number	percent	number	percent
Primary Medical Care	218	73.6%	88	80.0%
Laboratory Diagnostic Testing	186	62.8%	76	69.1%
Medications	173	58.4%	58	52.7%
Case Management	170	57.4%	63	57.3%
Medical Specialist	123	41.6%	67	60.9%
Oral/Dental Health	74	25.0%	23	20.9%
Food Bank/Home Delivered Meals	64	21.6%	27	24.5%
Health Insurance	52	17.6%	17	15.5%
Transportation	40	13.5%	14	12.7%
Nurse Care Coordination	38	12.8%		0.0%
Emergency Financial Assistance (help paying for utilities, appliances, etc.)	35	11.8%	15	13.6%
Mental Health Services	20	6.8%	7	6.4%
Support groups	18	6.1%	7	6.4%
Legal Services/Permanency	14	4.7%	1	0.9%
Substance Abuse Residential	13	4.4%	6	5.5%
Nutrition Counseling	13	4.4%	4	3.6%
Early Intervention Services (HIV testing & counseling, medical evaluation)	8	2.7%	3	2.7%
Outreach	7	2.4%	2	1.8%
Home Health Care	6	2.0%	1	0.9%
Health Education/Risk Reduction	4	1.4%	2	1.8%
Rehabilitation Services	3	1.0%	0	0.0%
Linguistics Services (interpretation & translation services)	3	1.0%	0	0.0%
Substance Abuse Outpatient	1	0.3%	0	0.0%
Hospice	1	0.3%	1	0.9%
Treatment Adherence	1	0.3%	0	0.0%

Other (e.g. housing, meeting people my age with HIV, appointment reminder)	5	1.7%	2	1.8%
No response	22	7.4%	8	7.3%
Total In Care Respondents	296	100.0%	110	100.0%

Service Needs and Utilization

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

- “need and use” if they utilize the service
- “do not need” if they do not utilize the service
- “need, can’t get” to show possible gaps in services
- “can get, won’t use” to show barriers in service utilization

Utilization: “Need and Use”

When asked to identify the services they need and use, in care African American female 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, medications, and medical specialists were the four most frequently utilized services by both groups. Among African American females, the fifth most frequently utilized service was case management.

Comparison of Service Utilization "Need and Use"

Utilized Service Categories	All In Care Respondents (n=296)			African American Women In Care Respondents (n=110)		
	rank	number	percent	rank	number	percent
CORE SERVICES						
Medical Care						
Primary Medical Care	2	225	76.0%	1	86	78.2%
Laboratory Diagnostic Testing	3	224	75.7%	2	82	74.5%
Medical Specialist	4	181	61.1%	4	75	68.2%
Nurse Care Coordination		56	18.9%		22	20.0%
Case Management		171	57.8%	5	71	64.5%
Medications	1	226	76.4%	3	81	73.6%
Oral/Dental Health	5	176	59.5%		69	62.7%

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

Comparison of Service Utilization "Need and Use"

Utilized Service Categories	All In Care Respondents (n=296)			African American Women In Care Respondents (n=110)		
	rank	number	percent	rank	number	percent
CORE SERVICES						
Medical Care						
Primary Medical Care	2	225	76.0%	1	86	78.2%
Laboratory Diagnostic Testing	3	224	75.7%	2	82	74.5%
Medical Specialist	4	181	61.1%	4	75	68.2%
Nurse Care Coordination		56	18.9%		22	20.0%
Case Management		171	57.8%	5	71	64.5%
Medications	1	226	76.4%	3	81	73.6%
Oral/Dental Health	5	176	59.5%		69	62.7%
Health Insurance		102	34.5%		30	27.3%
Mental Health Services		88	29.7%		33	30.0%
Substance Abuse Treatment						
Substance Abuse Residential		33	11.1%		10	9.1%
Substance Abuse Outpatient		28	9.5%		11	10.0%
Nutrition Counseling		94	31.8%		42	38.2%
Early Intervention Services		52	17.6%		19	17.3%
Home Health Care		24	8.1%		5	4.5%
Hospice		14	4.7%		4	3.6%
SUPPORT SERVICES						
Food Bank/Home Delivered Meals		99	33.4%		36	32.7%
Transportation		119	40.2%		54	49.1%
Outreach		47	15.9%		20	18.2%
Health Education/Risk Reduction		96	32.4%		40	36.4%
Treatment Adherence		96	32.4%		41	37.3%
Legal Services/Permanency		82	27.7%		32	29.1%
Rehabilitation Services		33	11.1%		12	10.9%
Emergency Financial Assistance		60	20.3%		25	22.7%
Linguistics Services		26	8.8%		8	7.3%
Support groups		89	30.1%		35	31.8%

Service Gaps: “Need, Can’t Get”

African American female in care respondents and all in care respondents most frequently identified the leading service gaps to be food bank/home delivered meals, emergency financial assistance, transportation, health insurance, and legal services. African American females also said they needed but couldn’t get oral/dental health services. The following table displays all responses to this survey item.

Comparison of Gaps "Need But Can't Get"

Service Categories	All in Care Respondents (n=296)			African American Women in Care Respondents (n=110)		
	rank	number	percent	rank	number	percent
CORE SERVICES						
Medical Care						
Primary Medical Care		11	3.7%		3	2.7%
Laboratory Diagnostic Testing		12	4.1%		5	4.5%
Medical Specialist		16	5.4%		7	6.4%
Nurse Care Coordination		6	2.0%		0	0.0%
Case Management		22	7.4%		5	4.5%
Medications		9	3.0%		5	4.5%
Oral/Dental Health		25	8.4%	5	11	10.0%
Health Insurance	4	33	11.1%	4	14	12.7%
Mental Health Services		21	7.1%		7	6.4%
Substance Abuse Treatment						
Substance Abuse Residential		11	3.7%		6	5.5%
Substance Abuse Outpatient		11	3.7%		3	2.7%
Nutrition Counseling		21	7.1%		9	8.2%
Early Intervention Services		11	3.7%		4	3.6%
Home Health Care		11	3.7%		3	2.7%
Hospice		9	3.0%		2	1.8%
SUPPORT SERVICES						
Food Bank/Home Delivered Meals	1	78	26.4%	1	38	34.5%
Transportation	3	42	14.2%	3	18	16.4%
Outreach		9	3.0%		2	1.8%
Health Education/Risk Reduction		14	4.7%		3	2.7%
Treatment Adherence		10	3.4%		4	3.6%
Legal Services/Permanency	5	24	8.1%	5	11	10.0%
Rehabilitation Services	5	24	8.1%		9	8.2%
Emergency Financial Assistance	2	63	21.3%	2	23	20.9%
Linguistics Services		19	6.4%		4	3.6%
Support groups		22	7.4%		4	3.6%
Other (housing, app't. reminders)		5	1.7%		2	1.8%

Barriers to Services: “Needed But Didn’t Know About Services”

All in care respondents and African American female respondents reported similarly low levels of barriers to services. The barriers most frequently cited by African American females were rehabilitative services and legal services/permanency.

Comparison of Barriers "Needed But Didn't Know About Services"

Service Categories	All In Care Respondents (n=296)			African American Women In Care Respondents (n=110)		
	rank	number	percent	rank	number	percent
CORE SERVICES						
Medical Care						
Primary Medical Care		3	1.0%		0	0.0%
Laboratory Diagnostic Testing		5	1.7%		0	0.0%
Medical Specialist		7	2.4%		0	0.0%
Nurse Care Coordination		9	3.0%		0	0.0%
Case Management		11	3.7%		1	0.9%
Medications		3	1.0%		0	0.0%
Oral/Dental Health		18	6.1%		1	0.9%
Health Insurance		15	5.1%		3	2.7%
Mental Health Services		19	6.4%		2	1.8%
Substance Abuse Treatment						
Substance Abuse Residential		10	3.4%		1	0.9%
Substance Abuse Outpatient		7	2.4%		0	0.0%
Nutrition Counseling		17	5.7%		2	1.8%
Early Intervention Services		5	1.7%		1	0.9%
Home Health Care		12	4.1%	4	6	5.5%
Hospice		10	3.4%	4	6	5.5%
SUPPORT SERVICES						
Food Bank/Home Delivered Meals	2	28	9.5%		3	2.7%
Transportation	5	19	6.4%	5	5	4.5%
Outreach	4	21	7.1%	5	5	4.5%
Health Education/Risk Reduction	5	19	6.4%	3	7	6.4%
Treatment Adherence		15	5.1%		4	3.6%
Legal Services/Permanency	1	33	11.1%	2	9	8.2%
Rehabilitation Services		17	5.7%	1	11	10.0%
Emergency Financial Assistance	1	33	11.1%	3	7	6.4%
Linguistics Services		7	2.4%		2	1.8%
Support groups	3	22	7.4%		4	3.6%

Focus Group Findings: Themes and Notable Quotes

The focus group responses from HIV positive African American Females were consistent with the survey responses from this population. The focus group was held in Riviera Beach, in the northeastern area of the county.

When participants were asked why they or people they know were not in care were asked why they were out of care, their discussion focused on various combinations of the following:

- Fear
- Lack of knowledge about the disease and available treatment
- Denial
- Addiction
- Barriers to accessing care due to lack of knowledge or financial resources

Examples of their responses include the following:

- “I feel that it’s denial...” When people are first diagnosed, they “become in a state of denial...no one accepts it...”
- “...They are out in the street on drugs and they don’t have time...to take care of themselves. That’s mostly what I see.”
- “Well I know one that they don’t have insurance and don’t have the money for it because their medicine is expensive. I know one, they want care but they don’t have insurance.”
- “When I was not in care I just wasn’t adhering to anything because part of me was in denial...a part of me wanted to get some help with my addiction ...the holdback because I felt like I wanted to keep getting high and the keep getting high off part of me was still in denial as it didn’t want to stop. Bet then I had a will to live one day and I went in to care and I’ve been in care 12 years.”

Participants discussed what they think it would take to persuade a person to get into care for the first time or to return to care after being out of care. Their responses focused on providing support and education:

- Education regarding the disease, medications available to treat it, and help to access care help a person to “...have the willpower to want to live”.
- Support groups to provide unity, trust, hope, concern, sharing, encouragement, information, experience.

“It’s just the type of unity the support groups provided back then, way back in 1989 when I went as it was the Health Department...at 36th Street and Broadway.”

“I can see other people in the frame of mind I used to be in and I let them know about the mindset. I try to encourage them that they can do what we are doing to live. You don’t have to die...it’s not a death sentence no more...we can live...”

There was extensive discussion among participants regarding the importance of assuring their access to medical care, especially prescription medications. Several participants discussed fear and worry regarding funding cuts, wait lists, and barriers:

“...I went 15 years without medicine so the support groups were very helpful. I couldn’t even get my medicine when I started ...now am I to lose all of that next month and I won’t be able to have my medicine anymore? So we need access to care and better medical care so that we can afford the drugs to take the medicine as it is a manageable treatable virus and you can live...”

“...I’m not getting out of care as long as they don’t stop paying for that stuff because I can’t pay for it. I need them to keep paying for my medicine, I can’t afford it.”

“You know the sad thing about that is the medicine, it does sustain our lives is so expensive.”

As participants discussed the complex maze of access to prescription medications, they mentioned a wide assortment of funding jargon and resources:

- Healthcare District (There was a lot of discussion about whether or not Healthcare District was a resource.)
- Health Department
- Bio Script (One participant commented, “I’ve never heard of it.”)
- Temporary Medicaid
- Medically Needy
- ADAP
- ADAP waiting list (One participant commented, “They got a what?”)
- Non-HIV drugs
- Co-pays
- Pharmacy from Dido script, the lady there helps you get Healthcare District
- COM care
- Delray Health Department
- Blue Cross Blue Shield
- Medicaid Option 3
- “...the case manager might be doing something else with you might not be aware of his action once two and three...”

One person succinctly expressed the solution to their conflicting opinions regarding how to access medication:

“You’ll need to call a case manager in here from CAP, (to tell you) what y’all need to know.”

Another articulated frustration with on-going barriers to access:

“Now that I’m not working I’m struggling to get that access that I need, struggling to get access to care, we need these focus groups.”

In addition to issues related to access, participants also discussed complications with medications and problems side-effects:

“I’ve been having problems with my medication and side effects. I can be on...two for about six months...last time my liver went out of whack...”

“I’ve been through so many meds, I just wanted to give at one point...(the doctor) is getting ready to do a genotype and now I’ve got to go try something else now.”

“...we/re used as guinea pigs...it’s okay with me if it’s going to make somebody else live ...because somebody else was a guinea pig before me and given me that chance to live...”

Several participants discussed a range of troublesome side effects and express that they think their doctors should tell them in advance.

“...all medications have side effects...my heart starts fluttering...I went to a seminar and they told me they say some medications make your hear flutter, some medications give you neuropathy...:

“...why don’t they tell us when we’re taking these medications...all this kind of stuff (i.e. sugar, salt, sodas) makes our stomach stand out and make us look like we’re nine months pregnant?”

“But what I’m saying is they should tell us the side effects of these medications and treat us for them.”

Participants made the following comments regarding HIV services they need and the quality of services they have received:

“...I’m denied a lot of services as they say I make too much money and this is so not true to be a single parent and I mean that’s why I don’t get all those care and services that I need.”

“...They tell you not to eat Ramen noodles but that’s all you can afford is cups of noodles.”

When one of the participants was explaining problems with getting authorization for prescription glasses, another participant advised, “...(bring it) to your case manager...and they’ll do that for you. I do that every year.”

“We can help somebody else so we need some more support groups for each other.”

4. MEN RECENTLY RELEASED FROM INCARCERATION

Recently Released Former Prisoners

In 2009, 3% of PLWH/A in Palm Beach County had been released from state corrections facilities within the past 3 years, compared to 0.2% of the county's general population. Thus, the rate of recent state incarceration among the PLWH/A population is 15 times the rate in the general population

The Florida corrections system has two types of incarceration facilities: prisons, which are funded and operated by the state Department of Corrections, and jails, which are operated and funded by local county governments.²⁰ The above figures pertain to the prisons; analogous data for jails and for Federal facilities are not available at this time.

The average length of stay in prisons is three to five years, and the prisons are mandated to test each inmate for HIV within 60 days of release. The average length of stay in jails is 23 to 46 days and the jails are not required to test inmates for HIV unless they have been convicted of a sex crime.²¹ In 2009, 3,235 jail inmates in Palm Beach County were tested for HIV and 0.4% of these tested positive.²²

In 2008 (latest date available), the average daily population in Palm Beach County jails was 3,006.²³ Applying the above HIV-positive jail rate (0.4%), it can be estimated that there are approximately 12 PLWHAs in Palm Beach County jails on an average day. Since the average jail stay is less than two months, all of these individuals would be released back into the community within a year's period.

The Florida Department of Health operates a Pre-Release Planning Program in all the state prisons. The program is responsible for offering pre-release services to all known HIV-positive prisoners. Four pre-release planners cover the entire state. The pre-release planners provide services directly to the inmate within six months of their release date to determine the community to which the inmate is returning and what type of services he/she will need. The pre-release planner contacts at least one or two social service agencies or medical providers to connect the client to the care system prior to their release. Upon release, the clients are given a copy of their medical records (if requested) and a 30-day supply of medication. Pre-release planners follow up with the ex-offender and/or provider after one month to determine if the initial medical or social service appointment was kept. Additionally, the Florida Department of Health operates a jail linkage program in Palm Beach County to implement transitional services in the local jails. This program includes counseling and testing for HIV/AIDS, tuberculosis, hepatitis, and STIs; prevention education; pre-release planning; and follow-up services.²⁴

²⁰ Florida Department of Health, Bureau of HIV/AIDS (2010). *Florida Corrections Programs*.

²¹ Ibid.

²² Florida Department of Health, Bureau of HIV/AIDS (2010). *Florida's Corrections Programs: 2009 Annual Report*.

²³ Florida Department of Corrections (2009). *Jail Populations and Incarceration Rates by County*.

²⁴ Florida Department of Health, Bureau of HIV/AIDS (2010). *Florida Corrections Programs: 2009 Annual Report*.

In 2009), 68 PLWHA inmates in Palm Beach County were linked to services, and 96% of them kept their initial appointment.²⁵

In 2010, the Palm Beach County's HIV CARE Council conducted a survey of 117 PLWH/As who had been released from jail or prison within the past 12 months. 17 of these were currently out of care. The most frequently cited reasons for being out of care were lack of insurance or money to pay for care (65%); using drugs or alcohol (65%); lack of transportation (42%); not being ready to deal with one's HIV status (35%); and homelessness (29%). The recently incarcerated out of care respondents most frequently cited financial assistance (89%); food and transportation (83% each); housing (72%); and substance abuse treatment (61%) as their most needed services.²⁶ In a focus group of recently incarcerated male PLWHA in care, respondents indicated that the linkage program had helped them get into care. They expressed 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.²⁷ Clearly, recently released former prisoners add to the cost and complexity of the service delivery system, particularly in regard to enhancing follow-through to help them remain in care upon release.

Unique Challenges

Because, 26 (96.3%) of the men who had been released within the past 12 months were African American, the following narrative focuses on their unique challenges.

HIV/AIDS service provision to the African-American community is complicated; the documented "down low" phenomenon among African-American men that contributes to increased STI and HIV infections in the community for both men and women. The economic and social ramifications of poverty in this community contribute to high levels of substance abuse, diagnosis at a later stage of illness, and other collateral problems. Stigma and lack of insurance are additional complicating factors that often result in late entry into care. African-Americans are also significantly more likely to drop out of care than other racial/ethnic groups.²⁸ Further, unique challenges to service delivery for recently incarcerated African-American men include substance abuse, lack of transportation, not being ready to deal with one's HIV status, and homelessness.²⁹

Service Gaps

The 2010 Needs Assessment survey included 27 men who had been incarcerated in the past 12 months. 10 of these were out of care, and 23 lived at or below 100% of the federal poverty level.

²⁵ Florida Department of Health, Bureau of HIV/AIDS (2010). *Florida Corrections Programs: 2009 Annual Report*.

²⁶ Treasure Coast Health Council (2010). *PLWH/A Released from Jail/Prison in last 12 months*.

²⁷ Treasure Coast Health Council (2007). *Comprehensive Needs Assessment 2007-2010*.

²⁸ Miami-Dade HIV/AIDS Partnership (2009). *Comprehensive Plan for HIV/AIDS 2009-2011*.

²⁹ Treasure Coast Health Council (2010). *PLWH/A Released from Jail/Prison in last 12 months*.

Out of Care Incarcerated Men Respondents

The ten respondents who are out of care were asked to describe their situation. As among all out of care respondents, out of care respondents who were recently incarcerated most frequently mentioned, “I had been receiving medical care for HIV, but I stopped more than 12 months ago.” Like all out of care respondents, the most frequently cited reasons for being out of care were “I did not feel sick” and “I did not want people to know that I have HIV.” As all out of care respondents, recently incarcerated out of care respondents most frequently cited food, financial assistance, transportation, and housing as the most needed services.

In Care Incarcerated Men Respondents

Recently incarcerated in care men and all in care respondents most frequently reported a service gap (“need but can’t get) regarding food/home delivered meals. Respondents in this special population mentioned transportation just as frequently as they mentioned food, followed by primary medical care. Generally, this population reported gaps regarding a fewer number of services, but at higher rates than among all in care respondents. The most frequently mentioned barriers (“needed but didn’t know about”) reported by recently incarcerated men were for food bank/home delivered meals and transportation.

Recently Incarcerated Men Focus Group Findings

Recently incarcerated men identified depression, stigma, and dislike of medication as barriers to care. They identified service gaps in housing, food, and ADAP (i.e. the recently-instituted waiting list). In regard to what helped them get into care, the respondents mentioned case management and having a support system.

Additional Data Regarding Recently Incarcerated Men

Of all survey respondents, 38 (10.4% of all respondents) indicated they had been in jail or prison within the past twelve months. Of the 38, 27 were male and 11 were female. Of the 27 males who had been released from incarcerated during the past twelve months, 26 were African American and 1 was White. Of these 27 (71.1% of all 38 respondents):

- 17 are in care and 10 are out of care.
- 17 used other (than injection drugs or methamphetamines) street drugs
- 23 live at or below 100% of the federal poverty level.

For additional data and analysis, please see the following pages.

The ten respondents who are out of care were asked to describe their situation. As among all out of care respondents, out of care respondents who were recently incarcerated most frequently mentioned, “I had been receiving medical care for HIV, but I stopped more than 12 months ago.” The following table summarizes all responses to this question.

Out of Care Circumstances

Survey Question 24A. What best describes your situation (check one only)				
Out of Care Situation	All Out of Care Respondents		Recently Incarcerated Out of Care Men Respondents	
	(n=69)		(n=10)	
	number	percent	number	percent
I have recently been diagnosed with HIV, and have not entered primary care.	31	44.9%	2	11.1%
I have <u>not</u> been recently diagnosed but have never been in care.	16	23.2%	2	11.1%
I had been receiving medical care for HIV, but I stopped more than 12 months ago.	18	26.1%	5	27.8%
Other (e.g. Don't want to be bothered; I found people I know will tell about me.)	2	2.9%	0	0.0%
No Response	2	2.9%	1	5.6%
Total	69	100.0%	10	55.6%

Like all out of care respondents, the most frequently cited reasons for being out of care were “I did not feel sick” and “I did not want people to know that I have HIV.” The following table summarizes all responses to this question.

Survey Question 25A. Why did you not get HIV/AIDS related medical care the past year? (check any or all that apply)				
Out of Care Reasons	All Out of Care Respondents		Recently Incarcerated Out of Care Men Respondents	
	(n=69)		(n=10)	
	number	percent	number	percent
I did not know where to go.	18	26.1%	2	20.0%
I could not get an appointment.	4	5.8%	0	0.0%
I could not get transportation.	13	18.8%	3	30.0%
I could not get childcare.	0	0.0%	0	0.0%
I was too busy taking care of my partner.	2	2.9%	0	0.0%
I could not pay for services.	26	37.7%	2	20.0%
I did not want people to know that I have HIV.	29	42.0%	4	40.0%
I was not ready to deal with having HIV.	22	31.9%	3	30.0%
I did not feel sick.	33	47.8%	6	60.0%
There are not enough doctors in my area.	0	0.0%	0	0.0%
I could not get time off work.	8	11.6%	0	0.0%
I was depressed.	25	36.2%	1	10.0%
I missed my appointment(s).	8	11.6%	1	10.0%
I had a bad experience with the medical staff.	6	8.7%	1	10.0%
Other (e.g. drugs; recently diagnosed; in process)	6	8.7%	2	20.0%

As all out of care respondents, recently incarcerated out of care respondents most frequently cited food, financial assistance, transportation, and housing as the most needed services.

The following table highlights the five most frequently mentioned responses.

Survey Question 27A. What services, other than medical care and medications, do you need to get into primary medical care? (check all that apply)				
Services	All Out of Care Respondents (n=69)		Recently Incarcerated Out of Care Men Respondents (n=10)	
	number	percent	number	percent
Financial assistance	34	49.3%	5	50.0%
Food	32	46.4%	6	60.0%
Housing	31	44.9%	4	40.0%
Case management	28	40.6%	2	20.0%
Transportation	25	36.2%	5	50.0%
Substance abuse treatment	15	21.7%	3	30.0%
Mental health services	12	17.4%	3	30.0%
Legal services	11	15.9%	1	10.0%
Labs	11	15.9%	3	30.0%
Dental care	6	8.7%	0	0.0%
Treatment Adherence	5	7.2%	0	0.0%
Other (e.g. job, late appointments, might need mental health services later)	3	4.3%	1	10.0%

Most (65.2%) of all out of care respondents and all recently incarcerated male out of care respondents cited “I get sick and know I need care” as the leading reason for entering primary medical care.

The following table highlights all responses to this question.

Reasons to Enter Primary Medical Care

Survey Question 28A. What would be some reasons you enter primary medical care? (check any or all that apply)				
Reasons	Out of Care Respondents (n=69)		Recently Incarcerated Out of Care Men Respondents (n=10)	
	number	percent	number	percent
I get sick and know I need care.	45	65.2%	10	100.0%
I am ready to deal with my illness.	20	29.0%	1	10.0%
Someone else with HIV/AIDS reaches out to me.	18	26.1%	1	10.0%
I get transportation to go to a doctor or clinic.	18	26.1%	3	30.0%
Someone arranges to have my care paid for.	18	26.1%	2	20.0%
I find a doctor or medical facility that ensures my confidentiality.	16	23.2%	1	10.0%
I find a doctor or clinic where I do not have to wait very long in the waiting room.	10	14.5%	0	0.0%
I get a referral to get into care.	7	10.1%	0	0.0%
I am able to deal with other problems in my life that keep me out of care.	7	10.1%	0	0.0%
I find a doctor or medical facility that I like and who accepts me.	6	8.7%	1	10.0%
An outreach worker finds me and helps me get into care.	6	8.7%	1	10.0%
I find a medical facility that has evening or weekend hours.	6	8.7%	0	0.0%
A family member or friend helps me get into care.	4	5.8%	0	0.0%
Other (insurance)	1	1.4%	0	0.0%

Prioritization of Service Categories

Recently incarcerated male respondents who are in care and all in care respondents identified primary medical care as the most important service. Transportation was the second most recently cited service by this population of respondents.

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.

Five Most Important Services

Survey Question 77A. Which five services do you think are most important for people with HIV/AIDS?				
Service Category	In Care Respondents (n=296)		Recently Incarcerated In Care Men Respondents (n=17)	
	number	percent	number	percent
Primary Medical Care	218	73.6%	10	58.82%
Laboratory Diagnostic Testing	186	62.8%	6	35.29%
Medications	173	58.4%	3	17.65%
Case Management	170	57.4%	5	29.41%
Medical Specialist	123	41.6%	1	5.88%
Oral/Dental Health	74	25.0%	2	11.76%
Food Bank/Home Delivered Meals	64	21.6%	5	29.41%
Health Insurance	52	17.6%	5	29.41%
Transportation	40	13.5%	6	35.29%
Nurse Care Coordination	38	12.8%	0	0.00%
Emergency Financial Assistance (help paying for utilities, appliances, etc.)	35	11.8%	4	23.53%

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

Five Most Important Services

Survey Question 77A. Which five services do you think are most important for people with HIV/AIDS?				
Service Category	In Care Respondents (n=296)		Recently Incarcerated In Care Men Respondents (n=17)	
	number	percent	number	percent
Primary Medical Care	218	73.6%	10	58.82%
Laboratory Diagnostic Testing	186	62.8%	6	35.29%
Medications	173	58.4%	3	17.65%
Case Management	170	57.4%	5	29.41%
Medical Specialist	123	41.6%	1	5.88%
Oral/Dental Health	74	25.0%	2	11.76%
Food Bank/Home Delivered Meals	64	21.6%	5	29.41%
Health Insurance	52	17.6%	5	29.41%
Transportation	40	13.5%	6	35.29%
Nurse Care Coordination	38	12.8%	0	0.00%
Emergency Financial Assistance (help paying for utilities, appliances, etc.)	35	11.8%		23.53%
Mental Health Services	20	6.8%	0	0.00%
Support groups	18	6.1%	0	0.00%
Legal Services/Permanency	14	4.7%	2	11.76%
Substance Abuse Residential	13	4.4%	2	11.76%
Nutrition Counseling	13	4.4%	0	0.00%
Early Intervention Services (HIV testing & counseling, medical evaluation)	8	2.7%	1	5.88%
Outreach	7	2.4%	1	5.88%
Home Health Care	6	2.0%	0	0.00%
Health Education/Risk Reduction	4	1.4%	0	0.00%
Rehabilitation Services	3	1.0%	0	0.00%
Linguistics Services (interpretation & translation services)	3	1.0%	1	5.88%
Substance Abuse Outpatient	1	0.3%	0	0.00%
Hospice	1	0.3%	0	0.00%
Treatment Adherence	1	0.3%	2	11.76%
Other (e.g. need all the services, housing, meeting people my age with HIV, app't. reminders)	5	1.7%	0	0.00%
No response	22	7.4%	0	0.00%
Total In Care Respondents	296	100.0%	17	100.00%

Service Needs and Utilization

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

- “need and use” if they utilize the service
- “do not need” if they do not utilize the service
- “need, can’t get” to show possible gaps in services
- “can get, won’t use” to show barriers in service utilization

Utilization: “Need and Use”

Recently incarcerated in care male respondents reported a similar pattern of service utilization all respondents who are in care. Both groups reported primary medical care, laboratory diagnostic testing, and medications as the three most highly utilized services. In care African American males who had been recently incarcerated utilized case management at the same rate as they utilized medications.

The following table highlights the most frequently utilized services.

Comparison of Service Utilization "Need and Use"

Utilized Service Categories	All In Care Respondents (n=296)			Recently Incarcerated In Care Men Respondents (n=17)		
	rank	number	percent	rank	number	percent
CORE SERVICES						
Medical Care						
Primary Medical Care	2	225	76.0%	1	13	76.5%
Laboratory Diagnostic Testing	3	224	75.7%	1	13	76.5%
Medical Specialist	4	181	61.1%	4	8	47.1%
Nurse Care Coordination		56	18.9%		3	17.6%
Case Management		171	57.8%	2	11	64.7%
Medications	1	226	76.4%	3	10	58.8%
Oral/Dental Health	5	176	59.5%		6	35.3%

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

Comparison of Service Utilization "Need and Use"

Utilized Service Categories	All In Care Respondents (n=296)			Recently Incarcerated In Care Men Respondents (n=17)		
	rank	number	percent	rank	number	percent
CORE SERVICES						
Medical Care						
Primary Medical Care	2	225	76.0%	1	13	76.5%
Laboratory Diagnostic Testing	3	224	75.7%	1	13	76.5%
Medical Specialist	4	181	61.1%	4	8	47.1%
Nurse Care Coordination		56	18.9%		3	17.6%
Case Management		171	57.8%	2	11	64.7%
Medications	1	226	76.4%	3	10	58.8%
Oral/Dental Health	5	176	59.5%		6	35.3%
Health Insurance		102	34.5%		5	29.4%
Mental Health Services		88	29.7%		2	11.8%
Substance Abuse Treatment						
Substance Abuse Residential		33	11.1%		1	5.9%
Substance Abuse Outpatient		28	9.5%		2	11.8%
Nutrition Counseling		94	31.8%		0	0.0%
Early Intervention Services		52	17.6%		0	0.0%
Home Health Care		24	8.1%		0	0.0%
Hospice		14	4.7%		0	0.0%
SUPPORT SERVICES						
Food Bank/Home Delivered Meals		99	33.4%		6	35.3%
Transportation		119	40.2%		7	41.2%
Outreach		47	15.9%		1	5.9%
Health Education/Risk Reduction		96	32.4%		4	23.5%
Treatment Adherence		96	32.4%		3	17.6%
Legal Services/Permanency		82	27.7%		2	11.8%
Rehabilitation Services		33	11.1%		6	35.3%
Emergency Financial Assistance		60	20.3%		5	29.4%
Linguistics Services		26	8.8%		6	35.3%
Support groups		89	30.1%		3	17.6%

Service Gaps: “Need, Can’t Get”

Recently incarcerated in care males and all in care respondents most frequently reported a service gap regarding food/home delivered meals. Respondents in this special population mentioned transportation just as frequently as they mentioned food, followed by primary medical care. Generally, this population reported gaps regarding a fewer number of services, but at higher rates than among all in care respondents.

Comparison of Gaps "Need But Can't Get"

Service Categories	All In Care Respondents (n=296)			Recently Incarcerated In Care Men Respondents (n=17)		
	rank	number	percent	rank	number	percent
CORE SERVICES						
Medical Care						
Primary Medical Care		11	3.7%	2	3	17.6%
Laboratory Diagnostic Testing		12	4.1%	3	2	11.8%
Medical Specialist		16	5.4%	3	2	11.8%
Nurse Care Coordination		6	2.0%	3	2	11.8%
Case Management		22	7.4%	3	2	11.8%
Medications		9	3.0%		0	0.0%
Oral/Dental Health		25	8.4%		1	5.9%
Health Insurance	4	33	11.1%	3	2	11.8%
Mental Health Services		21	7.1%		0	0.0%
Substance Abuse Treatment						
Substance Abuse Residential		11	3.7%	3	2	11.8%
Substance Abuse Outpatient		11	3.7%	3	2	11.8%
Nutrition Counseling		21	7.1%	3	2	11.8%
Early Intervention Services		11	3.7%	3	2	11.8%
Home Health Care		11	3.7%		0	0.0%
Hospice		9	3.0%		1	5.9%
SUPPORT SERVICES						
Food Bank/Home Delivered Meals	1	78	26.4%	1	4	23.5%
Transportation	3	42	14.2%	1	4	23.5%
Outreach		9	3.0%		0	0.0%
Health Education/Risk Reduction		14	4.7%		0	0.0%
Treatment Adherence		10	3.4%		1	5.9%
Legal Services/Permanency	5	24	8.1%	3	2	11.8%
Rehabilitation Services	5	24	8.1%		1	5.9%
Emergency Financial Assistance	2	63	21.3%	2	3	17.6%
Linguistics Services		19	6.4%		0	0.0%
Support groups		22	7.4%		0	0.0%
Other (housing, app't. reminders)		5	1.7%		1	5.9%

Barriers to Services: “Needed But Didn’t Know About Services”

The most frequently mentioned barriers reported by recently incarcerated in care African American males were for food bank/home delivered meals and transportation. The responses most frequently mentioned by each group are highlighted in the following table.

Comparison of Barriers "Needed But Didn't Know About Services"

Service Categories	All In Care Respondents (n=296)			Recently Incarcerated In Care Men Respondents (n=17)		
	rank	number	percent	rank	number	percent
CORE SERVICES						
Medical Care						
Primary Medical Care		3	1.0%	3	2	11.8%
Laboratory Diagnostic Testing		5	1.7%		1	5.9%
Medical Specialist		7	2.4%		1	5.9%
Nurse Care Coordination		9	3.0%		1	5.9%
Case Management		11	3.7%	3	2	11.8%
Medications		3	1.0%		1	5.9%
Oral/Dental Health		18	6.1%	3	2	11.8%
Health Insurance		15	5.1%	2	3	17.6%
Mental Health Services		19	6.4%	3	2	11.8%
Substance Abuse Treatment						
Substance Abuse Residential		10	3.4%		1	5.9%
Substance Abuse Outpatient		7	2.4%		1	5.9%
Nutrition Counseling		17	5.7%		1	5.9%
Early Intervention Services		5	1.7%	3	2	11.8%
Home Health Care		12	4.1%		1	5.9%
Hospice		10	3.4%		1	5.9%
SUPPORT SERVICES						
Food Bank/Home Delivered Meals	2	28	9.5%	1	4	23.5%
Transportation	5	19	6.4%	1	4	23.5%
Outreach	4	21	7.1%	3	2	11.8%
Health Education/Risk Reduction	5	19	6.4%	3	2	11.8%
Treatment Adherence		15	5.1%	3	1	5.9%
Legal Services/Permanency	1	33	11.1%		1	5.9%
Rehabilitation Services		17	5.7%		0	0.0%
Emergency Financial Assistance	1	33	11.1%		1	5.9%
Linguistics Services		7	2.4%		0	0.0%
Support groups	3	22	7.4%		1	5.9%

Focus Group Findings: Themes and Notable Quotes

Male PLWH/A who had recently been released from incarceration were recruited by the facilitator, who had a similar history. Participants were asked about themselves and other PLWH/A who are not in care, what it would take to persuade them to enter care, and to describe their experiences regarding HIV related treatment and services. Highlights of the discussion include a wide range of issues affecting access and barriers to care and treatment.

The initial shock and devastation of diagnosis

“This person just moved here from Jacksonville. He just found out a couple of weeks ago that he is HIV positive and he tried to commit suicide.

“...and I came back took another test three or four weeks ago, I found out I was positive it was a shock for me you know because I never thought would happen to me you know what I'm saying I never thought it would happen as I been a soldier in the field. I used to always look at depression. Now I look at it like where I'm at right now, where I'm at right now we all have to die you know. So I don't look at it as a death sentence not right now because I got a support system...”

“ my life was so fading away that I went... where I needed help and I was steered in the direction of the county health system Palm Beach County health system from that I started getting meds and building my health back up but I really didn't care at all. I was pretty suicidal you know it took a while for me to come around I took advice of God...that's how I felt. I took meds... the place I go on Dixie, Compass I go to that community Center, and met a few people, and before long I was being case managed to save my life. Literally it did save my life. Case management there they help me stay on my meds.”

Concerns about treatment and support services, especially medication and housing.

“One is trying to find decent place to live. I live in a halfway house...the government...offer you HOPWHA...how can I find a place like that?”

“ADAP doesn't have your pills anymore...have to go to stay up on this list make sure you go through the waiting list and have it anymore you cannot use the systems.”

“I've never like to take medication but I know the medication is good to help prolong your life. That's where I 'm at right now.

Losses associated with years of incarceration

“My son came and picked me up yesterday. When I left the street my son was four years old he's 19 now. He came to pick me up to take me looking for jobs.”

“I'm currently staying at the Salvation Army. I went to prison in 1995. I was diagnosed in 98, out of prison on the 21st. That sucks, my wife left me...”

Overcoming difficulties associated with deciding to continue or resume treatment

“You see God feeds the birds but he doesn't put food in their nests. That means they got to go get it. They got to go get it. Simple as that.”

“I really needed to case management. I was encouraged to keep up with my doctor's appointments, you know, participated in support groups and slowly I began to open up and feel alive again. It's not over. It changed my life, gave me hope.”

A participant who had stopped and then resumed care explained the importance of encouragement of others, “To have a support group...a support system of people that you go to help ...”

“I try to do it on my own...yeah I got right here.”

“I was tested for HIV in 1996...I was in prison...I used to call the support group of people that had HIV...I refused to take the medication...I just started going to get help this year...so low down...I fell back in the chair I was so weak so...when people go to the health department, where I go now...they're doing this great...”

“I was diagnosed 2003 without till 2007 any medication for seven out of care I was going...I came back in 2007 [after being out of state for several years] and like I said, God touch with United deliverance on Grant Street because I live in Dunbar and that's when I found out. Once I got back to them, gave them a call back, on you know I was on meds...”

Difficulties associated with the stigma of HIV

“I don't want anybody spread in my kids having to deal with ridicule from other kids all this is what I'm dealing with right now...”

“...I've been rejected from church in Dade Broward and Palm Beach County and try not to cry since day one. I've been denied the right to the tree of life they say what has God delivered you from seeking God to deliver me from homosexuality and bisexuality live in that lifestyle for over 33 years. I'm 39 now I was molested at age 6 by my uncle...I know for a fact if that had not happened to me I would not be homosexual or bisexual now...I look back and accept it this lifestyle is what caused me to catch HIV. Now what am I supposed to do?”

“I've had ministers, evangelists...look me in my face and tell me, ‘you're a demon, you're the devil, you're going to hell’ As the gospel preaches about Jesus I say about myself, and then the next church I attend the next preacher that tells me something like that I'm a turn that motherfucker out.”

Participants who were stable in treatment encouraged others with their success.

“I've been HIV positive long time three years now my TC Count is high...I remember taking medications and have an appointment this afternoon to see my doctor at three

o'clock. And it's to the point where I'm seeing my doctor and [he's] saying what are you doing, your [virus] is undetectable. They want to know what you're doing, what is it that you're doing that keeps you undetectable..."

5. LATIN/HISPANIC MEN AND WOMEN

Unique Challenges

The challenges of serving Hispanic PLWH/A 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.³⁰

Service Gaps

27 Hispanic respondents participated in the 2010 Needs Assessment survey. 18 of these were in care and 9 were out of care. The most frequently mentioned country of origin was the United States (10) followed by Puerto Rico (6) and Mexico (6). Other countries of origin include the Dominican Republic, Columbia, and Nicaragua. Over one-half were not working during the past year, over one-third had less than a high school education, and nearly two-thirds lived at or below the poverty level.

Out of Care Hispanic Respondents

The most frequent circumstance cited by out of care Hispanic respondents was “I have recently been diagnosed with HIV, and have not entered primary care.” As with all out of care respondents, out of care Hispanics most frequently said that the reason they did not get HIV/AIDS medical care during the past year was because they “did not feel sick.” Both groups also cited financial barriers and not being “ready to deal with having HIV.” Hispanics were more than twice as likely as all out of care respondents to report not knowing where to go for care. When asked what services, other than medical services and medication, they need to get into primary medical care, Hispanic respondents, like all out of care respondents, most frequently mentioned financial assistance. Other services needed by both groups included housing, food, and transportation.

In Care Hispanic Respondents

As with all out of care respondents, Hispanic in care respondents reported service gaps (“need but can’t get”) in food bank/home delivered meals, transportation, and emergency financial assistance. Unlike all in care respondents, Hispanics also reported gaps in case management and mental health services. Like all in care respondents, Hispanics most frequently reported barriers regarding food bank/home delivered meals and emergency financial assistance. Hispanics also identified nutrition counseling, oral/dental health, and health education/risk reduction among the top five services they needed but didn’t know about.

³⁰Miami-Dade HIV/AIDS Partnership (2009). *Comprehensive Plan for HIV/AIDS 2009-2011*.

Hispanic Focus Group Findings

Although all the Hispanic focus group participants said they were satisfied with their medical care and had access to medications, they complained about the pharmacy staff and about excessive waiting time and inconvenient hours of service at the pharmacy. Among the support the participant needed help accessing were financial assistance; transportation (gas cards, bus passes), food, housing, legal assistance, and work and job training.

Additional Data Regarding Latin/Hispanic Survey Respondents:

- Among the 27 Hispanic/Latin survey respondents, 18 were in care and 9 were out of care.
- The most frequently mentioned country of origin was the United States (10) followed by Puerto Rico (6) and Mexico (6). Other countries of origin include the Dominican Republic, Columbia, and Nicaragua.
- 51.9% were not working during the past year.
- 37% have less than a high school education.
- 59.3% are at or below 100% of the federal poverty level.
- 25.9% used street drugs, other than injection drugs within the past 12 months.
- 18.5% reported being diagnosed with Hepatitis C during the past 12 months, compared to 13.4% of all respondents.

Please see the following pages for additional data and analysis

When asked, “What best describes your situation?” none of the out of care Latin/Hispanic respondents said they had been receiving care but stopped more than 12 months ago. The most frequent circumstance by all out of care respondents and Latin/Hispanic respondents was “I have recently been diagnosed with HIV, and have not entered primary care” (44.9% and 66.7%, respectively). The following table summarizes all responses to this survey item.

Out of Care Circumstances

Survey Question 24A. What best describes your situation (check one only)				
Out of Care Situation	All Out of Care Respondents (n=69)		Latin/Hispanic Out of Care Respondents (n=9)	
	number	percent	number	percent
I have recently been diagnosed with HIV, and have not entered primary care.	31	44.9%	6	66.7%
I have <u>not</u> been recently diagnosed but have never been in care.	16	23.2%	3	33.3%
I had been receiving medical care for HIV, but I stopped more than 12 months ago.	18	26.1%	0	0.0%
Other	2	2.9%	0	0.0%
No Response	2	2.9%	0	0.0%
Total	69	100.0%	9	100.0%

As with all out of care respondents, out of care Latin/Hispanics most frequently said that the reason they did not get HIV/AIDS medical care during the past year was because they “...did not feel sick.” Both groups also cited financial barriers and not being “ready to death with having HIV.” As shown in the following table, Latin/Hispanics were more than twice as likely as all out of care respondents to report not knowing where to go for care (66.7% of Latin/Hispanics compared to 26.1% of all respondents). The following table summarizes all reasons cited.

Reasons for Not Getting Medical Care

Survey Question 25A. Why did you not get HIV/AIDS related medical care the past year? (check any or all that apply)				
Out of Care Reasons	All Out of Care Respondents		Latin/Hispanic Out of Care Respondents	
	(n=69)		(n=9)	
	number	percent	number	percent
I did not know where to go.	18	26.1%	6	66.7%
I could not get an appointment.	4	5.8%	3	33.3%
I could not get transportation.	13	18.8%	4	44.4%
I could not get childcare.	0	0.0%	0	0.0%
I was too busy taking care of my partner.	2	2.9%	0	0.0%
I could not pay for services.	26	37.7%	6	66.7%
I did not want people to know that I have HIV.	29	42.0%	4	44.4%
I was not ready to deal with having HIV.	22	31.9%	5	55.6%
I did not feel sick.	33	47.8%	7	77.8%
There are not enough doctors in my area.	0	0.0%	0	0.0%
I could not get time off work.	8	11.6%	5	55.6%
I was depressed.	25	36.2%	3	33.3%
I missed my appointment(s).	8	11.6%	0	0.0%
I had a bad experience with the medical staff.	6	8.7%	0	0.0%
Other (e.g. drugs; recently diagnosed; in process)	6	8.7%	1	0.0%

When asked what services, other than medical services and medication, do they need to get into primary medical care, Latin/Hispanic respondents, like all out of care respondents most frequently mentioned financial assistance. Other services needed by both groups include housing, food, and transportation. The table below displays the most frequently selected services by all out of care respondents as well as the Latin/Hispanic respondents.

Services Needed to Get Into Primary Medical Care

Survey Question 27A. What services, other than medical care and medications, do you need to get into primary medical care? (check all that apply)				
Services	All Out of Care Respondents (n=69)		Latin/Hispanic Out of Care Respondents (n=9)	
	number	percent	number	percent
Financial assistance	34	49.3%	7	77.8%
Food	32	46.4%	3	33.3%
Housing	31	44.9%	4	44.4%
Case management	28	40.6%	2	22.2%
Transportation	25	36.2%	3	33.3%
Substance abuse treatment	15	21.7%	1	11.1%
Mental health services	12	17.4%	0	0.0%
Legal services	11	15.9%	2	22.2%
Labs	11	15.9%	4	44.4%
Dental care	6	8.7%	0	0.0%
Treatment Adherence	5	7.2%	0	0.0%
Other (e.g. job, late appointments, might need mental health services later)	3	4.3%	1	11.1%

Latin/Hispanic 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.
- Someone else with HIV/AIDS reaches out to me.
- I get transportation to go to a doctor or clinic.
- Someone arranges to have my care paid for.

The table below displays the most frequent responses from all out of care respondents as well as the Latin/Hispanic out of care respondents.

Reasons to Enter Primary Medical Care

Survey Question 28A. What would be some reasons you enter primary medical care? (check any or all that apply)				
Reasons	Out of Care Respondents (n=69)		Latin/Hispanic Out of Care Respondents (n=9)	
	number	percent	number	percent
I get sick and know I need care.	45	65.2%	7	77.8%
I am ready to deal with my illness.	20	29.0%	0	0.0%
Someone else with HIV/AIDS reaches out to me.	18	26.1%	7	77.8%
I get transportation to go to a doctor or clinic.	18	26.1%	4	44.4%
Someone arranges to have my care paid for.	18	26.1%	4	44.4%
I find a doctor or medical facility that ensures my confidentiality.	16	23.2%	2	22.2%
I find a doctor or clinic where I do not have to wait very long in the waiting room.	10	14.5%	2	22.2%
I get a referral to get into care.	7	10.1%	3	33.3%
I am able to deal with other problems in my life that keep me out of care.	7	10.1%	0	0.0%
I find a doctor or medical facility that I like and who accepts me.	6	8.7%	1	11.1%
An outreach worker finds me and helps me get into care.	6	8.7%	1	11.1%
I find a medical facility that has evening or weekend hours.	6	8.7%	3	33.3%
A family member or friend helps me get into care.	4	5.8%	2	22.2%
Other (insurance)	1	1.4%	0	0.0%

Prioritization of Service Categories

As summarized in the table to the right, the most highly prioritized services identified by Latin/Hispanic respondents in care were similar to those identified by all respondents in care.

Five Most Important Services

Survey Question 77A. Which five services do you think are most important for people with HIV/AIDS?				
Service Category	In Care Respondents (n=296)		Latin/Hispanic In Care Respondents (n=18)	
	number	percent	number	percent
Primary Medical Care	218	73.6%	11	61.1%
Laboratory Diagnostic Testing	186	62.8%	10	55.6%
Medications	173	58.4%	12	66.7%
Case Management	170	57.4%	8	44.4%
Medical Specialist	123	41.6%	4	22.2%
Oral/Dental Health	74	25.0%	5	27.8%
Food Bank/Home Delivered Meals	64	21.6%	7	38.9%

Case management functions as the EMA’s single point of entry, providing primary access to the EMA’s continuum of care. Clients’ initial eligibility must be determined by case managers, necessitating high utilization and prioritization of case management services. Once eligibility is established, case managers assist clients in navigating the continuum of care, or clients may choose to access some services (e.g. primary medical care) independently.

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

Five Most Important Services

Survey Question 77A. Which five services do you think are most important for people with HIV/AIDS?				
Service Category	In Care Respondents (n=296)		Latin/Hispanic In Care Respondents (n=18)	
	number	percent	number	percent
Primary Medical Care	218	73.6%	11	61.1%
Laboratory Diagnostic Testing	186	62.8%	10	55.6%
Medications	173	58.4%	12	66.7%
Case Management	170	57.4%	8	44.4%
Medical Specialist	123	41.6%	4	22.2%
Oral/Dental Health	74	25.0%	5	27.8%
Food Bank/Home Delivered Meals	64	21.6%	7	38.9%
Health Insurance	52	17.6%	1	5.6%
Transportation	40	13.5%	5	27.8%
Nurse Care Coordination	38	12.8%	1	5.6%
Emergency Financial Assistance (help paying for utilities, appliances, etc.)	35	11.8%	4	22.2%
Mental Health Services	20	6.8%	2	11.1%
Support groups	18	6.1%	0	0.0%
Legal Services/Permanency	14	4.7%	2	11.1%
Substance Abuse Residential	13	4.4%	0	0.0%
Nutrition Counseling	13	4.4%	2	11.1%
Early Intervention Services (HIV testing & counseling, medical evaluation)	8	2.7%	0	0.0%
Outreach	7	2.4%	0	0.0%
Home Health Care	6	2.0%	0	0.0%
Health Education/Risk Reduction	4	1.4%	0	0.0%
Rehabilitation Services	3	1.0%	0	0.0%
Linguistics Services (interpretation & translation)	3	1.0%	3	16.7%
Substance Abuse Outpatient	1	0.3%	0	0.0%
Hospice	1	0.3%	0	0.0%
Treatment Adherence	1	0.3%	0	0.0%
Other (e.g. need all the services, housing, meeting people my age with HIV, app't. reminders)	5	1.7%	0	0.0%
No response	22	7.4%	1	5.6%
Total In Care Respondents	296	100.0%	18	100.0%

Service Needs and Utilization

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

- “need and use” if they utilize the service
- “do not need” if they do not utilize the service
- “need, can’t get” to show possible gaps in services
- “can get, won’t use” to show barriers in service utilization

Utilization: “Need and Use”

Among Latin/Hispanic respondents in care, the most frequently utilized services include primary medical care, laboratory diagnostic testing, nurse care coordination, and oral/dental health. Medications are the second most frequently mentioned service category by Latin/Hispanics and the first most frequently mentioned by all respondents. Latin/Hispanics reported utilization of nurse care coordination at nearly four times the rate as all in care respondents (77.6% compared to 18.9%). The table below highlights the most frequently utilized services by Latin/Hispanics and all in care respondents.

Comparison of Service Utilization "Need and Use"

Utilized Service Categories	All In Care Respondents (n=296)			Latin/Hispanic In Care Respondents (n=18)		
	rank	number	percent	rank	number	percent
CORE SERVICES						
Medical Care						
Primary Medical Care	2	225	76.0%	1	14	77.8%
Laboratory Diagnostic Testing	3	224	75.7%	1	14	77.8%
Medical Specialist	4	181	61.1%		12	66.7%
Nurse Care Coordination		56	18.9%	1	14	77.8%
Case Management		171	57.8%		10	55.6%
Medications	1	226	76.4%	2	13	72.2%
Oral/Dental Health	5	176	59.5%	1	14	77.8%
Health Insurance		102	34.5%		4	22.2%
Mental Health Services		88	29.7%		2	11.1%
Substance Abuse Treatment						
Substance Abuse Residential		33	11.1%		0	0.0%
Substance Abuse Outpatient		28	9.5%		0	0.0%
Nutrition Counseling		94	31.8%		4	22.2%
Early Intervention Services		52	17.6%		3	16.7%
Home Health Care		24	8.1%		1	5.6%
Hospice		14	4.7%		0	0.0%
SUPPORT SERVICES						
Food Bank/Home Delivered Meals		99	33.4%		6	33.3%
Transportation		119	40.2%		5	27.8%
Outreach		47	15.9%		7	38.9%
Health Education/Risk Reduction		96	32.4%		3	16.7%
Treatment Adherence		96	32.4%		3	16.7%
Legal Services/Permanency		82	27.7%		4	22.2%
Rehabilitation Services		33	11.1%		2	11.1%
Emergency Financial Assistance		60	20.3%		2	11.1%
Linguistics Services		26	8.8%		0	0.0%
Support groups		89	30.1%		4	22.2%

Service Gaps: “Need, Can’t Get”

As with all out of care respondents, Latin/Hispanic in care respondents reported service gaps in food bank/home delivered meals, transportation, and emergency financial assistance. Unlike all in care respondents, Latin/Hispanics also reported gaps in case management and mental health services. The most frequently identified services are highlighted in the following table of all responses to this survey item.

Comparison of Gaps "Need But Can't Get"

Service Categories	All In Care Respondents (n=296)			Latin/Hispanic In Care Respondents (n=18)		
	rank	number	percent	rank	number	percent
CORE SERVICES						
Medical Care						
Primary Medical Care		11	3.7%		2	11.1%
Laboratory Diagnostic Testing		12	4.1%		2	11.1%
Medical Specialist		16	5.4%		1	5.6%
Nurse Care Coordination		6	2.0%		1	5.6%
Case Management		22	7.4%	2	3	16.7%
Medications		9	3.0%		1	5.6%
Oral/Dental Health		25	8.4%		2	11.1%
Health Insurance	4	33	11.1%		2	11.1%
Mental Health Services		21	7.1%	2	3	16.7%
Substance Abuse Treatment						0.0%
Substance Abuse Residential		11	3.7%		0	0.0%
Substance Abuse Outpatient		11	3.7%		1	6.3%
Nutrition Counseling		21	7.1%		2	12.5%
Early Intervention Services		11	3.7%		0	0.0%
Home Health Care		11	3.7%		0	0.0%
Hospice		9	3.0%		0	0.0%
SUPPORT SERVICES						
Food Bank/Home Delivered Meals	1	78	26.4%	1	5	31.3%
Transportation	3	42	14.2%	2	3	18.8%
Outreach		9	3.0%		0	0.0%
Health Education/Risk Reduction		14	4.7%		1	6.3%
Treatment Adherence		10	3.4%		0	0.0%
Legal Services/Permanency	5	24	8.1%		2	12.5%
Rehabilitation Services	5	24	8.1%		1	6.3%
Emergency Financial Assistance	2	63	21.3%	2	3	18.8%
Linguistics Services		19	6.4%	2	3	18.8%
Support groups		22	7.4%	2	3	18.8%
Other (housing, app't. reminders)		5	1.7%		1	6.3%

Barriers to Services: “Needed But Didn’t Know About Services”

Like all in care respondents, Latin/Hispanics most frequently reported barriers regarding food bank/home delivered meals and emergency financial assistance. Latin/Hispanics also identified nutrition counseling, oral/dental health, and health education/risk reduction among the top five services they needed but didn’t know about. The table below highlights the most frequent responses to this survey item.

Comparison of Barriers "Needed But Didn't Know About Services"

Service Categories	All In Care Respondents (n=296)			Latin/Hispanic In Care Respondents (n=18)		
	rank	number	percent	rank	number	percent
CORE SERVICES						
Medical Care						
Primary Medical Care		3	1.0%		1	5.6%
Laboratory Diagnostic Testing		5	1.7%		1	5.6%
Medical Specialist		7	2.4%		2	11.1%
Nurse Care Coordination		9	3.0%		1	5.6%
Case Management		11	3.7%		2	11.1%
Medications		3	1.0%		2	11.1%
Oral/Dental Health		18	6.1%	2	3	16.7%
Health Insurance		15	5.1%		2	11.1%
Mental Health Services		19	6.4%		2	11.1%
Substance Abuse Treatment						
Substance Abuse Residential		10	3.4%		0	0.0%
Substance Abuse Outpatient		7	2.4%		0	0.0%
Nutrition Counseling		17	5.7%	1	4	22.2%
Early Intervention Services		5	1.7%		0	0.0%
Home Health Care		12	4.1%		3	16.7%
Hospice		10	3.4%		0	0.0%
SUPPORT SERVICES						
Food Bank/Home Delivered Meals	2	28	9.5%	1	4	22.2%
Transportation	5	19	6.4%		2	11.1%
Outreach	4	21	7.1%		1	5.6%
Health Education/Risk Reduction	5	19	6.4%	2	3	16.7%
Treatment Adherence		15	5.1%		2	11.1%
Legal Services/Permanency	1	33	11.1%		1	5.6%
Rehabilitation Services		17	5.7%		1	5.6%
Emergency Financial Assistance	1	33	11.1%	1	4	22.2%
Linguistics Services		7	2.4%		1	5.6%
Support groups	3	22	7.4%		1	5.6%

Focus Group Findings: Themes and Notable Quotes

The Latin/Hispanic focus group was conducted in Lake Worth which has a large population of Caribbean and Central and South American residents. There were a total of seven participants, four women and 3 men. All but one were in medical care. The focus group was conducted in Spanish. Highlights were summarized in English as follows:

- All were seen at the Riviera Beach Clinic, of the Palm Beach County Health Department.
- While all participants were satisfied with their care, they complained of one clinic worker who treated them in a negative way for not speaking English.
- All participants were satisfied with their physician and nurses at the clinic.
- Although very satisfied with Dental Clinic, some participants said they wish more dental care services, e.g., root canals, were provided.
- Diagnostic laboratory testing can be improved by reducing the waiting time.
- All participants complained about pharmacy staff, e.g. bad manners, language barriers, and service, e.g. excessive waiting time, inconvenient hours of service.
- Most participants know people who should be tested, or who are HIV positive and are not in care for HIV.
 - Suggestions
 - ✓ Provide incentives (i.e. gift cards) to those being tested.
 - ✓ Conduct testing at Latino gatherings and events.
 - ✓ Provide incentives to people who are already in treatment to provide outreach and bring people to get tested and into care.
- Participants said they needed support services and specified the following needs:
 - ✓ Help paying bills
 - ✓ Transportation (gas cards, bus passes)
 - ✓ Food vouchers should be increased.
 - ✓ Housing and help applying for HUD, (Section 8, HOPWA, Public Housing)
 - ✓ Help getting work
 - ✓ Help getting job training.
 - ✓ Legal assistance. None of these participants had been referred to Legal Aid; none had Medical Health Proxies.

Although not conducted as part of this study, findings from the needs assessment referenced below are included to enhance our understanding of low-income Latino/Hispanics in Palm Beach County.

Needs Assessment Study of the Low-Income Foreign Born Latino/Hispanic Population of Palm Beach County

A report entitled, “Needs Assessment Study of the Low-Income Foreign Born Latino/Hispanic Population of Palm Beach County” was published by Analytics Research Group for the Latin American Immigrant and Refugee Organization, Inc. (LAIRO) in 2007. There were 998 survey respondents. Some of the findings are relevant in planning for health services and health education programs specific for the Hispanic/Latin community.

- 73% indicated that they do not have medical insurance.
- When asked ‘Where do you look for medical services when you are sick?’
 - 53% indicated that they go to the public clinic (Health Department)
 - 12% indicated that they go to the emergency room
 - 28% indicated that they go to a private doctor
 - 7% indicated that they go to another source for medical services.
- When asked to “Indicate which of these programs are most important to you or your family, or are services you need the most,” health education programs ranked the highest (86%), followed by job training (84%).
- When asked to “Indicate which services and programs are most important to you or your family, or are services you need the most”, affordable and accessible medical/dental services ranked the highest (92%), followed by affordable housing (88%) and job placement (87%).
 - Service delivery location preferences
 - 44% indicated that they would prefer that services and educational programs were offered in several locations in the north, central and south parts of the county
 - 40% preferred the services to be in one centrally located place in the county
 - 16% indicated said they had no preference

6. WOMEN WHO USED DRUGS ILLEGALLY DURING THE PAST 12 MONTHS

Note: This section refers to women who used drugs other than those properly prescribed by a health care provider and taken as prescribed. The use or abuse of alcohol was not queried in the PLWHA survey and is therefore, not addressed in this section.

Question 17A. of the PLWHA survey asked the following:

“It is important that we try to meet the individual needs of all people living with HIV/AIDS. Please check any or all of the following that have applied to you at any time in the last 12 months.”

A total of 43 women (27.7% of all female respondents) indicated some type of drug use as follows:

- No women checked “Used illegal drugs through injection/needle”.
- 1 woman checked “Used methamphetamines” and did not indicate any other drug use.
- 42 women checked “Used other street drug (including marijuana)” only.
- 1 woman checked “Used methamphetamines” and “Used other street drug (including marijuana).”

Unique Challenges

The unique challenges of serving the population of women who use drugs illegally are complicated by other medical and psychosocial issues such as addiction, depression, anxiety, and other mental health issues.

Services Gaps

The 2010 Needs Assessment included 43 women who reported using drugs illegally within the previous 12 months. Of these, 79.1% are in care, and 92.5% were at or below 100% of the federal poverty level and had been unemployed during the past 12 months

Out of Care Women Who Had Used Drugs Illegally Respondents

When asked to describe their situation, 44.4% of women who had used drugs illegally said they have recently been diagnosed with HIV, about the same rate as all out of care respondents (44.9%). 44.9% said they had not been recently diagnosed but have never been in care, compared to 23.2% of all out of care respondents.

Out of care female respondents who had used drugs within the past 12 months most frequently identified similar reasons for being out of care as those identified by all out of care respondents. The reasons most frequently mentioned were, “I did not want people to know that I have HIV” (55.6%), “I did not feel sick” (55.6%), and “I was depressed” (44.4%).

The out of care female respondents who have used drugs within the past 12 months identified similar services they needed to get into care as all out of care respondents with one notable exception. While all out of care respondents most frequently identified

financial assistance food, housing, and case management, and transportation, women who have used drugs indicated their need for substance abuse treatment at more than twice the rate as other respondents (55.6% compared to 21.7%).

In Care Women Who Used Drugs Illegally Respondents

Unlike other respondents, in care female respondents who have used drugs within the past 12 months reported almost no service utilization at all. Only one woman in this category identified case management as a service she needs and uses. When respondents were asked to identify services they need but can't get, in care female respondents who have used drugs within the past 12 months most frequently mentioned transportation followed by food bank/home delivered meals, and health insurance.

In Care Women Who Used Drugs Illegally Respondents

No focus group of this population was convened for this needs assessment.

Additional Data Regarding Women Respondents who Reported Drug use During the Past 12 Months:

- Of the 155 women surveyed, 27.7% (43) reported using drugs during the previous 12 months.
- Of the 43 who had used drugs during the past 12 months
 - 30.9% (9) are out of care.
 - 79.1% (34) are in care.
 - 92.5% (37) are not employed.
 - 18.9% (10) are employed.
 - 41.9% (18) are on disability.
 - 92.5% (37) live at or below the federal poverty level.
 - 32.6% (14) have traded sex for money or drugs within the past 12 months.

Please see the following pages for additional data and analysis.

Nearly all (97.7%) of the women in this category reported using “other street drug (including marijuana) only”. None reported injection drug use.

Survey Question 17A. Women Respondents Who Reported Illegal Drug Use During the Past 12 Months			
Type of Illegal Drug Use	Number of Women	Percent of Women Who used Drugs Illegally During the Past 12 Months	Percent of All Women Respondents
		(n=43)	(n=155)
Illegal drugs through injection/needle	0	0.0%	0.0%
Methamphetamines only	1	2.3%	0.6%
Other street drug (including marijuana) only	42	97.7%	27.1%
Methamphetamines and street drugs	1	2.3%	0.6%

Of the 9 women with a history of substance abuse who were also out of care, all but one (88.9%) had never been in care and one (11.1%) had been receiving medical care for HIV, but I stopped more than 12 months ago”.

Out of Care Circumstances

Survey Question 24A. What best describes your situation (check one only)				
Out of Care Situation	All Out of Care Respondents (n=69)		Out of Care Women Who Used Drugs Illegally (n=9)	
	number	percent	number	percent
I have recently been diagnosed with HIV, and have not entered primary care.	31	44.9%	4	44.4%
I have <u>not</u> been recently diagnosed but have never been in care.	16	23.2%	4	44.4%
I had been receiving medical care for HIV, but I stopped more than 12 months ago.	18	26.1%	1	11.1%
Other	2	2.9%	0	0.0%
No Response	2	2.9%	0	0.0%
Total	69	100.0%	9	100.0%

Out of care female respondents who have used drugs within the past 12 months most frequently identified similar reasons for being out of care as those identified by all out of care respondents. The reasons most frequently mentioned by out of care women who had used drugs were, “I did not want people to know that I have HIV” (55.6%), “I did not feel sick” (55.6%), and “I was depressed” (44.4%).

Survey Question 25A. Why did you not get HIV/AIDS related medical care the past year? (check any or all that apply)				
Out of Care Reasons	All Out of Care Respondents (n=69)		Out of Care Women Respondents Who Used Drugs Illegally (n=9)	
	number	percent	number	percent
I did not know where to go.	18	26.1%	1	11.1%
I could not get an appointment.	4	5.8%	0	0.0%
I could not get transportation.	13	18.8%	2	22.2%
I could not get childcare.	0	0.0%	0	0.0%
I was too busy taking care of my partner.	2	2.9%	1	11.1%
I could not pay for services.	26	37.7%	3	33.3%
I did not want people to know that I have HIV.	29	42.0%	5	55.6%
I was not ready to deal with having HIV.	22	31.9%	3	33.3%
I did not feel sick.	33	47.8%	5	55.6%
There are not enough doctors in my area.	0	0.0%	0	0.0%
I could not get time off work.	8	11.6%	0	0.0%
I was depressed.	25	36.2%	4	44.4%
I missed my appointment(s).	8	11.6%	0	0.0%
I had a bad experience with the medical staff.	6	8.7%	1	11.1%
Other (e.g. drugs; recently diagnosed; in process)	6	8.7%	1	0.0%

The out of care female respondents who have used drugs within the past 12 months identified similar services they needed to get into care as all out of care respondents with one notable exception. While all out of care respondents most frequently identified financial assistance food, housing, and case management, and transportation, women who have used drugs indicated their need for substance abuse treatment at more than twice the rate as other respondents (55.6% compared to 21.7%).

Services Needed to Get Into Primary Medical Care

Survey Question 27A. What services, other than medical care and medications, do you need to get into primary medical care? (check all that apply)				
Services Needed	All Out of Care Respondents (n=69)		Out of Care Women Respondents who Used Drugs Illegally (n=9)	
	number	percent	number	percent
Financial assistance	34	49.3%	4	44.4%
Food	32	46.4%	4	44.4%
Housing	31	44.9%	6	66.7%
Case management	28	40.6%	3	33.3%
Transportation	25	36.2%	3	33.3%
Substance abuse treatment	15	21.7%	5	55.6%
Mental health services	12	17.4%	1	11.1%
Legal services	11	15.9%	0	0.0%
Labs	11	15.9%	1	11.1%
Dental care	6	8.7%	1	11.1%
Treatment Adherence	5	7.2%	1	11.1%
Other (e.g. job, late appointments, might need mental health services later)	3	4.3%	0	0.0%

All out of care respondents as well as women who have used drugs illegally in the past 12 months cited the same three reasons they would enter primary medical care. The most frequent responses among both groups were “I get sick and know I need care” (88.9% of women who had used drugs in the past 12 months and 65.2% of all out of care respondents) and “I am ready to deal with my illness” (44.4% of women who had used drugs and 29% of all out of care responses).

In addition, 33.3% of women who had used drugs mentioned, “I find a doctor or medical facility that I like and who accepts me” compared to only 8.7% of all out of care respondents who said this would be a reason. The following table highlights the most frequently mentioned responses to this question.

Reasons to Enter Primary Medical Care

Survey Question 28A. What would be some reasons you enter primary medical care? (check any or all that apply)				
Reasons to Enter Primary Medical Care	Out of Care Respondents (n=69)		Out of Care Women Respondents who Used Drugs Illegally (n=9)	
	number	percent	number	percent
I get sick and know I need care.	45	65.2%	8	88.9%
I am ready to deal with my illness.	20	29.0%	4	44.4%
Someone else with HIV/AIDS reaches out to me.	18	26.1%	3	33.3%
I get transportation to go to a doctor or clinic.	18	26.1%	3	33.3%
Someone arranges to have my care paid for.	18	26.1%	3	33.3%
I find a doctor or medical facility that ensures my confidentiality.	16	23.2%	3	33.3%
I find a doctor or clinic where I do not have to wait very long in the waiting room.	10	14.5%	1	11.1%
I get a referral to get into care.	7	10.1%	0	0.0%
I am able to deal with other problems in my life that keep me out of care.	7	10.1%	1	11.1%
I find a doctor or medical facility that I like and who accepts me.	6	8.7%	3	33.3%
An outreach worker finds me and helps me get into care.	6	8.7%	0	0.0%
I find a medical facility that has evening or weekend hours.	6	8.7%	0	0.0%
A family member or friend helps me get into care.	4	5.8%	1	11.1%
Other (insurance)	1	1.4%	0	0.0%

Prioritization of Service Categories

In care female respondents who have used drugs within the past 12 months as well as all in care respondents identified primary medical care and case management among the top five service priorities.

Other top service priorities identified by in care women who have used drugs include food bank/home delivered meals, health insurance, and emergency financial assistance.

The following table highlights the top five service priorities of all in care respondents and of females who have used drugs within the past 12 months.

Five Most Important Services

Survey Question 77A. Which five services do you think are most important for people with HIV/AIDS?				
Service Category	In Care Respondents (n=296)		In Care Women Respondents who Used Drugs Illegally (n=9)	
	number	percent	number	percent
Primary Medical Care	218	73.6%	7	77.8%
Laboratory Diagnostic Testing	186	62.8%	2	22.2%
Medications	173	58.4%	2	22.2%
Case Management*	170	57.4%	4	44.4%
Medical Specialist	123	41.6%	1	11.1%
Oral/Dental Health	74	25.0%	1	11.1%
Food Bank/Home Delivered Meals	64	21.6%	5	55.6%
Health Insurance	52	17.6%	4	44.4%
Transportation	40	13.5%	3	33.3%
Nurse Care Coordination	38	12.8%	1	11.1%
Emergency Financial Assistance	35	11.8%	5	55.6%

*Case management functions as the EMA’s single point of entry, providing primary access to the EMA’s continuum of care. Clients’ initial eligibility must be determined by case managers, necessitating high utilization and prioritization of case management services. Once eligibility is established, case managers assist clients in navigating the continuum of care, or clients may choose to access some services (e.g. primary medical care) independently.

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

Five Most Important Services

Survey Question 77A. Which five services do you think are most important for people with HIV/AIDS?				
Service Category	In Care Respondents (n=296)		In Care Women Respondents who Used Drugs Illegally (n=9)	
	number	percent	number	percent
Primary Medical Care	218	73.6%	7	77.8%
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Medical Specialist	123	41.6%	1	11.1%
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Food Bank/Home Delivered Meals	64	21.6%	5	55.6%
Health Insurance	52	17.6%	4	44.4%
Transportation	40	13.5%	3	33.3%
Nurse Care Coordination	38	12.8%	1	11.1%
Emergency Financial Assistance	35	11.8%	5	55.6%
Mental Health Services	20	6.8%	1	11.1%
Support groups	18	6.1%	0	0.0%
Legal Services/Permanency	14	4.7%	0	0.0%
Substance Abuse Residential	13	4.4%	1	11.1%
Nutrition Counseling	13	4.4%	0	0.0%
Early Intervention Services	8	2.7%	0	0.0%
Outreach	7	2.4%	1	11.1%
Home Health Care	6	2.0%	0	0.0%
Health Education/Risk Reduction	4	1.4%	0	0.0%
Rehabilitation Services	3	1.0%	1	11.1%
Linguistics Services	3	1.0%	0	0.0%
Substance Abuse Outpatient	1	0.3%	2	22.2%
Hospice	1	0.3%	0	0.0%
Treatment Adherence	1	0.3%	0	0.0%
Other (e.g. need all the services, housing, meeting people my age with HIV, app't. reminders)	6	2.0%	1	11.1%
No response	22	7.4%	1	11.1%
Total In Care Respondents	296	100.0%	9	100.0%

Service Needs and Utilization

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

- “need and use” if they utilize the service
- “do not need” if they do not utilize the service
- “need, can’t get” to show possible gaps in services
- “can get, won’t use” to show barriers in service utilization

Utilization: “Need and Use”

In care female respondents who have used drugs within the past 12 months reported almost no service utilization at all. Only one woman in this category identified case management as a service she needs and uses.

The following table highlights the services most highly utilized by each group.

Comparison of Service Utilization "Need and Use"

Utilized Service Categories	All In Care Respondents (n=296)			In Care Women Respondents who Used Drugs Illegally (n=9)		
	rank	number	percent	rank	number	percent
CORE SERVICES						
Medical Care						
Primary Medical Care	2	225	76.0%		0	0.0%
Laboratory Diagnostic Testing	3	224	75.7%		0	0.0%
Medical Specialist	4	181	61.1%		0	0.0%
Nurse Care Coordination		56	18.9%		0	0.0%
Case Management		171	57.8%	1	1	11.1%
Medications	1	226	76.4%		0	0.0%
Oral/Dental Health	5	176	59.5%		0	0.0%

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

Comparison of Service Utilization "Need and Use"

Utilized Service Categories	All in Care Respondents (n=296)			In Care Women Respondents who Used Drugs Illegally (n=9)		
	rank	number	percent	rank	number	percent
CORE SERVICES						
Medical Care						
Primary Medical Care	2	225	76.0%		0	0.0%
Laboratory Diagnostic Testing	3	224	75.7%		0	0.0%
Medical Specialist	4	181	61.1%		0	0.0%
Nurse Care Coordination		56	18.9%		0	0.0%
Case Management		171	57.8%	1	1	11.1%
Medications	1	226	76.4%		0	0.0%
Oral/Dental Health	5	176	59.5%		0	0.0%
Health Insurance		102	34.5%		0	0.0%
Mental Health Services		88	29.7%		0	0.0%
Substance Abuse Treatment						
Substance Abuse Residential		33	11.1%		0	0.0%
Substance Abuse Outpatient		28	9.5%		0	0.0%
Nutrition Counseling		94	31.8%		0	0.0%
Early Intervention Services		52	17.6%		0	0.0%
Home Health Care		24	8.1%		0	0.0%
Hospice		14	4.7%		0	0.0%
SUPPORT SERVICES						
Food Bank/Home Delivered Meals		99	33.4%		0	0.0%
Transportation		119	40.2%		0	0.0%
Outreach		47	15.9%		0	0.0%
Health Education/Risk Reduction		96	32.4%		0	0.0%
Treatment Adherence		96	32.4%		0	0.0%
Legal Services/Permanency		82	27.7%		0	0.0%
Rehabilitation Services		33	11.1%		0	0.0%
Emergency Financial Assistance		60	20.3%		0	0.0%
Linguistics Services		26	8.8%		0	0.0%
Support groups		89	30.1%		0	0.0%

Service Gaps: “Need, Can’t Get”

When respondents were asked to identify services they need but can’t get, in care female respondents who have used drugs within the past 12 months most frequently mentioned transportation followed by food bank/home delivered meals, and health insurance.

The following table highlights the most frequently mentioned service gaps.

Comparison of Gaps "Need But Can't Get"

Service Categories	All In Care Respondents (n=296)			In Care Women Respondents who Used Drugs Illegally (n=9)		
	rank	number	percent	rank	number	percent
CORE SERVICES						
Medical Care						
Primary Medical Care		11	3.7%	3	2	22.2%
Laboratory Diagnostic Testing		12	4.1%	3	2	22.2%
Medical Specialist		16	5.4%		1	11.1%
Nurse Care Coordination		6	2.0%		1	11.1%
Case Management		22	7.4%	3	2	22.2%
Medications		9	3.0%		0	0.0%
Oral/Dental Health		25	8.4%		1	11.1%
Health Insurance	4	33	11.1%	2	3	33.3%
Mental Health Services		21	7.1%		1	11.1%
Substance Abuse Treatment						
Substance Abuse Residential		11	3.7%		0	0.0%
Substance Abuse Outpatient		11	3.7%	3	2	22.2%
Nutrition Counseling		21	7.1%		0	0.0%
Early Intervention Services		11	3.7%		0	0.0%
Home Health Care		11	3.7%		0	0.0%
Hospice		9	3.0%		0	0.0%
SUPPORT SERVICES						
Food Bank/Home Delivered Meals	1	78	26.4%	2	3	33.3%
Transportation	3	42	14.2%	1	4	44.4%
Outreach		9	3.0%		0	0.0%
Health Education/Risk Reduction		14	4.7%		1	11.1%
Treatment Adherence		10	3.4%		0	0.0%
Legal Services/Permanency	5	24	8.1%		0	0.0%
Rehabilitation Services	5	24	8.1%		0	0.0%
Emergency Financial Assistance	2	63	21.3%	3	2	22.2%
Linguistics Services		19	6.4%		0	0.0%
Support groups		22	7.4%		0	0.0%
Other (housing, app't. reminders)		5	1.7%	2	3	33.3%

Barriers to Services: “Need But Didn’t Know About Service”

When asked to specify which services they need but didn’t know about, women who have used drugs within the past 12 months mentioned specific services at higher rates than all in care respondents. The most frequently mentioned services included case management, hospice, food bank/home delivered meals, outreach, health education/risk reduction, and emergency financial assistance.

The following table highlights the most frequently mentioned responses to this question.

Comparison of Barriers "Needed But Didn't Know About Services"

Service Categories	All In Care Respondents (n=296)			In Care Women Respondents who Used Drugs Illegally (n=9)		
	rank	number	percent	rank	number	percent
CORE SERVICES						
Medical Care						
Primary Medical Care		3	1.0%		3	33.3%
Laboratory Diagnostic Testing		5	1.7%		3	33.3%
Medical Specialist		7	2.4%		2	22.2%
Nurse Care Coordination		9	3.0%		2	22.2%
Case Management		11	3.7%	1	5	55.6%
Medications		3	1.0%		3	33.3%
Oral/Dental Health		18	6.1%		4	44.4%
Health Insurance		15	5.1%		3	33.3%
Mental Health Services		19	6.4%		2	22.2%
Substance Abuse Treatment						
Substance Abuse Residential		10	3.4%		3	33.3%
Substance Abuse Outpatient		7	2.4%		3	33.3%
Nutrition Counseling		17	5.7%		3	33.3%
Early Intervention Services		5	1.7%		2	22.2%
Home Health Care		12	4.1%		2	22.2%
Hospice		10	3.4%	1	5	55.6%
SUPPORT SERVICES						
Food Bank/Home Delivered Meals	2	28	9.5%	1	5	55.6%
Transportation	5	19	6.4%		3	33.3%
Outreach	4	21	7.1%	1	5	55.6%
Health Education/Risk Reduction	5	19	6.4%	1	5	55.6%
Treatment Adherence		15	5.1%		4	44.4%
Legal Services/Permanency	1	33	11.1%		3	33.3%
Rehabilitation Services		17	5.7%		2	22.2%
Emergency Financial Assistance	1	33	11.1%	1	5	55.6%
Linguistics Services		7	2.4%		2	22.2%
Support groups	3	22	7.4%		3	33.3%

Appendix A.
PLWHA Survey 2010

**SURVEY OF PEOPLE LIVING WITH HIV/AIDS
PALM BEACH COUNTY
2010**

Date _____

Time _____

Name of interviewer (please print clearly and sign name)

Print

Signature

Venue (i.e. provider and/or location, such as “respondents home”)

Survey # _____

GIFT CARD #: _____

Questions? Contact Sonja Swanson

Treasure Coast Health Council

600 Sandtree Drive, Ste. 101

Palm Beach Gardens, FL 33403

(561) 844-4220, Ext. 14

Fax: (561) 844-3310

Cell Phone (772) 985-4988

Sswanson@tchealthcouncil.org

Please mark the box beside the demographics that correspond to this survey.				
N=365				
Variable	Sample Size			
	In Care n=255 70%		Out of Care n=110 30%	
Race/Ethnicity	n	This Survey	n	This Survey
Black	161		69	
White	63		28	
Hispanic	31		13	
Total	255		110	
Gender	n	This Survey	n	This Survey
Male	150		73	
Female	105		37	
Transgender	-		-	
Total	255		110	
Age	n	This Survey	n	This Survey
0-24	16		2	
25-29	13		5	
30-39	51		22	
40-44	41		17	
45-49	50		20	
50-59	59		29	
60+	25		15	
Total	255		110	
Special Populations	n	This Survey	n	This Survey
MSM	117		58	
IDU	20		9	
Haitian	42		24	
Mayan	-		-	
WCBA	59		18	
Heterosexual	146		66	
Geographic Location	n	This Survey	n	This Survey
North East	5		2	
South East	51		22	
Central East	164		70	
West	36		15	
Total	256		109	

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.

3. Provide a private and confidential setting. 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.

4. Read the Introduction to the respondent 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 Sonja Swanson:

600 Sandtree Dr. Ste 101, Palm Beach Gardens, FL 33403

phone: 561-844-4220 ext. 14

fax: 561-844-3310

email: sswanson@thealthcouncil.org

Palm Beach County EMA
COMMUNITY NEEDS ASSESSMENT

Anonymous Persons Living with HIV/AIDS (PLWHA) Survey 2010

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 YOU 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 finding out some basic things about you. Please remember that you will never be identified as an individual but rather as part of the whole group of people that take this survey.”

Read the following questions. Probe to clarify, if necessary.

1A. Survey # _____

2A. What is your Zip Code? _____

3A/1B What is your gender? (*check one only*)

Male Female Transgender (Male to Female) Transgender (Female to Male)

4A/3B How do you identify yourself? (*check one only*)

Straight Gay Lesbian Bisexual

5A. What is your primary language? (*check one only*)

English Spanish Portuguese
 French Creole Central American Dialect (Specify: _____)
 Other (Specify: _____)

6A/4B What is your race? (*check one only*)

White/Caucasian Black or African American
 Asian Native Hawaiian or Pacific Islander
 American Indian or Alaskan Native Mixed/more than one race
 Other: (Specify: _____)

7A/5B What is your ethnicity? (*check one only*)

Hispanic/Latina/o Non-Hispanic/Latina/o Haitian

8A If you answered “Hispanic or Latino”, what is your country of origin? (*check one only*)

N/A I did not answer “Hispanic or Latino” Mexico
 Puerto Rico Guatemala
 El Salvador U.S.A
 Dominican Republic Other (Specify: _____)

9A/6B What year were you born? _____

10A What is your age group? (*check one only*)

- under 18 18-24 25-29 30-39 40-44
 45-49 50-59 60-69 70+

11A What is the highest level of education that you have completed? (*check one only*)

- No formal schooling Eighth grade or less Less than high school graduation
 High school graduation Technical/trade school GED (high school equivalency)
 Some college College graduate

12A/7B What best describes your work situation in the **past year**? (*check one only*)

- Working full-time job Working part-time job Self employed
 Working off and on Not working

13A/8B Why were you not working during the **past year**? (*check one only*)

- This does not apply to me. I worked during the past year.
 Student Looking for a job
 Attending job training For health reasons, on disability
 Retired For health reasons, NOT on disability
 Other (Specify: _____)

9B Where do you live? County: _____

14A In 2008, how many family members (including yourself) lived in your household? _____

15A In 2008, what was your annual family household income before taxes? \$_____

16A (Leave blank, for internal use only.) _____

17A It is important that we try to meet the individual needs of *all* people living with HIV/AIDS. Please check any or all of the following that have applied to you at any time in the last 12 months:

- | | |
|---|--|
| <input type="checkbox"/> Transgender | <input type="checkbox"/> Blind or visually impaired |
| <input type="checkbox"/> Deaf or hearing impaired | <input type="checkbox"/> Migrant or seasonal worker |
| <input type="checkbox"/> In jail or prison | <input type="checkbox"/> On probation/parole |
| <input type="checkbox"/> Used illegal drugs through injection/needle | <input type="checkbox"/> Runaway/street youth |
| <input type="checkbox"/> Used Methamphetamines | <input type="checkbox"/> Mental illness |
| <input type="checkbox"/> Used other street drug use (including marijuana) | <input type="checkbox"/> Traded sex for money or drugs |
| <input type="checkbox"/> Woman of child bearing age (15-44 years old) | <input type="checkbox"/> Domestic Violence |
| <input type="checkbox"/> Unable to find employment | <input type="checkbox"/> Other (Specify: _____) |

SECTION B: HIV/AIDS STATUS AND CARE

INTERVIEWER SAY, “Now, let’s talk about the first time you learned you were HIV positive.”
Read:

18A In what year did you first test positive for HIV? _____ (If you can’t remember, can you make a guess?)

19A/10B Where were you living when you first tested positive for HIV? (*check one only*)

- | | |
|--|--|
| <input type="checkbox"/> In Palm Beach County | <input type="checkbox"/> In another county in Florida (Specify: _____) |
| <input type="checkbox"/> In another state (Specify: _____) | <input type="checkbox"/> Outside of the United States (Specify: _____) |

20A Has a doctor told you in the past 12 months that you had any of the following?
(*Check any or all that apply.*)

- | | | | |
|---------------------------------------|---|---|--|
| <input type="checkbox"/> AIDS | <input type="checkbox"/> Hepatitis A | <input type="checkbox"/> Hepatitis B | <input type="checkbox"/> Hepatitis C |
| <input type="checkbox"/> Tuberculosis | <input type="checkbox"/> Syphilis | <input type="checkbox"/> Gonorrhea | <input type="checkbox"/> Chlamydia |
| <input type="checkbox"/> Other STD | <input type="checkbox"/> High Cholesterol | <input type="checkbox"/> Cancer | <input type="checkbox"/> Liver Disease |
| <input type="checkbox"/> Diabetes | <input type="checkbox"/> Coronary Heart Disease | <input type="checkbox"/> Other condition (Specify: _____) | |

11B Did you get HIV/AIDS related medical care OR a t-cell count OR a viral load lab test during the **past year**?

- Yes
 No

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

21A Lab work for CD4 count? Yes No

22A Lab work for viral load count? Yes No

23A Prescription for Anti-Retroviral Therapy (ART)? Yes No

INTERVIEWER NOTE: If the respondent answered YES to at least one of the last three questions please skip to Question 29A.
INTERVIEWER NOTE: If participant answered NO to all of the last three questions, please answer questions 24A-28A.

SECTION C: OUT OF CARE

24A What best describes your situation? (*check one only*)

- I have recently been diagnosed with HIV, and have not entered primary care.
- I have not been recently diagnosed but have never been in care.
- I had been receiving medical care for HIV, but I stopped more than 12 months ago.
- Other (Specify: _____)

25A/12B Why did you not get HIV/AIDS related medical care during the **past year**? (*check any or all that apply*)

- This does not apply to me. I did get HIV/AIDS related medical care this year.
- I did not know where to go.
- I could not get an appointment.
- I could not get transportation.
- I could not get childcare.
- I was too busy taking care of my partner.
- 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.
- I did not feel sick.
- There are not enough doctors in my area.
- I could not get time off work.
- I was depressed.
- I missed my appointment(s).
- I had a bad experience with the medical staff.
- Other (Specify: _____)

26A Approximately, how long have you been out of primary medical care? (*check one only*)

- Less than one month
- 1-5 months
- 6 months to 1 year
- 2-5 years
- I have never been in care

27A What services, other than medical care and medication, do you need to get into primary medical care? (*check any or all that apply*)

- Substance abuse treatment
- Mental health services
- Dental care
- Food
- Case management
- Legal services
- Transportation
- Housing
- Treatment Adherence
- Labs
- Financial assistance
- Other (specify) _____

28A What would be some reasons you would enter primary medical care? (*check any or all that apply*)

- I get sick and know I need care.
- I am ready to deal with my illness.
- I get a referral to get into care.
- I find a doctor or medical facility that I like and who accepts me.
- A family member or friend helps me get into care.
- Someone else with HIV/AIDS reaches out to me.
- An outreach worker finds me and helps me get into care.
- I find a medical facility that has evening or weekend hours.
- I find a doctor or medical facility that ensures my confidentiality.
- I find a doctor or clinic where I do not have to wait very long in the waiting room.
- I am able to deal with other problems in my life that keep me out of care.
- I get transportation to go to a doctor or clinic.
- Someone arranges to have my care paid for.
- Other (explain) _____

SECTION D: ACCESS AND AVAILABILITY ACCORDING TO NEEDS

29A During the past five years has there been a period of at least 12 months when you were *not* receiving HIV-related primary medical care (no lab work for CD4 or no lab work for viral load count or no Antiretroviral Therapy)?

- Yes No

If you answered NO to the last question skip to Question 37A.

30A If yes, for approximately how long were you out of primary medical care?

- Less than one month 1-5 months
 6 months to 1 year 2-5 years

31A What best describes your situation during that period? (*check one only*)

- I had recently been diagnosed with HIV, and had not yet entered primary medical care.
 I had been receiving primary medical care for HIV, but I decided to stop.
 Other (Specify: _____)

32A What zip code did you live in during the period when you were out of primary medical care?

33A Why were you not receiving primary medical care during that period? (*Check any or all that apply*)

- I did not have medical insurance and could not afford care.
 I did not know where to go to get care.
 I had heard bad things about the medications and their side effects.
 I knew where to go but I did not want to go there.
 I was not ready to deal with my HIV status.
 I was afraid of being identified as HIV-positive.
 I did not have transportation.
 I was homeless.
 I was using drugs or alcohol.
 I had mental health problems.
 I could not get an appointment.
 The wait was too long at the clinic/office/hospital.
 I did not think it would help.
 I was scared of immigration or other legal issues.
 Other (Specify: _____)

34A While you were out of primary medical care, what services other than medical care and medications did you need and not get? (check any or all that apply)

- | | |
|--|---|
| <input type="checkbox"/> Substance abuse treatment | <input type="checkbox"/> Mental health services |
| <input type="checkbox"/> Dental care | <input type="checkbox"/> Food |
| <input type="checkbox"/> Case management | <input type="checkbox"/> Legal services |
| <input type="checkbox"/> Transportation | <input type="checkbox"/> Housing |
| <input type="checkbox"/> Treatment Adherence | <input type="checkbox"/> Labs |
| <input type="checkbox"/> Financial assistance | <input type="checkbox"/> Other (specify) _____ |

35A What are the reasons that caused you to return to primary medical care? (check any or all that apply)

- I got sick and knew I need care.
- I was ready to deal with my illness.
- I got a referral to get into care.
- I found a doctor or medical facility that I like and who accepts me.
- A family member or friend helped me get into care.
- Someone else with HIV/AIDS reached out to me.
- An outreach worker found me and helped me get into care.
- I found a medical facility that has evening or weekend hours.
- I found a doctor or medical facility that ensures my confidentiality.
- I found a doctor or clinic where I do not have to wait very long in the waiting room.
- I was able to deal with other problems in my life that kept me out of care.
- I got transportation to go to a doctor or clinic.
- Someone arranged to have my care paid for.
- Other (explain) _____

36A If someone that had been involved in your care or an outreach worker helped get you back into care, what organization were they from? (check one only)

- (Specify: _____) N/A

37A How often does your case manager encourage and help you get regular medical care (CD4 test, or viral load test, or Antiretroviral Therapy)? (check one only)

- | | |
|---------------------------------|--|
| <input type="checkbox"/> Always | <input type="checkbox"/> Sometimes |
| <input type="checkbox"/> Never | <input type="checkbox"/> I don't have a case manager |

38A When you have missed a medical appointment, has someone (case manager, clinic staff person, mental health counselor, treatment adherence counselor, etc.) contacted you and tried to reschedule and/or find out why you did not come and if they could help you get to the next appointment? (*check one only*)

- I have never missed a medical appointment
- Always
- Sometimes
- Never

39A If someone has contacted you, please specify the clinic/organization/facility where they work.

- Specify: _____
- N/A

40A/13B Where did you regularly receive your HIV/AIDS medical care during the **past year**? (*check one only*)

- This does not apply to me. I did not receive HIV/AIDS-related medical care this year.
- Walk-In/Emergency Clinic (Specify: _____)
- Doctor's Office (Specify: _____)
- Hospital Emergency Room (Specify: _____)
- Veteran's Administration (Specify: _____)
- Public Clinic/Health Department (Specify: _____)
- HIV Specialty Clinic
- Other (Specify: _____)

41A/14B In which county did you get your HIV related medical care in the **past year**?
County: _____

42A/15B Why did you get your HIV/AIDS related medical care in a different county than you live? (*check one only*)

- This does not apply to me. I got medical care in the same county I live.
- Services were not available in my county.
- I did not want people to know that I have HIV
- I got care closer to where I live or work
- Other: (Specify _____)

43A/16B Have you been hospitalized for an HIV/AIDS related condition during the **past year**?

- Yes
- No

44A/17B Have you been to the Emergency Room for an HIV/AIDS related condition during the past year? Yes No

45A/18A Do you have private health insurance? Yes No

46A/19B How often do you take your medications to treat your HIV/AIDS just as the doctor said you should? (*check one only*)

- This does not apply to me. I have not been prescribed HIV medications.
- Always
- Most of the time
- Some of the time
- Never
- I do not know what the directions are.

47A/20B Why do you sometimes miss taking medications to treat your HIV/AIDS? (*check any or all that apply*)

- This does not apply to me. I have not been prescribed HIV medications or I always take my HIV medications as prescribed.
- I do not know where to get them.
- I cannot afford the cost.
- They make me feel really bad.
- I am on a 'Drug Holiday' directed by my doctor.
- I am on a 'Drug Holiday' directed by myself.
- I do not like taking medications.
- These medications are not a priority for me.
- I have trouble understanding how to take my medications.
- My doctor wanted to treat another medical problem first.
- Religious/Cultural beliefs.
- I have an abusive spouse or partner.
- Other (Specify: _____)

77A/42B. **PRIORITIES:** Which five (5) services do you think are most important for people with HIV/AIDS? Place a by the most important services to you.
 48A-74A/21B-39B. **NEED:** The services below MAY or MAY NOT be available. Please place a 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.

77A/42B	#A	#B	Service Category	Need and Use	Need, Can't Get	Need, Didn't Know	Don't Need
			CORE SERVICES				
		21	Medical Care				
	48		Primary Medical: Regular doctor visits for HIV medical care				
	49		Laboratory Diagnostic Testing				
	50		Medical Specialist: Eye doctor, woman's doctor (GYN), Dermatology, etc.				
	51		Nurse Care Coordination: RN acts as clients' main link to medical services				
	52	22	Case Management: Case managers help clients receive services and then follow-up on their care				
	53	23	Medications: Pills for HIV and related issues				
	54	24	Dental/Oral Health: General teeth and mouth care, dentures, oral surgery, etc.				
	55	25	Health Insurance: Helps pay insurance costs or co-pays if client has private insurance				
	56	26	Mental Health Services: Professional counseling, therapy, or support groups				
	57	27	Substance Abuse Treatment:				
	58		Residential: Professional counseling for drug or alcohol addiction				
	59		Outpatient:				
	60	28	Nutritional Counseling: Professional counseling for healthy eating habits				
	61	29	Early Intervention Services: Assistance getting a doctor appointment and other needed services				
	62	30	Home Health Care: Professional healthcare services in client's home by a licensed/certified home-health agency				
	63	31	Hospice Services: Nursing and counseling services for the terminally ill and their family				
			SUPPORT SERVICES				
	64	32	Food Bank or Food Vouchers: Food bags, grocery certificates, home-delivered meals, and nutritional supplements				
	65	33	Transportation: Help getting to the doctor's office and other HIV related appointments				
	66	34	Outreach: Someone who finds people with HIV not in care and helps them to visit their doctor and get services they may need				
	67	35	Health Education/Risk Reduction: Someone who tells clients about HIV, how it's spread, current medications, and how to live with HIV				
	68	36	Treatment Adherence: Instructions on how to take HIV medications properly				
	69	37	Legal Support: Help clients with HIV related legal issues (Social Security hearings, wills, health care proxy)				
	70	38	Rehabilitation: Physical, occupational, and speech therapy, low vision training, etc.				
	71		Emergency Financial Assistance: Help paying for utilities, appliances, etc.				
	72		Linguistics Services: Interpretation & translation services				
	73		Support groups				
	74	39	Other:				

75A/40B What kept you from getting the services you needed during the **past year**?
(check all that apply)

- This does not apply to me. I did get the services I needed this year.
- I did not know where to get services
- I could not get an appointment
- I could not get transportation
- I could not get childcare
- I was too busy taking care of my partner
- I could not pay for services
- I did not want people to know that I have HIV
- I could not get time off work
- I was depressed
- I missed my appointment(s)
- I had a bad experience with the staff
- Services were not in my language
- I was put on the waiting list
- I did not qualify for services
- Other (Specify: _____)

76A/41B Where do you get most of your information about HIV/AIDS services in your area? (check all that apply)

- Clinic/doctor's office
- Health Department
- Case manager
- Community health fair
- Community based organizations
- AIDS organization/advocacy group
- Place of worship
- Friends/family
- Internet Newspaper/radio/TV
- Other: (Specify _____)

78A/43B Were you in jail and/or prison during the **past year**?

- Yes, I was in jail
- Yes, I was in prison
- Yes, I was in jail and prison
- No (If you answered No, you can skip to Question 83A/48B)

ONLY answer the next four questions if you answered yes, you were in jail and/or prison during the past year.

79A/44B Did the jail/prison medical staff know you had HIV?

- Yes
- No

80A/45B Did you receive HIV/AIDS-related medical care while in jail/prison?

- Yes
- No

81A/46B When you were released from jail/prison, which of the following did you receive?

(check all that apply)

- Information about finding housing
- Referral to medical care
- Referral to case management
- A supply of HIV medication to take with you
- Other: _____

82A/47B What prevented you from getting the HIV/AIDS services you needed after you were released?
(check all that apply)

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

For the questions in the housing section you will be asked to think back over the past six months

83A/48B Place a in both of the columns that tell us where you live **now** and where you lived **6 months ago**, even if it is the same.

Housing Situation	Now	6 months ago
In an apartment/house that I own		
In an apartment/house that I rent		
At my parent's /relative's/ someone else's apartment/ house		
In a room or boarding house		
In a "supportive living" facility (Assisted Living Facility)		
In a half-way house, transitional housing, or treatment facility (drug or mental health)		
Nursing home		
Homeless (on street/in car/abandoned building)		
Homeless shelter		
Domestic violence shelter		
Other housing provided by the city, county, or state (such as Section 8 voucher or Shelter+care)		
In jail/prison		

84A/49B Think about where you live now: which of the following stop you from taking care of your HIV/AIDS?

(check all that apply)

- This does not apply to me. Nothing where I live now stops me from taking care of my HIV/AIDS.
- I do not have a safe and private room
- I do not have a bed to sleep in
- I do not have a place to store my medications
- I do not have a telephone where someone can call me
- I do not have enough food to eat
- I do not have money to pay for rent
- I do not have heat and/or air conditioning
- I am afraid of others knowing I have HIV
- I cannot get away from drugs and/or alcohol in the neighborhood
- I do not feel safe in the neighborhood
- I have an abusive spouse or partner
- Other: _____

85A/50B In the **past 6 months**, how many nights have you NOT had a place of your own to sleep?

86A/51B How much do you and/or your household contribute monthly to the rent or mortgage? (How much you and your household members **actually pay**.) \$_____

87A/52B Now we're interested in the HIV/AIDS housing services you needed and what HIV/AIDS housing services you got in the **past 6 months**.

The services below MAY or MAY NOT be available in your area. Please fill in the circles next to the housing services that you have used or needed in the past year. HOUSING	Needed Service & Got Service	Needed Service, But Could Not Get Service	Needed Service, But Did Not Know About Service	Did Not Need Service
Help finding a place to live				
Permanent, independent housing				
Temporary short-term housing				
Housing where my child(ren) can live with me				
Nursing home				
Money to pay utilities				
Money to pay rent/mortgage				
House for persons living with HIV/AIDS				
Assisted Living facility				

88A/53A What kept you from getting the housing services you needed? (*check all that apply*)

- This does not apply to me. I did get the housing services I needed.
- I did not know where to get services
- Services were not in my language
- I could not get there when the agency was open
- I did not want anyone to know I have HIV
- I did not qualify for housing services
- I have not been treated with respect at the agency
- I was put on the waiting list
- Other: _____

89A/54B Now we are interested in general problems you had getting housing, in the **past 6 months**, did you have trouble getting housing?

- Yes
- No

90A/55B What problems did you have getting housing? (*check all that apply*)

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

91A/56B Are you aware of any HIV Planning or Advisory Committees in your area?

- Yes
- No

92A/57B If yes, do you currently participate on any of these committees?

- Yes
- No

93A Are you enrolled in any of these programs? (check all that apply)

- | | | |
|---|--|---|
| <input type="checkbox"/> TANF | <input type="checkbox"/> ADAP | <input type="checkbox"/> Insurance Continuation |
| <input type="checkbox"/> Medicare | <input type="checkbox"/> Medicaid | <input type="checkbox"/> Social Security Disability |
| <input type="checkbox"/> Veteran's Administration | <input type="checkbox"/> Food stamps | <input type="checkbox"/> Medically Needy |
| <input type="checkbox"/> Compassionate Use (Medications) | | <input type="checkbox"/> Healthcare District |
| <input type="checkbox"/> Housing Opportunities for Person with AIDS | | <input type="checkbox"/> WIC |
| <input type="checkbox"/> Ryan White A (CSN Form) | <input type="checkbox"/> Ryan White B (notice of eligibility form) | |
| <input type="checkbox"/> Other (Specify: _____) | | |

94A What is the estimated amount that you have spent out-of-pocket (i.e., health insurance deductibles, co-payments, premiums, etc) on your personal healthcare needs over the past 12 months? (check one only)

- | | |
|---|--|
| <input type="checkbox"/> Under \$100 | <input type="checkbox"/> \$101-\$500 |
| <input type="checkbox"/> \$501-\$1000 | <input type="checkbox"/> \$1001-\$2500 |
| <input type="checkbox"/> More than \$2500 please specify \$ _____ | |

95A Have you had any of the following problems while trying to get needed services? (check any or all that apply)

- | | |
|--|--|
| <input type="checkbox"/> Didn't know <u>how</u> to apply | <input type="checkbox"/> Didn't know <u>where</u> to apply |
| <input type="checkbox"/> Application process too complicated | <input type="checkbox"/> Cost of service is too high |
| <input type="checkbox"/> Service sites located too far away | <input type="checkbox"/> Transportation problems |
| <input type="checkbox"/> Needed evening appointment | <input type="checkbox"/> Needed weekend appointment |
| <input type="checkbox"/> Too busy taking care of child | <input type="checkbox"/> Too busy taking care of partner |
| <input type="checkbox"/> Drug or alcohol addiction | <input type="checkbox"/> Other health problems |
| <input type="checkbox"/> I don't want people to know I have HIV | <input type="checkbox"/> Trouble communicating |
| <input type="checkbox"/> On waiting list | <input type="checkbox"/> Had to wait too long for service |
| <input type="checkbox"/> Turned down/not eligible because: _____ | |
| <input type="checkbox"/> Did not have any problems trying to get needed services | |
| <input type="checkbox"/> Other (Specify: _____) | |

96A Are you satisfied with the support and medical services you receive? Yes No

97A If no, please explain.

Questions 98A through 107A are for women only.

98A Have you received a pelvic exam (pap smear) in the last 12 months? Yes No

99A/B2 Have you been pregnant in the last 12 months? Yes No

If you answered No to the last question skip to Question 108A/58B

100A Was your pregnancy planned? Yes No

101A Did you receive contraception counseling from a medical provider? Yes No

102A What type of contraception did you use?

I was not using any contraception.

Type: _____ (condoms, pills, Depo shots, ring, patch, IUD, implants)

103A Did your pregnancy go to term? Yes No

104A Did you receive prenatal care? Yes No

105A If no, what were the reason/s that you did not receive prenatal care?

106A If yes, what month of pregnancy did you begin receiving prenatal care?
_____months

107A During your pregnancy did your OB doctor and HIV (ID) doctor communicate regarding your treatment?

Yes

I was not seeing an ID doctor

I was not seeing an OB doctor

No

I do not know.

108A/58B Overall, did you think this survey was:

Too long, but covered all the information

Too long, and I did not want to finish it

Too short, there were more things you could have asked

Just right

109A/B59 Is there anything else you would like to tell us?

“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.
Focus Group Script 2010

Comprehensive Needs Assessment 2011-2014 Focus Group Script

1. Introduction:

Facilitator: “My name is _____. I will be facilitating this focus group. I would like to welcome you all. Please help yourself to the food and beverages. We will be meeting for about an hour and a half. We appreciate you coming to discuss general issues about HIV care in Palm Beach County. At the end, each participant will receive a \$25.00 gift card to Winn Dixie.”

2. Overview of the comprehensive needs assessment purpose and process:

Facilitator: “I would like to thank you all for agreeing to participate in the focus group. Every three years we conduct a large county-wide needs assessment. This needs assessment is required for all areas that receive Ryan White CARE Act funding. The information that you provide helps the CARE Council plan to meet the needs of Persons Living with HIV/AIDS in our county, by prioritizing service categories and allocating funding for each service category. We are also able to identify service gaps, and assess the overall functioning of the HIV/AIDS system of care. We are gathering data through 5 focus groups as well as 365 surveys.”

3. Statement of confidentiality:

Facilitator: “We would like to have everyone here agree that whatever is said during the focus group will be strictly confidential. Your names will not be used, only the identification that you have written on your name tag. We are going to tape record the focus group session for accurate transcription of what is said, but again your names will not be used.” PAUSE “Can we all agree to that?”

4. Focus Group Guidelines and Definitions:

Facilitator: “We 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 a lot about PLWHA that are in and out of primary medical care. The federal government has adopted a definition for what is considered to be in primary medical care. This definition is written here on your handout. 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 (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-retro viral therapy.

5. Unmet Need:

Facilitator: “Now we would like to talk about PLWHA that are in and out of primary medical care. Do you know of any PLWHA in Palm Beach County who know they are positive but are not in primary medical care, as it is defined in your handout?”

Allow participants to discuss.

“Why do you think they are not in primary medical care?”

Allow participants to discuss.

“What do you think it would take to persuade them to get back into primary medical care?”

Allow participants to discuss.

“Now we are going to discuss your personal pattern of care. Since you were diagnosed with HIV/AIDS, have you been in primary medical care continuously?”

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.

“For those of you, who were out of care for sometime or are currently out of care, please tell us about your situation.

- If you have been in care at one point how long were you in care before you stopped receiving care, why did you stop receiving care, and how long were you (or have you been) out of care?
- Are you still out of care?
- If yes, what would help you get back into care?
- If no, what helped you get you back into care?

Do you have any other 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.

6. 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. Let’s go category by category.”

“For the services that you ARE using:

- Where are you currently getting these services?
- Are these services meeting your needs?
- How could these services be improved?
- Are these services easy to access and easy to use?”

Allow participants to discuss.

“For the services you are NOT using:

- Are they services that you want but can’t get?
- What are the specific barriers you face in accessing these services?”

Allow participants to discuss.

“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.

“Do you have any final thoughts or comments on HIV/AIDS services in Palm Beach County?”

Allow participants to discuss.

7. 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.

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 Handout

Service Category
CORE SERVICES
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:
Residential: Professional counseling for drug or alcohol addiction
Outpatient:
Nutritional Counseling: Professional counseling for healthy eating habits
Early Intervention Services: Assistance getting a doctor appointment and other needed services
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
Outreach: 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 (Social Security hearings, wills, health care proxy)
Rehabilitation: Physical, occupational, and speech therapy, low vision training, etc.
Emergency Financial Assistance: Help paying for utilities, appliances, etc.
Linguistics Services: Interpretation & translation services
Support groups

Appendix C.
Provider Survey 2010

1. Provider Survey 2010

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 September 1, 2010.

Thank you for taking the time to assist us with this project. If you have any further questions, please do not hesitate to contact Sonja Swanson Holbrook (telephone 561-355-4730, SHolbroo@pbcgov.org).

* **1. Name of agency**

* **2. Address**

3. Telephone

* **4. Contact person and title**

5. Which area in Palm Beach County does your agency provide HIV/AIDS care-related services? (check all that apply)

- North East
- East Central
- South Central
- Western

6. Which of these best describes your agency? (Check one response only.)

- AIDS service organization
- Health clinic
- Community-based organization (not AIDS-specific)
- Hospital
- Multi-service agency that includes HIV/AIDS services
- Substance abuse treatment facility
- Public Health Department
- Other (please specify)

**7. For how many years has your agency provided HIV/AIDS care-related services?
(Check one response only.)**

Less than 1 year

1 to 4 years

5 to 9 years

10 years or more

8. Do you target a particular population? (Race, ethnicity, gender, age group, special needs, homeless, IDU)

9. For the last fiscal year, please estimate the total number of patients/clients infected with HIV/AIDS that you served.

10. For the last fiscal year, please estimate the percentage of your patients/clients who were HIV-positive but had not been diagnosed with AIDS.

11. For the last fiscal year, please estimate the percentage of your patients/clients who were HIV-positive and had been diagnosed with AIDS.

12. Which of the following does your agency most often provide? (Check all that apply.)

- Primary medical care
- Access services (e.g., transportation)
- Medications/Pharmacy
- Benefits/Financial assistance
- Mental health services
- Housing
- Substance abuse treatment
- Family support services (e.g., respite care, kinship care, legal assistance)
- Oral health/dental services
- Case management
- Other (please specify)

13. How is your organization working to address racial, gender, and geographic disparities health outcomes for PLWH?

14. What is the single most important change you would suggest to improve services for individuals or families infected with HIV?

15. List three barriers that your organization has faced when providing care to people living with HIV/AIDS.

16. Which of the following services would help you to better serve your clients/patients living with HIV? (Check all that apply.)

- Training in working with people from other cultures
- Training to learn other languages
- Opportunities for networking among providers to share information and HIV/AIDS care and available resources
- 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
- 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)
- Training on how to better advocate for clients/patients
- Other (please specify)

17. Which services do your clients need that are not available?

18. If your agency has any HIV-specific verbal agreements, commitment letters, letters of collaboration, binding agreements, or signed Memoranda of Understanding (MOUs) with other agencies in the area please list them below.

19. When you refer clients, does your agency have a way of tracking referrals?

Yes

No

20. If yes, please describe.

21. Does your agency have a way of tracking people put on a waiting list?

Yes

No

22. If yes, please describe.

23. Are you, or is someone from your agency, a member of any of the following? (Check all that apply.)

- Palm Beach County CARE Council
- HIV Community Prevention Planning Group
- Minority AIDS Network
- No
- Other (please specify)

24. What could the CARE Council do to help your agency better coordinate services with other providers in the area?

25. 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.

26. 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)? (Check all that apply.)

- Do not know where to go.
- Cannot get an appointment.
- Cannot get transportation.
- Cannot get childcare.
- Is too busy taking care of partner.
- Cannot pay for services.
- Do not want people to know that they have HIV.
- Is not ready to deal with having HIV.
- Do not feel sick.
- Not enough doctors in their area.
- Cannot get time off work.
- Is depressed.
- Missed appointment(s).
- Had a bad experience with the medical staff.
- Other (please specify)

27. 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.)

- Substance abuse treatment
- Mental health services
- Dental care
- Food
- Case management
- Legal services
- Transportation
- Housing
- Financial assistance
- Labs
- Other (please specify)

28. What would be some reasons people living with HIV/AIDS would enter primary medical care? (Check all that apply.)

- Get sick and know they need care.
- Ready to deal with their illness.
- Get a referral to get into care.
- Find a doctor or medical facility they like.
- A family member or friend helps them get into care.
- Someone else with HIV/AIDS reaches out to them.
- An outreach worker finds them and helps them get into care.
- Find a medical facility that has evening or weekend hours.
- Find a doctor or medical facility that ensures their confidentiality
- Find a doctor or clinic where they do not have to wait very long in the waiting room.
- Able to deal with other problems in their life that are keeping them out of care.
- Get transportation to go to a doctor or clinic.
- Someone arranges to have their care paid for.
- Other (please specify)

29. If we have limited funding, what are the five (5) most important services?

- 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
- Treatment Adherence: Instructions on how to take HIV medications properly. Counseling and follow up on medical compliance.
- 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 Residential: Professional counseling for drug or alcohol addiction
- Substance Abuse Treatment Outpatient
- Nutritional Counseling: Professional counseling for healthy eating habits
- Early Intervention Services: Assistance getting a doctor appointment and other needed services
- 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
- 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
- Outreach: 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
- Legal Support: Help clients with HIV related legal issues (Social Security hearings, wills, health care proxy)
- Rehabilitation: Physical, occupational, and speech therapy, low vision training, etc.
- Emergency Financial Assistance: Help paying for utilities, appliances, etc.
- Linguistics Services: Interpretation & translation services
- Support groups
- Other (please specify)

30. Is there anything else you would like to add?

Appendix D.
Ryan White Service Category Definitions 2010

**PALM BEACH COUNTY HIV CARE COUNCIL
PART A - RYAN WHITE CARE ACT GRANT
MARCH 1, 2010- FEBRUARY 28, 2011**

SERVICE CATEGORY DEFINITIONS

CORE MEDICAL SERVICES

1. Medical Care

a Ambulatory/Outpatient Primary 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. NOTE: Early Intervention Services provided by Ryan White Part C and Part D Programs should be included here under *Outpatient/ Ambulatory medical care*.

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, tuberculin skin-tests, 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 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.

Pediatric AZT

d Specialty Outpatient Health 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

Diagnostic, preventive, and therapeutic services provided by general dental practitioners, dental specialists, dental hygienists and auxiliaries, and other trained primary care providers.

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 to extent of immune deficiency, tests to provide information on appropriate therapeutic measures); referrals; other clinical and diagnostic services regarding HIV/AIDS; periodic medical evaluations for individuals with HIV/AIDS; and providing therapeutic measures.

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.

- 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.
- 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. Also 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.
- j Hospice Services
Includes room, board, nursing care, counseling, physician services, and palliative therapeutics provided to clients in the terminal stages of illness in a residential setting, including a non-acute-care section of a hospital that has been designated and staffed to provide hospice services for terminal clients.
- k 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.
- l Medical nutrition therapy
Provided by a licensed registered dietitian outside of a primary care visit and includes the provision of nutritional supplements. Medical nutrition therapy provided by someone other than a licensed/registered dietitian should be recorded under psychosocial support services.
- m 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.

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.

n 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)

Includes the provision of advice and assistance in obtaining medical, social, community, legal, financial, and other needed services. Non-medical case management does not involve

coordination and follow-up of medical treatments, as medical case management does.

3. Referral for Health Care/Supportive Services

The act of directing a client to a service in person or through telephone, written, or other type of communication. Referrals may be made within the non-medical case management system by professional case managers, informally through support staff, or as part of an outreach program.

4. Housing Services

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).

6. Food Bank/Home Delivered Meals

Food bank/home-delivered meals include the 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

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.

NOTE: Part A and Part B programs must be allocated, tracked and report these funds under specific service categories as described under 2.6 in DSS Program Policy Guidance No. 2 (formally Policy No. 97-02).

8. Medical Transportation Services

Includes conveyance services provided, directly or through voucher, to a client so that he or she may access health care 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), not HIV counseling and testing nor 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; including information dissemination about medical and psychosocial support services and counseling to help clients 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.

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. Respite Care

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.