PALM BEACH COUNTY, FLORIDA
CARE SYSTEM ASSESSMENT DEMONSTRATION PROJECT
FINAL REPORT

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PALM BEACH COUNTY, FLORIDA

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TABLE OF CONTENTS

LIST OF TABLES

EXECUTIVE SUMMARY

The Care System Assessment Demonstration Project (CSAD) is a Special Project of National Significance funded by the U.S. Department of Health and Human Services, Health Resources and Services Administration, HIV/AIDS Bureau. The purposes of the project are to (1) assess systems of HIV/AIDS care; and (2) determine the barriers to care faced by persons living with HIV/AIDS (PLWH) who are not in regular primary care, especially those from racial and ethnic minority groups. Palm Beach County, Florida is one of three sites selected nationally for this project (the other two are Orange County, California, and Minneapolis). The special population under consideration for the CARE System Assessment Demonstration Project in Palm Beach County is Black women.

The CSAD consists of two complementary components: (1) Rapid Assessment, Response, and Evaluation (RARE), which examines the research topic from the perspectives of the affected population (i.e., HIV+ Black women who are not in care); and (2) Service System Assessment, which examines the research topic from the perspectives of persons within the HIV/AIDS care system (e.g., health care providers, HIV+ Black women in care).

In this study, a variety of qualitative methods were used to capture the perspectives of members of the system of care. The qualitative data collection techniques used were:

- Document review
- Individual interviews
- Group-administered interviews
- Focus groups
- Cultural consensus survey
- Direct observations
- Geo-mapping

The major findings in relation to seven domains of care are shown in Table 1 on the following page. Overall, the findings yielded a conceptual framework that identifies eight factors that influence HIV/AIDS care utilization. Four of these are system factors and four are client factors.

The system factors are:
- *Insufficiency:* the care system lacks comprehensiveness and capacity
- *Inconvenience:* services are located at multiple sites that are difficult for clients to get to
- *Impersonality:* some staff treat clients disrespectfully and the atmosphere in the care settings is unappealing
- *Impediments:* there are features of the care system that obstruct access to services

The client factors are:
- *Poverty:* clients lead lives of hardship lacking in basic resources
- *Powerlessness:* clients lack agency to act on their own behalf
- *Prioritization:* clients place other individual and family needs before the need for HIV care
- *Privacy:* clients do not use the care system because they fear having their HIV status exposed to members of their community.

Table 1
Summary of Study Findings

DOMAIN	DOCUMENTS SAY	PROVIDERS SAY	THOSE NEEDING CARE SAY
Comprehensiveness	▪ There are many types of case management and medical services ▪ Funding is used as intended ▪ There are multiple funding sources	▪ Medical care and case management are the top priorities, but ▪ It is difficult to coordinate effectively with other services within their own agencies or to collaborate with other providers	▪ Financial services are more important to them than medical services ▪ They are not too sure what case management is ▪ They don't want to have to be clean from drugs or speak to case managers to qualify for medical care
Capacity	▪ There are gaps in every service category ▪ About 800 black females are not receiving primary medical care	▪ They do not have enough time, money or staff to administer all of the needed services	▪ They are sick and can't get services ▪ They can't get referrals ▪ The wait is so long that they get discouraged, leave providers' offices, and take care of themselves
Integration	▪ There is formal coordination between and within agencies ▪ Case management is in place as gateway to services ▪ There is an effort to centralize information technology	▪ Agencies are top-heavy and too bureaucratic ▪ There is no coordination between services ▪ There is no one specifically to provide treatment adherence and other forms of follow-up ▪ Formal agreements are not implemented	▪ They can't figure out what to do, where to go, or how to get there ▪ They can't get referrals for what they need ▪ They are reluctant to take the medicine because it makes them sick (side effects) ▪ They need to have other services in place before they even think about getting medical care—things like food, shelter, safety
Accessibility	▪ There are convenient provider locations, with most services being located close to each other ▪ Public transportation information is available in 3 languages	▪ The eligibility process is time-consuming and labor-intensive, so they bypass difficult eligibility forms for other funding streams and use the CARE Act immediately	▪ Getting eligibility is too hard; they would rather go home and die ▪ The buses come only once in a while, and the stops are far away from where people live ▪ They work and have families, and the doctors and other workers are off work when they're off work
Acceptability	▪ There are established standards of care ▪ A monitoring system is in place ▪ Providers are in safe and secure locations	▪ They are confident in the services they provide ▪ There are too many clients and not enough time ▪ Burnout and frustration among staff are high	▪ Side effects are unacceptable ▪ Some workers are short-tempered, disrespectful, and rude ▪ They are afraid to go to any services because they don't want friends, family, and neighbors to see them
Technical Competency	▪ Providers are aware of each other ▪ Providers are well-trained in HIV-related services ▪ There is availability of HIV medical specialists	▪ Clients' beliefs are incompatible with scientific understanding of HIV ▪ Clients have limited knowledge of HIV disease and treatment	▪ They are 'carriers' of HIV but don't really have it ▪ They don't need to go to care because they're not sick ▪ They get healed in their own way ▪ HIV isn't a disease, it's a curse/punishment, and they pray for healing
Client Health-Seeking Behaviors	▪ Clients have a misunderstanding of HIV/AIDS, experience stigma, and a mistrust of the health care system	▪ Clients typically use the emergency room to access primary health care. Use of preventive health care is not common.	▪ They prefer to use home remedies and faith healing.

Through a strategic planning process, the following recommendations for system change were developed based on the study findings:

Goal I: Education

To continue to expand the education about HIV/AIDS in terms of prevention and clinical care to 100% of Live AIDS-diagnosed and to 65% of those Live HIV-diagnosed and aware. Reach such individuals through leadership, support and education. Incorporate peer educators as trainers and strive to achieve 100% involvement by Providers in this initiative. Cross-train these individuals together in a team collaborative. Tailor messages to those we intend to reach.

Goal II: Single Point of Entry:

To develop mechanisms for clients to receive comprehensive care through access at a single point of entry in the HIV care system.

Goal III: Confidentiality

To strengthen the mechanism for confidentiality training; comprehensive education and enforcement for all staff at all providers. Accountability will be designed and implemented by quality assurance and performance improvement criteria in achieving EMA standards of care relating to confidentiality and how it's defined and measured.

Goal IV: Treatment Adherence

To maximize Treatment Adherence implementation and utilization by the network of care at 100% for all clients.

Goal V: Stigma

To address the issue of stigma that makes it difficult for individuals to disclose their status and receive care for HIV-spectrum disease. The mechanisms to address stigma will be varied and appropriate for the targeted populations with an emphasis on those special populations that are disproportionately affected by HIV/AIDS.

Goal VI: Cultural Beliefs, Practices, And Behaviors

To provide outreach and encouragement to populations at risk for HIV/AIDS in Palm Beach County and create the most effective models of HIV/AIDS CARE maintenance among communities that are disproportionately affected by HIV-spectrum disease.

1. INTRODUCTION

The Care System Assessment Demonstration Project (CSAD) is a Special Project of National Significance funded by the U.S. Department of Health and Human Services, Health Resources and Services Administration, HIV/AIDS Bureau. The purposes of the project are to (1) assess systems of HIV/AIDS care; and (2) determine the barriers to care faced by persons living with HIV/AIDS (PLWH) who are not in regular primary care, especially those from racial and ethnic minority groups. Palm Beach County, Florida is one of three sites selected nationally for this project (the other two are Orange County, California, and Minneapolis). The special population under consideration for the CARE System Assessment Demonstration Project in Palm Beach County is Black women. The project period is calendar years 2004-2005.

The CSAD consists of two complementary components: (1) Rapid Assessment, Response, and Evaluation (RARE), which examines the research topic from the perspectives of the affected population (i.e., HIV+ Black women who are not in care); and (2) Service System Assessment, which examines the research topic from the perspectives of persons within the HIV/AIDS care system (e.g., health care providers, HIV+ Black women in care). The CSAD is conducted within the framework of participatory action research. This means that stakeholders (i.e., the above-identified constituencies) are integrally involved in all phases of the research. Within this framework, this report presents the research methodology and findings for the purpose of development of action recommendations by these stakeholders.

1.1 DEMOGRAPHICS OF THE EPIDEMIC AND RATIONALE FOR SELECTING BLACK WOMEN

1.1.1 National Epidemiology

Although Acquired Immunodeficiency Syndrome (AIDS) was primarily diagnosed in men in the early 1980s, by the 1990s the disease had become more prevalent among women. In 1993, the Centers for Disease Control and Prevention expanded the criteria for AIDS cases to include persons with severe immunosuppression, pulmonary tuberculosis, recurrent pneumonia, or invasive cervical cancer. The expanded case definition had the effect of greatly increasing the number of reported AIDS cases. In 2001, 25.8 percent (11,082 cases) of all reported U.S. AIDS cases among those age 13 years and older occurred in females. AIDS cases among these females were attributed to two major exposure categories: heterosexual contact and injecting drug use. Cases with no identifiable modes of transmission accounted for another 4,606 cases. AIDS cases due to heterosexual contact and injecting drug use were highest among non-Hispanic Black women in 2001 (2,606 and 1,257 cases, respectively). Non-Hispanic Black women represented 63 percent of all AIDS cases in women attributable to heterosexual contact and 57 percent of AIDS cases among women attributable to injecting drug use. (*Centers for Disease Control and Prevention, 1993. Impact of the Expanded AIDS Surveillance Case Definition on AIDS Case Reporting- United States, First Quarter, 1993. MMWR, April 30, 1993. 42(16); 308-310.)*

1.1.2 Epidemic in Palm Beach County

As of August 2003, 4,752 individuals (including pediatric cases) were presumed to be living in the Palm Beach County with an AIDS diagnosis. An additional 2,328 individuals (including pediatric cases) were presumed to be living with HIV in the county. 79% of those living with AIDS/HIV in Palm Beach County were identified in the coastal regions of the county, which includes the cities of West Palm Beach, Lake Worth, Riviera Beach, Boynton Beach and Delray Beach. The remaining 21%were residents of the western rural portion of the county. This area encompasses Belle Glade, Pahokee, South Bay, and Canal Point. It is important to note that the Western section of the county has between 30,000 year round residents to 80,000 seasonal residents, making the number of HIV/AIDS cases in the rural communities disproportionately high.

A unique aspect of the HIV/AIDS epidemic in Palm Beach County is that it has historically and continues to be largely centered in the Black (non-Hispanic) population. Further, there continues to be a strong increase in the heterosexual risk category. The cumulative number of AIDS cases as of 8/20/03 in Palm Beach County among men who have sex with men was 2,531. The cumulative number of HIV cases (a more recent and therefore more representative picture of the virus in the county) among men who have sex with men in Palm Beach County, was 427. The cumulative number of AIDS cases as of 8/20/03 for heterosexuals in Palm Beach County was 3,112, while the cumulative number of HIV cases among heterosexuals was 1,052 *(Community Planning Partnership: Palm Beach County; Summary Statistics, 2002).*

In general, new trends in the HIV/AIDS epidemic in Palm Beach County revolve around women, people of color, recent entrants, and heterosexuals comprising a larger proportion of the epidemic and white men who have sex with men and injection drug users composing a less significant proportion of the population.

Of those living with AIDS in Palm Beach County, 25 percent are white, 67 percent are black, and 8 percent are Hispanic. Of those living with HIV, 24 percent are White, 62 percent are Black and 8 percent Hispanic. The historical patterns established by the epidemic in Palm Beach County continue to increase with respect to those who become infected. For example, only 20 percent of the new cases of AIDS diagnosed over a two-year period (01/01/01 to 12/31/02) were among Whites and 72 percent of the new AIDS diagnoses were among Blacks.

Palm Beach County experienced a shift in the majority of diagnoses from white men who have sex with men to people of color who engage primarily in heterosexual sex as far back as five years ago. This trend continues to increase as reflected by the percentages above. In Palm Beach County, approximately 13 percent of the population is Black, 12 percent Hispanic and about 75 percent White. These population estimates highlight the disparate proportion of Blacks infected with AIDS, considering that blacks represent a small percentage of the total Palm Beach County population. Such a disproportionate impact of AIDS/HIV on the Black community is consistent with national trends.

Consistent with nationwide data is that the overwhelming majority of people living with AIDS cases (96%) in the county are adults over the age of 19. As of 12/31/02, Palm Beach County had

105 living AIDS cases in children under the age of 19 years and 11 AIDS cases reported during the two-year period ending 12/31/02. There are however, 34 youth less than 19 years of age living with HIV infection in Palm Beach County as of 12/31/02. This age group accounted for about 2 percent (2%) of all living HIV cases in Palm Beach County.

Women are increasingly at risk for HIV infection as reflected by the epidemiological data. Women account for 35 percent of the live AIDS cases, 37 percent of recent AIDS cases and 46 percent of live HIV cases. This trend exceeds the national epidemic where 18 percent of cumulative AIDS cases are females. It is estimated that there are approximately 2,000 Black women living with HIV/AIDS in Palm Beach County today, and that about 800 of these women, or more than one-third, are not in primary medical care. These data support the selection of HIV+ Black women for the purposes of this study. Figures 1-4 in Appendix A provide a visual depiction of the foregoing epidemiological data.

1.2 RATIONALE FOR SITE SELECTION

Even though 79 percent of the county's total living AIDS cases and 91 percent of the new HIV cases are in the coastal region, with the remainder in the western and rural communities, there are further distinctions that can be better portrayed by the HIV/AIDS data arranged by zip code. A total of 1,994 cases of HIV were diagnosed in Palm Beach County through September 2002. A total of 3,868 cases of AIDS were diagnosed as of September 2002. These total 5,862 cases of HIV/AIDS reported in Palm Beach County as of September 2002. Ten zip codes accounted for nearly 70% (N=4,064) of all cases in Palm Beach County. The distributions of cases by zip code are shown in Figures 5-8 in Appendix A.

This CSAD study focuses specifically on three sites: Belle Glade, Riviera Beach, and Delray Beach. Although many factors were considered when selecting these three areas, the major determining factor was the recent epidemiological report of HIV infection in Palm Beach County by zip code. The zip codes with the highest number of HIV cases reported were considered the highest priority areas. Another factor considered was anecdotal information alluding to hidden pockets of populations who are not in care or dropped out of care for a variety of reasons. The CSAD team and the Advisory Board listened to anecdotal reports of people in these areas who had tested HIV+ and had "fallen through the cracks" (dropped out of care) or had tested HIV+ but were not receiving appropriate medical care. It was agreed that the top priority for this initiative should be reaching those currently underserved populations. Table 2 on the next page shows selected demographic characteristics of the target sites.

1.3 RESEARCH QUESTIONS

The overall guiding research questions for the project were:

- Why are HIV+ Black women not in primary medical care?
- Why do HIV+ Black women drop out of primary medical care?

Table 2
Demographic Highlights of Study Sites

CHARACTERISTIC	BELLE GLADE	RIVIERA BEACH	DELRAY BEACH
Total population:	7331	16,413	11,042
Blacks as percent of population	77	78	69
Foreign-born as percent of population	28	14	31
Country of origin as percent of foreign-born:			
Haiti	69	31	65
Jamaica	7	15	
Mexico	15	12	10
Cuba	3		
Guatemala		11	4
Black Population:	5676	12,884	7643
Hispanic/Latino as percent of Black population	1	1	1
Foreign-born as percent of Black population	16	9	27
Noncitizens as percent of foreign-born Black population	77	55	79
Limited English ability as percent of foreign-born Black population	40	15	40
Median annual household income ($)	15,701	25,613	24,670
Percent of households with no vehicle available	39	23	18
Percent of households with no telephone available	20	9	8
Black female population age 15-50:	1429	3350	1979
Percent living in poverty	51	28	33
Percent not high school graduates (Age 25+)	51	37	49
Percent not in labor force (Age 16+)	56	43	43
Percent with children under age 6	17	18	15

Belle Glade: Census Tracts 82.01, 82.02, zip code 33430
Riviera Beach: Census Tracts 14.02, 14.03, 14.04, 15, 16, zip code 33404
Delray Beach: Census Tracts 65.02, 67, 68.01, zip code 33444

2 METHODOLOGY OVERVIEW

In this study, a variety of qualitative methods have been designed to capture the perspectives of diverse constituencies. The RARE portion of the project examined the perspectives of the target population (i.e., HIV+ Black women who are not in care). This research was aimed at understanding the meanings attached by the participants to events in their lives regarding why they have elected not to be in primary medical care, why they have dropped out of care, and the reasons why others may not be in care. The systems assessment portion of the project examined the perspectives of members of the system of care (i.e., providers, administrators, researchers, grantees, politicians and Black women who are HIV+ and in care). These qualitative protocols assist in understanding the meanings attached by the participants to the system of care they have either created or are responsible for, regarding why Black women have elected not to be in primary medical care or have dropped out of care. Together, these methods provide information that can be aggregated into a comprehensive description of the care system as seen from a variety of perspectives. The qualitative data collection techniques used in this study are shown in Table 3. All data collection was done during the spring and summer of 2004. Data analysis occurred simultaneously and continued through the spring of 2005.

Table 3
Study Methods

METHOD	RARE	SYSTEMS ASSESSMENT
Document review	Not applicable	18 documents
Individual interviews	70 HIV+ Black women not in care	89 care providers (combined with group-administered interviews) 6 HIV+ Black women in care
Group-administered interviews	Not applicable	89 care providers (combined with individual interviews)
Focus groups	4 groups of HIV+ Black women not in care	2 groups of care providers 2 groups of HIV+ Black women in care
Cultural consensus survey	28 HIV+ Black women not in care	14 care providers
Direct observations	24 health care sites	Not applicable
Geo-mapping	Health care sites	Health care sites/public transportation

2.1 DOMAINS OF CARE

The following seven domains of care identified by the federal project team were used to guide the data collection and analysis:

- System Comprehensiveness
- System Capacity
- System Integration
- System Acceptability
- System Accessibility
- Technical competencies
- Client health-seeking behaviors

The following sections provide further details of the methodology of each data collection strategy. Within each data collection strategy, the findings are presented in relation to each of the above domains of care.

3 DOCUMENT REVIEW

A wide variety of existing documents was reviewed in relation to the domains of the care system in Palm Beach County. Table B-1 in Appendix B shows the documents that were reviewed for each domain. Further methodological details and the findings in each domain are presented in the following sections. It is important to note that the document review in and of itself provides only a limited perspective on the research topic. The document review findings must be considered within the context of the other methodologies to be used in this CSAD project, which follow. Most notably, information about the actual operation of programs cannot be discerned from a document review. Reality often differs from what appears on paper.

3.1 METHODOLOGY

3.1.1 System Comprehensiveness

A list of services that comprise a comprehensive care system was obtained from the Care System Assessment Demonstration (CSAD) Project Framework for Care Service System Assessment. A table was developed listing these services (Appendix B, Table B-2). Then, for each allocation and reimbursement document above, a check was placed in the table if that service was funded by that funding source. More checks would indicate a more comprehensive system. Additionally, data from the Care Council Needs Assessment indicated what percentage of respondents to a needs survey indicated that they needed and used each service. These data were also entered into the table.

3.1.2 System Capacity

A table was developed listing the same services as described above under "System Comprehensiveness" (Appendix B, Table B-3). For each service, data from the documents were entered pertaining to the estimated number of consumers in need and the number of consumers served. The latter number was then subtracted from the former in order to provide an estimated service capacity gap. A second estimate of service gap was also taken from the Needs Assessment document. This estimate was previously calculated within the needs assessment, based on a consumer survey. The two estimates were both included in this document review for purposes of triangulation – that is, providing different perspectives and methodologies to address the same issue. Using both estimates yields an estimated service gap range, shown in the table.
An estimated service gap percentage was computed by dividing the numbers in the estimated range by the total number of estimated consumers in need.

3.1.3 System Integration

To assess inter-agency integration, a matrix was created listing all the service providers from the PBC HIV/AIDS Service Directory. Then, the Ryan White Title I grant applications were reviewed for formal agreements included as part of the application package. When a formal agreement between two providers existed, it was checked off on the matrix (Appendix B, Table B-4).

The information from this matrix was then summarized to indicate the total number of inter-agency agreements per agency. Additionally, the agencies were categorized by type of services provided and type of service linked with, in order to assess linkages across services types (Appendix B, Table B-5).

To assess intra-agency integration and referral systems, the program descriptions within each Ryan White Title I Grant Application were read. Finally, the Care Council 2002-2005 Comprehensive Plan contained information on a county-wide Management Information System (MIS).

3.1.4 System Accessibility

System accessibility was assessed in relation to geographic, linguistic, and temporal accessibility. Regarding geographic accessibility, the locations of primary (i.e., HIV testing sites, private physicians, and hospitals/clinics) and ancillary care (e.g., case management) providers listed in the Service Directory were mapped onto a bus/train route map using geo-mapping. Additionally, the locations of the target population (Black females living with HIV/AIDS) were mapped. Regarding linguistic and temporal accessibility, the Service Directory listed the languages and hours of operation of each provider; these were compiled into a table (Appendix B, Tables B-6, B-7).

3.1.5 System Acceptability

Within the Ryan White Title I grant applications, the following sections were reviewed for evidence of cultural competence and client-centeredness: Organizational History and Experience, Current and Proposed Services, and Barriers to Care. In relation to the latter, a table was developed summarizing the agency-identified barriers to care and the agency responses to them as documented in the grant applications. The various barriers and solutions were grouped into categories (Appendix B, Table B-8).

3.1.6 Technical Competencies

The educational and training qualifications of the primary care and social service providers were examined and compiled in tables (Appendix B, Table B-9, B-10).

3.1.7 Client Health-Seeking Behaviors

The Palm Beach County RARE report (2001) was read for descriptions of client health-seeking behaviors.

3.2 FINDINGS

The document review yielded the following findings in relation to the HIV/AIDS care system in Palm Beach County:

- The system funds a comprehensive array of services. All of the services are needed and used to varying degrees.
- Service gaps exist in all the service categories. Large gaps exist in the following services: direct emergency financial assistance; housing; health insurance continuation; food bank/home-delivered meals; transportation; rehabilitation care; outreach/referral; ambulatory/outpatient care; dental care; case management; and counseling. In general, there is a match between service gaps and funding priorities and allocations.
- From the consumers' perspective, the top needs are financial (i.e., housing, groceries, etc.), not medical.
- The care system appears is integrated in several ways.
- The care system appears to be geographically accessible by public transportation. However, the buses run infrequently, which poses a barrier.
- Limited hours of operation may be a barrier to some potential users.
- Limited French/Creole capability is a barrier for the Haitian population.
- The care providers appear to have addressed issues of acceptability, including cultural competence and client-centeredness. All appear to be cognizant of barriers to care and have made efforts to decrease such barriers. The extent to which this has been successful cannot be determined from the document review.
- The physicians and social service staff appear to be technically competent. The target population of PLWH appears to have limited technical competency.
- Members of the target population may not be in primary medical care due to incompatible beliefs about the etiology and treatment of HIV/AIDS, fear of stigmatization and social isolation, and mistrust of the formal helping system.

4 DIRECT OBSERVATION AND GEOMAPPING

4.1 METHODOLOGY

The RARE portion of the study included direct observation and geomapping. These were the least threatening methodologies for Field Team Members, especially for those who were doing research and/or qualitative research for the first time. Direct observation was considered to provide Field Team Members with an opportunity to develop confidence to execute other methodologies that would require more active involvement. In addition, this method was first chosen because no ID card was needed and this activity would allow time to make plans for obtaining identification cards for subsequent methodologies.

Twenty-four direct observations were completed. These observations were conducted at a broad cross-section of service providers in Palm Beach County ranging from private to public. The types of services included substance abuse centers whose clientele include the study target population. Observations were conducted in Belle Glade and Delray Beach. Up-to-date maps of the target sites were obtained. Field Team Members conducted a walk/drive-through of the sites a number of times. A number of things were observed, including boundaries of the area, types of behavior, locations, kinds of people, and other relevant activities.

The Field Team Coordinator used mapping software to develop basic maps for all three sites as well as mapping the epidemiological data related to HIV+ women in the respective zip codes.

Field Team Members were instructed to visit their respective sites and indicate areas of risk conditions, behaviors, barriers and facilitators to accessing care, and the physical context of activities in each respective site. Field Team Members were advised to identify potential respondents for individual interviews while conducting mapping in their communities.

The observations for each site are described below. Appendix C contains the Field Team Members' hand-drawn maps of each target area, highlighting hot spots, providers, and other points of interest.

4.2 FINDINGS

Table 4 on the following page provides a summary of the observation findings by their applicable domains.

5 INTERVIEWS AND FOCUS GROUPS

For the RARE portion of this study, interviews were conducted with HIV+ Black women not in care. For the systems assessment portion of the study, interviews were conducted with the providers of care, such as administrators, planners, researchers, health care workers, and other key stakeholders. They were asked about how they perceive services for HIV+ Black women. Additionally, analogous interviews were conducted with HIV+ Black women in care. Further, in the RARE portion, focus groups with HIV+ Black women not in care were conducted. For the systems assessment, focus groups with providers and women in care were conducted. Methodological details and findings for each of these data collection strategies are presented in the following sections.

5.1 METHODOLOGY FOR INTERVIEWS

5.1.1 Selection of Participants

5.1.1.1 *Systems Assessment*

Members of the following groups were interviewed:

- The Palm Beach County HIV Care Council
- The administrators from case management agencies
- The administrators for the Palm Beach County Department of Health (DOH)
- The front-line workers at the DOH
- Doctors and nurses at the DOH
- Private infectious disease doctors
- The Grantees from Ryan White Titles I and II
- The Planning Staff at the Treasure Coast Health Council
- Members of Haitian and African-American worship communities
- The CSAD Advisory Committee
- Local policy makers

Table 4. Observation Findings

Domain	Health Care Provider Site	Observations
Accessibility	County Health Dept., Delray Beach	Near bus route, tri-rail station, close proximity to mental health facility and other health care providers.
	Private Physicians Office, Delray Beach	Located in strip plaza directly across main street and bus stop
	Hospital/Medical Center, Delray Beach	Near other healthcare providers. Bus stop located across busy street (potential safety hazard)
	Drug Abuse Foundation, Delray Beach	Close proximity to established "hot zones" and not readily accessible by public transport
	Comprehensive AIDS Program (CAP), Delray Beach	Located in strip plaza, accessible by bus stop (client need to cross busy street)
	Florida Lighthouse, Delray Beach	Located in professional center, office location shared with multiple health care providers (some non-HIV related services
	Private Physician's Office, Belle Glade	Located in strip plaza. Limited parking.
	Comprehensive AIDS Program (CAP), Belle Glade	Located in strip plaza.
	Case management agency, Belle Glade	Close proximity to public transportation and pharmacy. Adequate parking.
	Hospital, Belle Glade	Easily accessible from main street and public transportation.
	Substance abuse facility, Belle Glade	Easily accessible from main street and in close proximity to provider services.
	Mental health facility (PANDA), Belle Glade	Not readily accessible by public transportation.
	Public Health Clinic, Belle Glade	Located in hub of other human services providers including Sheriff's Office and other government offices. Adequate parking. Public transportation available in parking lot.
Client Health Seeking Behavior	Drug Abuse Foundation, Delray Beach	Close proximity to more than one hot zone. Potential threat in distracting clients in their attempt to seek health care services. Premises is secured (fenced)
	Comprehensive AIDS Program (CAP), Delray Beach	Mini shopping plaza location has negative implications for clients seek heath care services (confidentiality issues)
	Hospital/Medical Center, Delray Beach	Relatively close proximity to hot spots. Potential negative impacts on clients health seeking behavior
	Provider sites, Belle Glade	Providers located in strip plaza sparked concerns related to confidentiality.
Acceptability	Health Department, Delray Beach	Location seemingly acceptable to client seeking services
	Private Physician, Delray Beach	Due to difficulty in accessing public transportation, office location may be considered unacceptable to clients seeking services
	Provider sites, Belle Glade	Most provider sites in good state of repair. Services seemed acceptable to observed clients.
Comprehensiveness	Provider sites, Belle Glade	Due to relatively small community, existing providers are in close proximity to one another.

Selection of the participants was based on their expertise related to providing either case management or primary health care to HIV+ Black women of color, administering programs for such women, and/or making policy decisions with the intent of providing services for this population.

These key informants were determined primarily on the basis of their knowledge of HIV/AIDS among of women of color and HIV-spectrum disease in Palm Beach County, Florida. These key informants are fairly knowledgeable about the composition of the targeted community and our HIV/AIDS system of care. In addition, key informants selected for this study have had professional experience with our targeted population for years and bring a wealth of personal experiences to this project. Additionally, they have been helpful in identifying those not in care, those who dropped out of care, and those who have recently entered the CARE system. Finally, most of the key informants have long-standing and varied connections with the HIV/AIDS community or the community at large. For example, some are active members of organizations that advocate for services and are currently providing or administering HIV/AIDS services. A total of 89 key informants were interviewed. The interviews were conducted by the Site Coordinator and Site Assistant.

5.1.1.2 *RARE*

The RARE portion of the project focused on the target population: HIV+ Black women not in care. These interviews were conducted by Field Team Members, who were Black women and men, some of whom were HIV+. The Field Team Members were asked to generate a list of potential interviewees while. Some of these individuals were also contacted and informed of the research project being conducted and that follow-up attempts would be made to get their participation. The word-of-mouth approach was widely used to reach participants because this approach resulted in a greater willingness by participants to share pertinent intimate information.

Selection of the respondents was intended to identify those individuals who were likely to contribute information that would be beneficial to the research project. Respondents were identified and determined primarily based on the knowledge of Field Team Members. Some Team Members reside in the research site and were fairly knowledgeable of the composition of the community. In addition, Field Team Members who were employed previously (in a prevention-focused RARE) established rapport with individuals to help them identify those women of color not in care and those who dropped out of care. In addition, most of the team members have long-standing and varied connections with the HIV/AIDS community. For example, some are active members of organizations that advocate for services and others represent the infected community.

Distinguishing between people in and/or not in care was challenging for some team members while for others it was relatively easy. Some members of the team who are affected by the disease chose to self-disclose their status as a means of reaching those they believed to be infected and in denial and/or reluctant to access care. By so doing, Field Team Members got individuals to open up and to confide in them and consequently shared information freely.

In addition to the above-mentioned approach toward identifying those that are not in care, plans were made to contact counseling sites to get the word out to individuals who wished to share their experiences. The Field Team Coordinator consulted with the Minority AIDS Coordinator and obtained assistance in developing a flyer to promote the research and solicit participation from the target population.

Respondents were provided with $10.00 supermarket gift certificates as an incentive. Respondents were rewarded for their participation at the end of the activities in which they participated. There were a total of 70 respondents.

5.1.2 Data Collection Procedures

5.1.2.1 *Systems Assessment*

Interviews with providers were conducted using either group-administered written interviews or individual one-on-one interviews. Data from these two data collection strategies were combined for analysis. Initially, the group-administered written interviews were conducted to accommodate the time constraints of those who were originally identified to be interviewed. Case management providers were notified about the needs of this project, yet their time requirements had to be primary. Instead of conducting individual interviews, the researchers administered a group written interview, whereby questions from the structured individual interview were read aloud, questions of clarification were addressed aloud, and the participants wrote down their responses individually and independently of each other. Because the responses from the case management agency were rich, powerful, and abundant, we decided to duplicate this methodology with the Grantees office, the planning/advisory committee, and a second case management agency. One-on-one interviewing was the next methodology to be implemented. These interviews were considered a prerequisite for the focus group sessions and were intended to provide data for the cultural consensus survey.

5.1.2.2 *RARE*

Field Team Members individually interviewed the members of the target population.

5.1.3 Instrumentation

A 50-item semi-structured interview asked open-ended questions across the seven study domains (questions are shown in Appendices D and E). A pre-interview survey gathered data on reasons why Black women who are HIV+ are not in care or why such women have dropped out of care. Additionally, information on providers' education and agency were collected. A post-interview form collected subjective impressions from the interviewer about the session.

A multifaceted approach was used in the development of the questionnaire. The initial approach was to involve Advisory Committee members by allowing them to make suggestions regarding possible questions. This initial approach was used to secure Advisory Committee members' advice and co-opt them into the process. A set of questions was developed based on the recommendations from the Advisory Committee; it was then presented to the Field Team members, who made further recommendations. The questions used in the RARE portion of the project were adapted to be relevant for the systems interviews, using the same domains and questions, yet framing them differently to make sense for providers/administrators/policy-makers/grantees, instead of clients. The final instruments were then field-tested by having staff at the Palm Beach County HIV Care Council respond to, comment on, and refine the instrument.

In the systems assessment, the same questionnaire was administered in the group setting as was administered individually. The only difference was the methods of administering the questionnaire. We read the questions and clarified them verbally, and the respondents wrote their responses in the group-administered written interviews.

5.1.4 Data Analysis

All interview responses were handwritten by the interviewee (group-administered written interviews) or the interviewer (one-to-one interviews). The responses were then transcribed into a computer text file. Subsequently, the grounded theory/constant comparative method of qualitative data analysis was used to identify themes/categories that emerged from the data. This process was done in four stages:

- First, a content analysis was conducted, wherein responses to each interview question were grouped into initial themes, and frequencies of the themes were counted. The results of this initial stage of data analysis are shown in Appendices D and E.
- Second, several illustrative quotations were selected for each of the five most frequent responses to each question.
- Third, the initial emergent themes were grouped into larger categories, and these were grouped according to the seven domains that guide this study. The illustrative quotations from stage two were grouped according to these larger themes. These results are presented in the “Findings” section below.
- Finally, these larger categories were grouped into still larger categories to yield an overall explanatory framework, or grounded theory, that answers the overall research questions. This is presented in the “Conclusions” section at the end of this report.

4.1 5.2 METHODOLOGY FOR FOCUS GROUPS

5.2.1 Systems Assessment

Four focus groups were conducted. Two groups consisted of care providers. One of these was case managers and the other was members of the HIV Care Council. The two other groups consisted of HIV+ Black women in care in two different substance abuse residential treatment facilities. Each group had 6 participants.

5.2.2 RARE

Four focus groups were conducted in the three geographic areas that contain the target population for this study. Across the three target sites, the majority of focus group participants were HIV+ women of color who are out of care. Focus group attendance ranged between eight and ten individuals per group.

5.2.3 Data Collection and Analysis

Nine questions excerpted from the individual interviews were used to guide the group discussions (questions identified in Appendices D and E). Each group lasted 1.5-2 hours. The groups were audio recorded and then transcribed verbatim. The method of data analysis was the same as that used for the individual provider interviews. The emergent themes are presented by domain in the Findings section below. Frequencies of responses to each question are provided in Appendices D and E.

5.3 METHODOLOGY FOR WOMEN IN CARE INTERVIEWS

In the systems assessment, 6 women in care, who were in a residential substance abuse treatment facility, were interviewed individually. The same questionnaire that was used with the providers was used with these women. The responses were written on the questionnaire, then transcribed and analyzed in the same way as the provider interviews. Frequencies of responses to each question are provided in Appendix D.

5.4 DEMOGRAPHICS OF RESPONDENTS

5.4.1 Systems Assessment

The majority of providers worked in case management, health, and administrative agencies. The largest group of providers was case managers, followed by administrators and planning committee members and coordinators. In general, the providers were highly educated, with about three-fourths having college or graduate degrees (see Appendix D). Among the women in care, 3 had a high school education, 2 had trade school, and 1 college. Demographic data were not collected on the focus group participants.

5.4.2 RARE

Most of the RARE interview respondents had low educational levels; less than 30% had completed high school. Almost 90% were unemployed. Accordingly, most did not identify having a position in the community; among those that did, the most frequently identified position was sex worker (see Appendix E).

5.5 FINDINGS

As noted earlier, data from the initial coding process are presented in Appendices D and E. This section presents the results of the intermediate level of analysis – the grouping of responses into thematic categories organized by the seven guiding domains. These thematic categories were further grouped into system strengths – i.e., features of the care system that enhance service utilization by members of the target population – and system challenges – i.e., features of the care system that hinder service utilization by members of the target population. The results are integrated for the individual interviews, group-administered interviews, and focus groups within both the RARE and systems assessment components of the study.

The emergent themes are summarized in Table 5 on the following page. The table also indicates which of these themes emerged from which data collection strategy. Additional triangulation data for the RARE component of the study are provided in Appendix F. Overall, most of the themes emerged from more than one data collection strategy, thereby verifying the validity of the findings. The themes are elaborated in the following text. For each thematic category, illustrative quotations from the respondents are provided to “ground” the data.

5.5.1 Comprehensiveness

5.5.1.1 *Strengths*

Availability of Primary Medical Services

According to respondents, primary medical care for HIV+ persons is available in the community. Respondents felt that primary medical care was among the best services for patients:

- “Primary care. Very comprehensive.”
- “Getting health care.”
- “Medical treatment and meds.”

5.5.1.2 *Challenges*

Lack of Ancillary Services

The findings indicate that the HIV care system in Palm Beach County is not comprehensive. Respondents repeatedly emphasized that the target population has multiple unmet needs. Their lives appear to be largely defined by poverty and its correlates, including inadequate food, housing, and transportation. These findings are corroborated by the census data for this population presented earlier. HIV disease is only one among many challenges facing this population. There is a lack of ancillary services to address their basic needs. Respondents indicate that having patients’ basic needs met would promote their health care utilization:

- “Clients need clean housing environment, medical care, pharmaceutical, transportation, mental health counseling.”
- “Need housing to be able to maintain health – without basics you don’t care about other stuff – medical care means zilch if you live under a bridge.”
- “Housing helps them to remain stable.”

Table 5
Palm Beach County HIV Care System
System Strengths and Challenges by Domain

	STRENGTHS	CHALLENGES
COMPREHENSIVENESS	• Availability of primary medical services (1, 3, 4)	• Lack of ancillary services – e.g., food, housing, mental health treatment (1, 3) • Lack of placements for clients with multiple diagnoses (2)
CAPACITY	• Multiple provider mix (4)	• Long waits at clinics (1, 2, 4)
INTEGRATION	• Case management (1, 3, 4) • One-stop clinics (1,2, 3)	• Services at different sites (1, 4) • Lack of follow-up (1, 4) • Cumbersome referral process (1, 3, 4)
ACCESSIBILITY	• Case management (1, 3) • Some convenient clinic locations (1, 3, 4) • Peer advocates (2, 3)	• Lack of insurance (1, 2, 3, 4) • Lack of transportation/some inconvenient locations (1, 2, 4) • Red tape (1, 2, 3) • Limited clinic hours (1, 2, 4) • Interpreter shortage (1, 3) • Client lack of phone (3)
ACCEPTABILITY	• Case management (1, 3) • Client-centered providers (1, 2, 3, 4) • Belief in services (1, 3, 4) • Some safe and secure locations (1, 2, 3, 4) • Peer advocates (2, 3, 4) • Confidentiality officially protected (3)	• Stigma (1, 2, 3, 4) • Unappealing clinic environment/some unsafe and insecure locations (1) • Red tape (1, 2, 3) • Lack of respect (1, 2, 4) • Lack of cultural competence (1, 3) • Poor communication with provider/poor care (2, 3) • Difficulty with medication regimen and side effects (2, 3)
TECHNICAL COMPETENCIES	• Well-trained providers (1, 3, 4) • Client education (1, 3) • Belief in services (1, 3, 4) • Availability of medical specialists (1, 3)	• Client lack of knowledge of disease and treatment (1, 3, 4) • Lack of provisions for non-English speakers (4) • Lack of provisions for illiterate (4)
CLIENT HEALTH-SEEKING BEHAVIOR	• Client knowledge of where to go for health care (1, 2, 3, 4)	• Other priorities (1, 4) • Denial/Fear (1, 2, 4) • Hopelessness (1, 4) • Frustration (1, 4) • Non-expression of needs (1) • Self-remedies (1, 4) • Use of emergency room (1, 4) • Lack of familiarity with health care system (1) • Substance abuse (2, 3, 4) • Asymptomatic (2, 3)

1-Provider Interviews; 2-Provider and Women in Care Focus Groups; 3-Women in Care Interviews; 4-RARE Interviews and/or Focus Groups.

Lack of placements for clients with multiple diagnoses

According to respondents, HIV+ Black women have multiple life needs besides HIV care. The care system does not appear to be well suited to serve their needs comprehensively:

- “I have a client that’s in the hospital, and she got hit by a car and her legs are crushed, but she’s also an addict, and we’re having a lot of trouble trying to find her a placement, because of her history. She has a criminal record, she also has mental illness but she also has HIV, she’s got different problems. Nobody will take her. There’s no facilities available. You would think like in the past if you had a lot of mental health problems that there were facilities that would take you, close the door and lock it and throw the key away. But that’s where you stay for the rest of your life. You think as time has evolved that they would have a facility that would provide care for people who have mental illnesses with medical conditions because we’re dealing with people with dual diagnosis we’re not just dealing with HIV but all different illnesses, they don’t have facilities that will accommodate people who have multiple problems. So if you have HIV and then all of the others. They had to put her in a rehab over at St. Mary’s to buy some time because nobody would take her, because of the background and the illnesses, and she can’t walk anymore. The discharge nurse at the hospital calls us and asks us what are we going to do about it so as case managers we’re dealing with HIV but we have to somehow have to get together with case managers at the hospitals so they can deal with them as clients, but they’re just not doing it.”

5.5.2 Capacity

5.5.2.1 *Strengths*

No strengths emerged from the data in regard to system capacity.

5.5.2.2 *Challenges*

Long Waits at Clinics

The findings indicate that the HIV care system in Palm Beach County has insufficient capacity to serve the number of people in need. A very dominant theme throughout the interviews was that waits for care are very long. All-day waits in the waiting room are reportedly not uncommon:

- “Long wait at clinic”
- “They do not want to wait five hours to see a doctor when they have to work and care for their children.”
- “Wait time average 4 hours – can’t take time off work.”

Most respondents indicated that waiting time for both an appointment and in the waiting room depends on numerous factors, including whether the clinic is public or private, whether the client has insurance, and the severity of the health problem:

- “Too long, especially in the public health system.”
- “No insurance, huge time lapse. With insurance, no wait.”
- “The most annoying service that I’ve had when I was going to the clinic, they schedule everybody at the same time. Everbody’s appointment is at 10:00 o’clock. What time your appointment? 10 o’clock. Mine’s at 10:o’clock!”
- “I was seeing someone came to the lab and they had an 8:00 o’clock appointment and didn’t get lab until 11 and then they was fasting and they didn’t have any food in their stomach.”

Long waiting times have negative effects on clients’ feelings and actions. Feelings of frustration and powerlessness lead clients to leave the clinic and not return. Because of feeling powerless, few clients take proactive actions to change the situation:

- “Will get angry, feel more devalued, frustrated, feel more powerless.”
- “Shut down and turn off. If they don’t leave they aren’t in the right mindset to listen and talk to the nurse or doctor.”
- “[They feel] like they are unimportant, not worthy of care and like they are a burden to those providing services.”

The most difficult service for patients to get was reported to be specialty medical care. Other hard to get services were medications/ADAP, insurance, housing, and dental care:

- “Specialty med. Housing for more than 24 months. When HOPWA started average life span 2-5 years. Now up to twenty yet only allow 24 months.”
- “AIDS insurance continuation program, AIDS drug assistance program, housing and/or rental assistance, medical care, dental care (and not just tooth-pulling, but real care), mental health counseling, ancillary services such as massage, nutritional counseling, and other programs which are no longer funded.”
- “Health Care District [county insurance program for indigent] impossible to get. Takes 6 weeks. Medicaid not possible for people who are not Florida residents for 5 years. Case management.”

These findings of insufficient capacity are supported by the findings of the document review, which indicated that the population in need was substantially larger than the population receiving services.

5.5.3 Integration

5.5.3.1 *Strengths*

The Palm Beach County HIV care system has some integrative features:

Case Management

If a client has a case manager, the case manager facilitates integration of various services:

- "The case manager takes time to help them locate different places where they can find help, make referrals."
- "Case managers help get information so that people don't have to go all around."

Both providers and women in care had a clear understanding of case management functions as related to referral and integration. Case managers themselves were familiar with the available services, benefits, and client eligibility requirements:

- "Case managers verify eligibility for clients, guide/assist for services. Work hard for lots of clients – transportation vouchers, etc."
- "Case management facilitates HIV individuals by recognizing their needs and finding the different services available that best suit them."

Most respondents indicated that clients are referred to other services at least sometimes, depending on their needs or the provider:

- "[Clients are referred] with case manager's help and if doctor and nurse make referrals."
- "At our agency [clients are referred]. Most of the times I have found out that hospitals don't refer clients to other agencies."
- "Sometimes, if providers are aware of community resources."

Clients are most frequently referred to case management, food and nutrition resources, mental health treatment, specialty medical care (e.g., gynecology, dermatology), and housing services.

All the women in care agreed that when patients first get into HIV care, they are referred to other services. Most indicated that the time it took to get a referral was not long and that the referral process was easy. Most agreed that patients go to the referred services. However, most of the women not in care did not have an understanding of case management.

One-Stop Clinics

Another integrative feature of the care system is that some Health Department clinics are one-stop sites that provide comprehensive services. This makes it easier for clients to get their multiple needs addressed.

- "We offer comprehensive care. Dental, case management, medical, mental health, nutrition, gynecologist, psychiatrist, all at one site."
- "Everything is in one site."
- "When I first started with this job, I went to the health department and talked to women that were in the waiting room and believe it or not the stories that they told me about the care that they got there. it almost made me envious to want to go there because, your regular doctors that I've dealt with are not like that. They said that you know, they got everything taken care of, they got their medications, they got their exams, they got their pap smears, they got their kids taken care of, so it sounded like a really nice situation for them so that, and these were not people that the health department picked for us to talk to, this was just in the waiting room, at random."

5.5.3.2 *Challenges*

For clients who do not have a case manager and/or whose health care sites are not one-stop clinics, services are not integrated. Even when clients do have a case manager, there is sometimes a lack of follow-up by the case manager or other providers. And for the case managers themselves, the referral process appears to be overly cumbersome.

Services at Different Sites

When clients cannot obtain all necessary services at one site, it is difficult for them to get comprehensive, integrated care:

- "Only have certain services at each place. Nothing is comprehensive so they have to go all around, with doctors' appointments on different days at different places."

Lack of Follow-Up

According to respondents, sometimes case managers and clinic staff do not follow up on referrals to ensure that clients receive the referred service:

- "[Clients may not go to referrals due to] no set appointment, no transportation and lack of follow through or prompting from case managers."
- "Don't know percentage of total [clients that go to referrals]. Requires hands-on case management."
- "Lack of follow through by providers."

This lack of follow-up appears to be due to high caseloads. When respondents were asked what they would like to see case managers do more, the most frequent response was to work more closely with clients:

- "Have less clients and more time to assist clients."
- "Spend more time with client, less paperwork."
- "Decrease caseloads so have more time with clients, do case management instead of crisis management."

Thus, case managers have the desire, but not always the time, to follow up on client referrals.

Cumbersome Referral Process

When asked to describe the referral process, many respondents portrayed a Byzantine procedure:

- "Difficult. Stuff is missing from referral – have sent back a couple of times – can't get in touch with client – hard to coordinate with provider – they call over and over when it's already set up and case manager has to fax info again and again."

- "It's a difficult process and frustrating when a client doesn't have the access to go to providers."
- "The doctor does a specialty referral, then the nurse gives it to the case manager, then the case manager fills out the specialty referral, then it is signed by the nurse in charge, then the case manager mails it out, then wait until it is mailed back to the case manager, then it is given to nurse in charge, then she makes the appointment, then it is mailed to client."

5.5.4 Accessibility

5.5.4.1 *Strengths*

As with system integration, case management contributed to system accessibility, and some clinics were identified as being accessible:

Case Management

Case managers clearly provide access to needed services. This case management function was articulated by all providers. Thus, for those clients with a case manager, access is easier.

- "Assist client in getting services they need to improve lives."
- "Provides support and helps clients access services and overcome barriers to access services in other systems."
- "They were able to obtain resources that they were able to utilize."

In terms of specific services accessed, those most frequently reported were housing, food, medical referrals, and transportation.

Some Convenient Clinic Locations

According to respondents, some of the health clinics are located in central, accessible areas:

- "In area that needs services."
- "Centrally located."

5.5.4.2 *Challenges*

Despite some system strengths, services are frequently not accessible to clients in poverty. Clients often do not have insurance or transportation to get to services. Red tape also hinders access. Some inconvenient clinic locations, limited clinic hours, and a shortage of Creole interpreters are also contributing factors.

Lack of Insurance

Most services require either private or public insurance. Members of the target population often have neither. Even if a service does not require insurance, individuals are often unaware of that fact. They believe that without insurance they cannot get health care:

- "Lack of access. They think they won't be able to be seen without insurance."
- "Without insurance you're stuck with a bill you can't pay (which isn't worth it)."
- "Insurance needed to help with getting HIV meds."
- "Sometimes they don't have money to make the co-payments."

Lack of Transportation/Inconvenient Locations

Many members of the target population do not have cars. This is supported by the census demographic data presented earlier (Table 1). Some clinics are located far from the target population concentration areas. Although, as indicated by the findings of the document review, all the health care providers are located near public bus routes, nonetheless, public transportation is not a viable option for most clients. At least one clinic is not within a safe walking distance from the bus stop. Additionally, buses run infrequently. HIV+ clients often do not have the stamina to wait and walk in the typical Palm Beach County heat and humidity:

- "Can't coordinate kids, finances, transportation."
- "Buses don't always run right and get you to the doctor's office close enough, especially for people with HIV who have to stand out in the heat."
- "If you don't have no transportation that's a distance and the health department is a distance. If you're sick but if you're up and able, you might be able to go catch that bus to go there. But if you're sick you can't go and if it's raining you can't catch that bus to go and meet your appointment."

Red Tape

The process of identifying, applying for, establishing eligibility, and accessing diverse services is daunting for clients, and even for case managers. Excessive paperwork, differing program eligibility rules, requirements for frequent re-applications, and rude staff contribute to client frustration and resignation:

- "They don't have their paperwork, so they don't keep track and they don't have records. You have to keep records of everything in order to go to an AIDS doctor to get the medication, and the resources are there but you have to be a very organized paper orientated person to get help from the services and if you don't, you get frustrated, so why start to do it in the first place."
- "The trouble is when you have to apply at 17 different offices to get services, that creates a big hardship. You gotta go here for this and there for that."
- "The medical assistance is really important. When I lived in Minnesota they had a program, I think it was called "Every Penny Counts" which paid straight Blue Cross/Blue Shield for us which allowed me to go to any doctor at any time anywhere in the country and then Medicaid picked up whatever Blue Cross/Blue Shield didn't. I had straight insurance and medical assistance and it didn't cost me a thing, and I only had to go to the medical assistance office once every six months and down here they require you to go lot more often and bring a file cabinet with you. And then as soon as you get there you have to get 62 more other pieces of paper work to come back with."

Limited Clinic Hours

Most of the health care providers operate only during weekday, daytime hours. This is not convenient for working clients:

- "Not convenient if working."
- "Not convenient – need evening and weekend hours."
- "Not convenient for sex workers. For everyday, yes. Need later hours."

These findings are supported by the document review.

Interpreter Shortage

There is an insufficiency of Creole-speaking staff. This limits access for many Haitian members of the target population. Again, these findings are supported by the document review.

- "Issues interpreting Creole dialect. Sad situation. Provider waits for translation."
- "They do not know where to get the services that they need, or that speak their native language."
- "They miss a lot of important information if there's no one for translation."

Lack of Client Phone

This theme is supported by the demographic data presented earlier (Table 1).

5.5.5 Acceptability

5.5.5.1 *Strengths*

Case management again emerged as a strength of the care system. Client-centered providers who believe in the services they provide are another strength. Additionally, some locations are safe and secure. All of these factors contribute to acceptability of the care system to clients.

Case Management

Respondents almost uniformly praised the dedication and hard work of case managers:

- "Our caring staff – our push and drive to get the client what they need and deserve. Assistance with utilities, meds, housing."
- "Empathy, warmth, support, financial supportive services, and advocacy. The case manager is often the "go to" person or "confidante" of the client. The client (in the majority of cases) has someone to confide in, knowing that they will not be judged and that we will try as hard as we can to get them the services they need."
- "Case managers take money from their own pockets to buy patients food."

Client-Centered Providers

About half of respondents thought that patients were treated well. Descriptions of good treatment illustrated client-centered care:

- "If you can get a doctor that can understand you and work with you, they can encourage you to do some things that you might not want to do. God knows sticking myself 2 times a day fixing that meds cause I'm taking that infusion and that's a lot, but Doc I trust her so much and her insight with this disease until whatever she tell me I be willing to do it and when I get a little tired of her then me and her have to go back to the table you know and try something else. But that's the kind of relationship that I have with her and I thank God for that. That makes a difference."

- "I have to say that they have not treated me with anything but all the care and concern. I can also say that everyone of them has gone out of their way to get bills paid, get medication when I couldn't afford it within a certain amount of reason because they don't always have samples of those $1400 pills and if they do they don't have a six month supply like you get from the insurance, but I have been lucky that way."

- "The nurses, they know me by name when I walk in now. The new infectious disease doctor I have I like a lot, he spends a lot of time with me, answers all my questions, makes everything very understandable, language, the terminology, just took the time with me and I feel very comfortable there."

- "I'd have to say 301 [Health Department clinic] is like a family, and every single appointment I have, if I have an appointment on a different day, they ask where were you yesterday, your appointment was yesterday and they'll call me to remind me I have an appointment and all this care and concern, you know, how are you feeling and is everything going all right, they take their time, especially the doctor, it's not like some of the doctors who want to get up and run, you know, my doctor takes all the time that I need."

Belief in Services

According to respondents, the providers have belief and confidence in their services:

- "I believe providers/agencies in the continuum have dedicated staff providing good services."
- "Yes [providers believe in the services]. The system just becomes frustrating and in this type of social service positive outcomes are rarely identified or acknowledged. Constant reports on needs but not progress outcomes."
- "We work on availability of services but are confident in our referrals. If it doesn't work out, we work on a solution."

Some Safe and Secure Locations

Some clinic locations are considered safe and secure:

- "Safe."
- "OSHA monitors safety."
- "No reason not to think it is."

Peer advocates

HIV-positive Black women who are skilled in navigating the care system can serve as motivating forces for their peers who are not in care:

- "I think if you can get somebody to stick with a person to walk them through it and stick with them until they get help, you know then that might make a difference, but you gotta stick with them, like you know what I'm saying that people want me to come back and try and get them in treatment. I got to stick with it because the first two times I go up there they might not be in control, if I can get them started and get them, you know, rolling, but will I have the time to do that? I think I could do that, but my time schedule won't permit that, you know I got to run down and stick with them, you know, I got to make sure that the doctor going to see them whenever I can get them. The young lady that works at the health department anybody that I would bring to her, she'll try and work them in there and put them on a regime, you know what I'm saying. So I already go that lined up, but my problem is to get that person to get them in there."

- "I have a girl that I'm trying to get tested, she has been going with my, my stepsister had died from AIDS and my stepsister's cousin had died from AIDS now this girl is 52 yrs old and she's going with this boy, this boy is like 38 yrs old and he's been with both of the ones that had died. Now this lady has found out that she's having some symptoms that she never had before and so I'm trying to get her into care now. But she don't want to go to Delray to get tested, she wants to come up this way, so right now I'm just trying to tag up with her to get her to go to the White's. (United Deliverance Church, Reverend White). Now that she don't want to got to the clinic, so go out to Pastor White to get tested."

Confidentiality officially protected

This theme emerged from the interviews with women in care. Most of them thought that the health care provider protected their confidentiality.

5.5.5.2 *Challenges*

A major factor affecting acceptability of services is stigma. Other factors are unappealing clinic environments, red tape, some staff that are disrespectful and not culturally competent, and some locations that are unsafe and insecure.

Stigma

Stigma was a very dominant theme throughout all the data collection strategies. According to respondents, HIV+ Black women in Palm Beach County fear having people they know find out about their disease. The fear of being seen by someone they know, in or near a known HIV clinic, is a significant barrier to care. The fact that they can be recognized as HIV patients makes the services unacceptable to clients:

- "They don't want the stigma that goes with being HIV positive, you go to the doctor's office in Riviera Beach, is not a big place, it's not like New York where you can go across town and no one knows you."

- "A lot of it is stigma. They don't want to be associated with AIDS because they are looked down upon, you're going to be ostracized at a certain degree by society whether it's going to be family, friends, co-workers, community as a whole."

- "In Belle Glade, they're separated; they have a special place for people with HIV to go. So they know everyone in that everybody back there has got HIV. It's not like we have everybody all together so nobody knows what you're there for, so in Belle Glade the HIV clients aren't protected."

- "Even picking up meds at Walgreens and all of that, it's not really protected either, because I can go pick up my client's meds, and they'll just hand it to me, all I say is the name, if I want to be nosey all the labels and notes are attached to the outside of the bag, so I could just read all the meds that they're on right there."

Clients' fears are well-founded, as respondents themselves indicated that the general public views HIV+ patients as dirty and shuns and condemns them:

- "HIV patients are shunned, put down. Friends/family accept them, community probably does not accept them."
- "People don't want to be around them."
- "People think they are contaminated and you have to be careful around them.

Unappealing Clinic Environment/Some Unsafe and Insecure Locations

Respondents felt that the ambience within the clinics was negative and that some locations were not safe or secure:

- "Clinic is hectic, so many people go and they've been waiting and they're upset."
- "I feel like wanting to leave. It is not personal or intimate."
- "I feel frustration, lack of hope, fear, confusion, anger."
- "I feel repulsed. It's dirty, cold (not temperature), there's an attitude."

Red Tape

Excessive paperwork and guidelines are other factors that make services unacceptable to clients:

- "It's just such a process of red tape to get you new services. Like you have to go to Medicaid and get a Medicaid denial. For a person who's undocumented you don't want a paper trail with your name on it, especially if you're not supposed to be here anyway. Then you have to go to Social Security to do a printout of your wages, what if you don't have a SS#, how are you going to get a printout. It's a lot of red tape and it's hard."
- "To establish eligibility, it's the waiting, you know. You're waiting for insurance, Medicaid can take up to three months, Health Care District 3 to 6 months. And you have to have labs before you're seen first. So everything, even lately, specifically with a couple of our offices within the agency, they had to wait to come to us, because we were inundated with people that need services, need care, that need help negotiating all these systems, I couldn't do it by myself. You know, sometimes I look at these applications myself and go, "what are they talking about?" But we've seen so many new clients coming to the county, I can speak particularly for South County, we have a 77 client waiting list right now. We can't keep enough staff to serve everyone's needs and we're the people that are trying to help these clients with accessing services, so if they can't rely on us and we have to wait it's very frustrating and anything for them is a waiting process and when the waiting process is over then it's eligibility and you need to get papers 1 thru 10 to even be considered for that, so it may be a few months before the client even gets the service, and a lot of women they get fed up, they don't want to deal with it. Someone at home needs them."
- "I'm dealing with a young lady that's recently passed. I went to speak with her mom yesterday and her mom said that they had filled out all the paper work trying to get her where she can get on, on meds but it taken so long, it took so much time till she could get a chance to get put on the meds that she passed in the process of it. They had me running around finding out what she had to do at the health department and she went back up there and got sick and the health department didn't put her on a cocktail, but they had to do some more work, so this hospital had me getting all this paper and all this stuff to them and they still let her lay there and die."

Lack of Respect

According to respondents, some staff treat clients in a disrespectful manner:

- "I've actually gone to places as a case manager, and had people talk to me like I was nothing, because they thought I was their client, and then I had to say, excuse me I'm here representing my client, then all of a sudden they talk nicely. If that was me I would have gone back to my case manager and tell them kiss my butt, I'm never going back there again, I don't care how sick I am. So, I'm not saying that everyone in DCF is like that, Health Care District, these people talk down to you like you're nothing, and you're sick and you had a bad day, you have an ache, when you're sick you want someone to have a little compassion for you. There is not a lot of compassion out there for my clients, and some of them, a lot of them have had drug problems in the past, and they've rebound, you don't always want, when you're getting help, someone to bashing them down. A lot of times they get a bashing, I've seen that. That's the most annoying thing I think, when you go for help and you know that help is there, it's hard sometimes to get that help."

- "The way they treat you, sometimes. Disrespectful, you know, they act like you dirty and they know you HIV positive and they treat you with a negative attitude, then they sitting there whispering, looking back, you know that kind of stuff hurts you. That bothers you, you have to get past that. You know, but that really aggravates me, I can't take that and that hurts. When I first got in care and that kind of stuff happened to me, they had to call the police, I was kinda, you know I wasn't tight, you know what I'm saying. You get more care than just the doctor, you get other services, where I used to get my food stamps, when I get the application for the food stamps and stuff like that, people know you HIV positive, they treat you nasty, they take your stuff and not even sometime even turn it in, you know what I'm saying? Yeah, they had to call the police on me one time, yeah, because I lost it, but now I don't act like that, I'm different. You know, that's the truth, I'm sitting there to get help, I guess I grew up with that instinct to defend myself. You mess with me, you gotta do what you gotta do, you know, and I felt that, but now it's not right that I sit there and I pay you no attention you know, but there was a time when I couldn't do that, you know."

- "It depends on who it is or who you are. In other words if you know the staff, if you know those people that have been working you up and doing all that, you can go out there and be treated like royalty. But if you don't know them that well, you got to wait, you go to do everything and they just look over you and every perspective, but if you know them, sometimes you feel bad because you know everybody and when you get an appointment they'll take and put you up there and me being where I am, sometimes I can't deal with it because I feel bad for the person that you try to put me before, because now that I straightened up I'm not the little dirty foot that, you know what I'm saying, and I know people, if I go out there they might tell me to come if I got a cold, you know, to get me in at a certain time to get you in there to get you seen, so it's who you know. Then again you can go there with such an attitude yourself until you sit there until they close."

Lack of Cultural Competence

Some respondents thought there was discrimination within the care system based on race and/or nationality:

- "People of different races/nationalities are treated differently and it's common knowledge."
- "Creole and Guatemalans get very bad treatment. If you don't speak English, you're screwed."
- "Ailments of black women are not treated with same intensity as others."

Poor communication with provider/poor care

According to respondents, relationships with physicians and quality of medical care are sometimes poor:

- "When they do go to the doctor, they don't have understanding of what they're talking about, because they don't break it down in terms that they understand it. So they're telling them this and that, they're talking but the people that they're telling are not really understanding what's going on."

- "They feel like they're gonna die, so they can be so cold and callous when a client is trying to get information to get help. So they can be more compassionate about AIDS. I have had clients who also said that doctors have treated them cold or nasty."

- "Something that one client said, the doctor just didn't have time for you. You go in there to see the doctor you're in and out in 2 minutes. What can a doctor do in 2 minutes? Hi and bye. You know a lot of clients dropped out of care because they say the doctor wasn't really taking care of them."

Difficulty with medication regimen and side effects

According to respondents, a major reported reason why women drop out of care is the hassle of the medication regimen and the side effects:

- "A lot of clients take the medications and they get sick and then they get fed up, and they get depressed, and then they're feeling bad and then they give up, and then if they do give up then they do get sick, then there is like major stuff going on that they have to deal with, and if they do give up they have to start all over with the programs because they didn't do whatever they needed to do to keep up with them. And they're making the medications, the dosages smaller than they used to but still it's hard to keep up with that."

- "It's like all of us, I'm the worst pill taker in the world and if I get sick ok, I cannot imagine the regime they have to take. Give me 7 days of antibiotics, after the first few days if I don't feel better, then the next few days are gone, otherwise I say OK I'll keep taking them for the next few days. Now I have to take a regime of antibiotic for just 7 days maybe 3 times a day with a support system and I have trouble taking it. I can't imagine all they have to take for the rest of their lives. Now some of them have to take these pills and instead of feeling better they feel worse, so they get discouraged and stop taking it. They can't handle some of the side effects of some of the medications. I'm the worst! 3-4 days I'm starting to feeling better that's it, I'm cured. So can you imagine someone taking 20 pills a day for the rest of their lives, and then what if they start to feel better instead after awhile, then they say, oh I'm cured."

- "I have noticed that there's a few people that I know that was in care and they had stopped going to the clinic because of the process, because they say that they have to keep taking these medications, they have to keep going to the doctors and it's just like their life. They don't have no other life besides the clinic and they just get tired of going. Just stop medicines and everything."

5.5.6 Technical Competencies

5.5.6.1 *Strengths*

Well-Trained Providers

Most respondents providers thought medical and other staff are well-trained:

- "They are trained to answer questions about their medical needs and their needs outside medical, like housing."
- "They are well experienced."
- "They help with everything."

The providers were well-informed about many aspects of HIV/AIDS, including transmission modes, the nature and treatment of the disease, and its local prevalence:

- "A virus that can be transmitted via bodily fluids which attacks the immune system and allows opportunistic infections/diseases to attack as well."
- "It's a virus that there's no cure for."
- "HIV is a virus that causes AIDS, and it affects the immune system."

Providers also indicated a high degree of desire to learn more about various aspects of the disease, including new research and information on new medications and on the potential for a vaccine:

- "More case studies – what affects more and why some people get it and others don't."
- "How to improve the effectiveness of prevention methods. Current options and methods do not seem as pertinent or effective as they once did. Perhaps more involvement of those heavily impacted today in development of new approaches may be helpful."
- "Are there successful programs we can implement?"

Client Education

Providers frequently educate clients who approach them with questions on issues such as medication, transmission, and life expectancy:

- "How will I get medications? Will I need to go through all the paperwork?"
- "Doctor changed meds – why? Am I worse? Questions that health care providers should take time to discuss, or implement treatment adherence programs explaining medical treatment protocols."
- "Will this medication make me sick?"

Belief in Services

As described earlier, there is reportedly a high degree of belief in services. This supports the technical competency as well as acceptability of the services.

Availability of Medical Specialists

Respondents reported that HIV/AIDS doctors were available in Palm Beach County. Patients are mainly seeing primary care and infectious disease doctors and a wide variety of specialists.

5.5.6.2 *Challenges*

Client Lack of Knowledge of Disease and Treatment

Client technical competency is limited. Respondents indicate that clients do not have a good understanding of HIV disease and its treatment:

- "Intergenerational lack of knowledge."
- "Most of them don't know what to do."
- "Lack of education. Patients don't know why they take meds."
- "Lack of understanding the disease."

These findings are supported by those of the document review.

5.5.7 Client Health-Seeking Behavior

5.5.7.1 *Strengths*

Client Knowledge of Where To Go for Health Care

Most respondents thought most patients know where to go for health care. The most common sites for receiving care were reported to be the Health Department and private doctors.

5.5.7.2 *Challenges*

A primary reason why clients reportedly do not use the care system is that they have other priorities in their lives, particularly meeting basic needs and taking care of families:

Other Priorities

- "Most women take care of their children first before themselves."
- "Need other basic needs met first (housing, food, etc.)"
- "Prioritizing their health is not common because of several factors, which are family, addictions, just being a minority and dealing with that issue in society on a daily basis."

The target population's health-seeking behaviors are also influenced by pervasive feelings of denial and fear, hopelessness, and frustration:

Denial/Fear

- "Denial. Know that they are HIV positive, but don't accept the truth."
- "Don't believe diagnosis."
- "What prevents me from getting there is the downright fear, I don't like to be reminded how sick I am, and by going even without drugs is a very scary thing. I've been positive for almost a full ten years now and I'm hearing things that I don't want to hear, like I'm wasting because my muscles from not doing anything except getting high and getting drunk, I have no muscles left, so I have that wasting disease and I don't like to be told that and I don't want to be reminded of it."

Hopelessness

- "I'm going to die anyway, so why should I care or go to doctor."
- "Lose hope, get discouraged."
- "Give up."

Frustration

- "Get sick and tired of dealing with red tape."
- "Feel the system is against them."
- "They get care until it becomes a hassle."

Consequently, clients reportedly do not express their needs to providers, and they prefer self-remedies to formal health care. When self-remedies fail, clients seek help in the emergency room. The system-favored health-seeking behaviors of calling or going to the doctor or clinic are used less frequently:

Non-Expression of Needs

- "Clients are not receiving the services because they are not expressing their needs."

Self-Remedies

- "Keep working and only go to doctor if they feel like they're dying. If they feel like that's how they're supposed to feel and think it's normal, don't do anything if they don't have insurance."
- "They have a lot of interesting cultural things, things they've learned from grandparents. They go to local markets to get stuff."
- "They stay in bed, they all of a sudden want to be adherent to the medication regimen and overdose."

Use of Emergency Room

- "Go to ER."
- "They will go to the emergency room a lot of the time."
- "Some suffer, others go to ER."

Another factor affecting health-seeking behavior is that some members of the target population are unfamiliar with the health care system:

Lack of Familiarity with Health Care System

- "Do not know where to go for services."
- "Lack of understanding the system."
- "Knowledge of system."

Substance Abuse

Substance abuse is another barrier that keeps women from care. The addiction overtakes all other needs and desires. In addition, however, as the following quotations illustrate, the substance abuse itself is often a coping mechanism for dealing with the fear associated with the disease, and also for dealing with medication side effects. Thus, there is a vicious cycle between denial, iatrogenic symptoms, and substance abuse:

- "Black women are not in care mainly if they're on some drugs, they don't have nothing else on their minds but getting the next fix and if they allow themselves to try and get some help or somebody wants to try and help them they go back to get them and take them to their appointment or whatever, they're not home cause they started to get high, so they miss out like that."

- "That particular relapse was basically I would say because of the fear of not being able to continue on my HIV meds, the damage that it does when you decide to stop taking your HIV medication, the fear of the unknown because I can't afford it and then how am I going to pay for it in another way? It was insane, of course it was an insane decision to go out and use, but I was very overwhelmed."

- "When I'm using I'm not responsible and I'm not able to say I'm going to have the bus here or the transportation or the phone call or change to ask somebody for a ride. I often don't have a clue what day it is so I mean may have had every intention of getting to my appointment and I might hear that it's Thursday and I think it's Monday, and I'm going up to the doctor's office and have been totally off sometimes by several days, even a week, because I didn't realize I was in such a drug coma or blackout from alcohol or drug combination or maybe I went to bed on Monday and woke up on Friday so I think it's Tuesday, from using."

- "When I first found out I thought, you're gonna die. So I did nothing but use, eight years I refused to go see a doctor or take medicine, because other people told me that if I took

> medicine it would make me sick, and me listening to what they were saying, I said I'm not going to take no medicine to make me sicker. You know? So finally I decided to go, you know the expression, get educated, and I found out I should get health care, it's been eight years but let me see, so I started going. I thought I was going to die, you know, quick, soon. I had a cousin that was sick less than a year and got sick and really suffered and died. Here it was eight years and he I was wondering, nothing was happening to me and I was wondering why I was still alive. And I was looking at that first day that hurt me, oh year, that's what's wrong, HIV killing me you know. I didn't know any better, I really thought like this, one day I'm just gonna die. Since I'm going to die I might as well go and get high, that's the only thing I know how to do best is get high."

Asymptomatic

According to respondents, women do not access care because they do not feel sick:

- "Some women do it just to look good, do their hair, they still have a nice body so they say I'm ok, I'm not really sick because they feel OK"
- "As long as the person like, they know they're HIV positive and as long as they don't feel sick they don't want to go."

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5.5.8 Additional Comments

Respondents were asked to provide open-ended comments about the topic of why HIV+ Black women in Palm Beach County are not in care. The following comments are illustrative of the multitude and interconnectedness of the themes identified above:

- "HIV/AIDS care here is better than some places, but there are still significant barriers, including: an extremely poor public transportation system, complex application procedures for some benefits, cultural and linguistic differences which pose additional hurdles, stigma, misinformation on a number of levels (i.e. – there is a cure, that HIV only affects certain groups, that some "habits" are not transmission modes)."

- "A lot of the providers don't resemble the people that access care. You need to understand their thinking. Haitians view doctors as God. They don't "talk back" to doctors. Even if they disagree with the doctor, they don't say anything. Also the language problem – patients just shake their heads and agree even if they don't understand. The doctor appears rushed, patients don't want to be trouble. A difference between Haitians and African-Americans is that Haitians are more subservient, go with the status quo, don't want to rock the boat, they're grateful for anything given them. African-American women feel 'this country owes me, I'm entitled to everything I've got.' African-American women might be more likely to ask the doctor questions but they don't want to appear stupid."

- "Some people just don't care. They don't want the help, the guilt and shame of letting people know they are positive. Some drop out of care because of how the staff treat them at the Health Department. Being angry that they have it could stop a person from going back for care. There's a whole range of reasons why a person is not in care or dropped out of care."

- "No matter how much you probe you cannot change people's habits and mindsets. Those that want help seek services and will go through many obstacles to stay in service. Many not in services I feel have mental health issues that also need to be treated. Depression and feelings of hopelessness are big problems."

- "I think this is a very sad situation. Unfortunately until we take care of people's basic needs they cannot be bothered with their health care needs. I am not an HIV positive woman of color and I do not reside in Palm Beach County, however I can tell you that until basic needs of people are met and their self-worth is brought up this problem is going to continue to increase."

- "In general women of color are usually the primary caregiver for their children. The children's needs come first. Then there are the other basic needs that must come first: shelter, food, clothing. Then there are domestic issues. If any of the above is happening it is unlikely that health care will be obtained. Lack of self-esteem is a big issue."

- "Women of color deal with a lot of issues in their life in general. Talk about social issues they've been dealing with first. To be black in a white world, it's an issue. The fact that they've become sick is like another issue to deal with. Being women is another issue to deal with in a men's world. Therefore how does someone with so many things to affect their functional life worry about their health? Then comes the problematic in obtaining the services they need in order to obtain all care that individual needs. It's like adding problems to their plate. Also, lack of education."

- "Most women are the head of the household. They have to support the family, take care of everyone else's needs and think less about themselves. Most black women's men are in jail, dead, on drugs, sleeping with other men, and not taking responsibility for anyone. Then all the burden is left on the women. They have to keep going when everyone and everybody has given up. They have to make decisions for the future, have visions and hopes for what they want for the family. Health care is not important to them when they have responsibilities bigger than they are on their shoulders each day. Their self-esteem is low, trust issues are hindrances as well. Facing the fact they're HIV+ is very hurtful and it becomes hidden in their mind, until they get sick or have to face it. Black women are strong people that have a lot of burdens on their mind and shoulders. Provide better income, housing, transportation, better education. Educate our men, men of all races."

- "Women of color that are HIV+ want respect. Some of the women need to have drug treatment programs available to them. Sometimes there are not enough openings for drug addiction. Women of color want to get treatment if the hours of services fit within their work schedule. Sometimes people have so much on their mind such as how will I be able to pay for rent, lights, buy food and other things their children need, and they put themselves on hold."

- "If you are a Black woman and positive we as a people find it hard to share with family members and friends because of what people think about us. Women need a place to share their feelings and not be judged. And because of religion if they are married they are not going to ask the spouse or boyfriend if they are cheating on them. They are afraid of what might happen to them so a lot of black women are in denial."

- "I feel the most important reason why is that they feel ashamed and that people will talk about them."

- "There are multiple factors involved – some practical: child care, transportation, lack of insurance, lack of knowledge about available services. Some cultural/religious: fear of stigma/discrimination, distrust of government, need to put family's needs above one's own, lack of community support, language/literacy issues."

- "So much of it has to do with self-esteem. Self-esteem comes from family, your childhood, even your community has a tremendous impact. The church, sometimes the tenets are uplifting. Other times, like during the epidemic, the church is having a devastating effect on the black community. How many more blacks will die before the church responds properly? I guess the churches wait until financially they are broke. Dead people cannot give money to the church. I work in this field. I am told we cannot talk about sex and risk in our small staff meetings. One employee was "offended." People like her are the reason this epidemic is clobbering her own community. If she (black woman) can't talk or hear about risk, and she works in the HIV field, then her community is doomed!!"

5.5.9 Proposed Solutions

Respondents were asked what it would take to get patients back in care. The major solutions to the problem were reported to be social support/case management, education, easier access, friendly staff, and money:

5.5.9.1 *Social support/case management*

- "Help them with whatever issues thy have that we could help them with."
- "An understanding that they're worth care and family support."
- "Give them hope. Disease and meds are manageable."
- "Lots of follow up, make them feel valued."

5.5.9.2 *Education*

- "Bring out positive benefits of medical care. Education, offer hope, emphasize not a death sentence."
- "Give them more knowledge about the disease."
- "Patient education, provider education."
- "Work with them on adherence. Shift meds and cocktails to eliminate cocktails. Train with Skittles. Use Skittles to represent drugs."

5.5.9.3 *Easier access*

- “Easier access to resources.”
- “Easily accessible, affordable care.”
- “Easier access to medications, dental.”

5.5.9.4 *Friendly staff*

- “Try to talk to them, explain to them, make them understand it’s not the end of the world, show them you care so that they’ll care.”
- “Talk to them very nicely.”
- “New, improved, patient-friendly clinic.”

5.5.9.5 *Money*

- “Money.”
- “Pay them.”
- “Economics.”

5.5.10 Women In Care

Overall, the data from the women in care indicate that their experiences and perceptions of the HIV care system are much more positive than the reported experiences and perceptions of their counterparts who are not in care. Specifically:

- Most of the women in care did not think waiting times in the waiting room were too long.
- Most of the women in care indicated that patients get all the services they need at the health care provider and that patients do access HIV care again on the basis of their first experience with the system.
- The women in care were generally satisfied with the services received. All of them liked the way agency staff talked to them and thought that both the staff and physicians were properly trained to meet their needs and answer their questions. Most of the women reported being treated in a caring and competent manner. Most reported getting good feelings when at the health care provider. For example:
    - [The providers] “are very supportive, kind, and respectful, which helps me be more open to talk about what I need and helps them to help me.”
    - Patients are treated by staff “in a caring way”; “with respect, kindness, compassion, very encouraging.”
    - [My doctor] “is an excellent infectious disease doctor. She is sharp, kind, caring, and supportive.”
    - “If they can’t help they will find someone who can.”

- All the women in care had knowledge of the disease and its treatment, including the need to follow through with care. For example:

  - "It's a chronic disease that can be arrested for the most part with HIV meds."
  - [I know] "how it is transmitted, CD4 and viral load tests, it's important to take meds on time."
  - [I know] "how it affects the body. Medication. It's not a death sentence."Most of the women in care indicated that when patients feel sick they go to the doctor (as opposed to doing nothing or going to the ER)

- All the women in care accurately understood the function of case management. For example:

  - "They help you get connected to other agencies."
  - "Someone who assists clients in their needs."
  - "To help HIV/AIDS clients where thy can find help and what works best for them."

- The locations of services were generally thought to be convenient.

6 CULTURAL CONSENSUS SURVEY

6.1 METHODOLOGY

The final data collection strategy employed was the cultural consensus survey. This was a structured, closed-ended written questionnaire. The questions were developed based on the findings from the previous data collection strategies as well as from the findings of the RARE component of the project. The purpose of the survey was to validate the qualitative findings from the other data collection strategies and to compare and contrast the responses of providers and HIV+ Black women not in care. The survey was individually administered to fourteen providers and 28 HIV+ Black women not in care. The questionnaire items are shown in Appendix G.

6.2 FINDINGS

The response frequencies are shown in Appendix G. In general, the results confirmed the prior findings from the other data collection methods.

The women not in care who responded were primarily African American and Haitian heterosexual women. Their primary reported HIV risk behaviors involved sex trade (i.e., sex for drugs, money, and/or commodities). Half reported that their immediate family members were not aware of their HIV+ status. Most of the provider respondents were women. In agreement with the women's reports, the providers reported that their clients were primarily African-American and Haitian heterosexual women whose primary HIV risk behaviors were unprotected sex and whose families were not aware of their HIV positive status.

Overall, both the women not in care and the providers considered themselves to be highly knowledgeable about HIV care and most of them knew of at least three places that provide HIV care. Most of the women not in care knew of more than ten other such women; in contrast, most respondents either did not know any HIV positive people who are not in care, or they knew more than ten such people.

About two-thirds of the women not in care thought that women of color would not get into care until they got over their fear or denial. On the other hand, two-thirds of providers thought that women of color would not get HIV care until they developed symptoms or AIDS. The primary reasons given by the women for not getting HIV care were shame and fear. On the other hand, the primary reasons reported by the providers were denial, stigma, no time due to work, and putting family first. Most of the women reported that incarceration was not a factor in their not getting HIV care; on the other hand, most of the providers reported hearing that this was a factor.

The primary reasons given by the women for dropping out of care were lack of insurance and substance abuse/prostitution. The primary reasons given by the providers were the difficulty of the medication regimen and side effects, and lack of knowledge. The women primarily reported that they would get back into care if they had transportation, confidentiality, or had a good doctor or choice of doctors. The providers' primary reasons why women would go back into care were if they get sick, if they perceive advantages to being in care, and if they get disability income.

Items of general agreement between the women not in care and the providers were the following.

More than half of both groups responded affirmatively to the following items:

- Do women of color wish to get health care in this community?
- Do women of color avoid HIV medical care because they don't want people to know they are positive?
- Do women of color feel ashamed of being positive?
- I/have you heard women of color discuss that I/they can get a miracle from God and not have the virus?
- [Have you heard women of color say] I don't ask anybody about their HIV and I don't tell about my HIV?
- [Have you heard women of color say] I go to the emergency room if I'm sick?
- Have you dropped out of care/have you heard women say they dropped out of care because my/their man will hurt me/them if he finds out I/they go for HIV treatment?
- Have you dropped out of care/have you heard women say they dropped out of care because your/their faith will heal you, so you/they don't need medical care?
- Have you dropped out of care/have you heard women say they dropped out of care because your/their drinking/drug use prevents you/them from getting medical care?
- Have you dropped out of care/have you heard women say they dropped out of care because the providers tell your/their business, so you/they won't go?
- Have you dropped out of care/have you heard women say they dropped out of care because you/they go to the ER when you/they feel sick?
- [Women of color report that] the clinic takes a whole day, and I'm/they're not doing that.
- I/some women of color don't have insurance so it's too hard to get the eligibility for the doctor/clinic.
- The ADAP Nazis at the clinic are nasty and have too many rules, so I/some women of color have dropped out of care.
- It's too hard for me/some women of color to get to the clinic/doctor. I'm/they're not going back.

Less than half of both groups responded affirmatively to the following items:

- Is it difficult to get health care in this county?
- If the man (husband, boyfriend, John, partner) of a woman of color finds out the woman has been to the clinic he'll beat the woman.
- Do pharmacies give out shots for HIV?
- [Have you heard women of color say] I'm not HIV if the babies I give birth to are negative?
- [Have you heard women of color say] I'm a "carrier" of HIV so I'm not really HIV positive?
- [Have you heard women of color say] I don't need HIV care because I only have sex with a small group of friends I've known my whole life?
- [Have you heard women of color say] My babies are born or turn HIV negative, so I'm HIV negative?
- [Have you heard women of color say] I only have sex with educated people, so I don't have to worry about catching HIV?
- [Have you heard women of color say] I trade sex for stuff for me and my kids so I can't go for HIV care; they'll find out, and I won't have anyone to take care of us anymore?
- [Have you heard women of color say] I'm a member of the Black middle class. I have a job, a family and money. This means I'm not at risk for HIV and don't need to wear a condom, get tested, or even be worried about HIV?
- [Have you heard women of color say] I don't reach for condoms because this makes sex real?
- [Have you heard women of color say] I'm too sick to get HIV care, so I stay away and try to deal on my own?
- [Have you heard women of color say] I've never been in any health care so I'm not going for HIV?
- [Have you heard women of color say] Getting health care is not what my people do?
- [Have you heard women of color say] I dropped out of HIV care because I went to jail?
- [They say] the providers hurt me/them when I/they go, so I/they don't go.
- The Black community doesn't go to the doctor or clinic for medical care.
- The Black community believes that they are not responsible for the virus, so they're not dealing with it.
- [Black females say that] the people are the clinic/doctor are too nasty. I'm/they're not going back.

Items of disagreement between the women not in care and the providers were the following.

More than half of providers but less than half of women not in care responded affirmatively to the following:

- [Have you heard women of color say] If I'm not feeling sick I'm not HIV?
- [Have you heard women of color say] I don't have any HIV symptoms so I'm not HIV?
- [Have you heard women of color say] I get sick through a spell from my enemies so I'm not really HIV?
- [Have you heard women of color say] I don't take meds because they make me sick?
- Are you aware of women of color treating themselves/I treat myself for HIV with home remedies?

- [Are you aware of women of color suggesting] I don’t believe I’m HIV so I go back to get tested to see if results change?
- [Have you heard women of color say] I don’t believe the HIV test results, so I’m not positive?
- [Have you heard women of color say] If a viral load is undetectable I don’t have HIV?
- [Have you heard women of color say] I’ll get treated for HIV when I’m sick enough to go to the hospital?
- Women of color drop out of care/I dropped out of care because they/I have no symptoms.
- I dropped out of care/women of color drop out of care because my/their kids come first so I/they don’t have time to go for HIV care.
- I dropped out of care/women of color drop out of care because I/they have a hard time getting to doctors appointments because of work.
- I am/women of color are tired of hiding all the medicines from everybody, so I dropped out/they drop out of HIV care.
- The wait times are too long, so I/women of color do not go to the doctor any more.
- When I/women of color feel better, I/they believe I/they don't need the doctor any more and drop out of care.
- I/women of color get tired of lying to everybody about where I/they go to get care, so I dropped out/they drop out of care.
- I dropped/women of color drop out of care because the medicines made me/them too sick.
- [Women of color believe that] when I/they look good I/they don't need medical care.
- I/Women of color need to work and that's more important than going to the doctor.
- I/women of color take care of myself/themselves with natural remedies.
- I/Haitian women go to the Voodoun Healers to take the HIV spell off them.
- I/Women of color get the healing from the Believers so they're no longer sick.
- I am/Black women are too ashamed of being HIV to go to the clinic or HIV doctor.
- I/Black women don't want to make my/their family embarrassed, so I dropped/they drop out of care.
- I/Black women believe that I am/they are being punished by God. I/They believe that medicine won't help me/them.
- I am/Women of color are worried that the people at the clinic/doctor will tell my/their business, so I’m/they're not going back.
- I/Some women of color use drugs/alcohol and that comes first before the HIV care.
- I/Women of color don't want my/their employers to find out I’m/they're positive so I/they won't go back to the clinic/doctor.
- I am/Some women of color are just too tired of doing everything that it takes to stay healthy. I’ve/They've got burnout from all I/they have to do.

Less than half of providers but more than half of women not in care responded affirmatively to the following:

- Most people can get healed of HIV if they pray and get healings.
- [Have you heard women of color say] I would go back to an HIV doctor if I could get drug/alcohol treatment?
- [Have you heard women of color say] the reason I won’t go to the clinic is that they treat me wrong?

- [Have you heard women of color say] I need to care for my husband and kids. There's no time for me to go to HIV care?
- [Have you heard women of color say] If I go into care for HIV I have to stop using drugs/alcohol?
- I dropped out of care/women of color drop out of care because [they say] the providers are nasty, so I/they won't go for help.
- I dropped out of care/women of color drop out of care because [they say] the providers are too far to get to, so I/they don't access care.
- It is difficult to get HIV medical care in the Black community.

7 CONCLUSIONS

In the final level of analysis, all of the findings from all the data collection strategies were considered together. The above-identified thematic categories were grouped into larger "supra-themes" to yield a grounded theory or explanatory framework for the topic under study.

This framework focuses on the factors that hinder utilization of the care system by members of the target population. This focus on hindrances rather than strengths corresponds to the overall research questions for this study, which concern why the members of the target population *do not* use services. Such a focus is not intended to detract from the existing strengths of the system, but rather to identify challenges for improvement.

The framework identifies eight factors that influence service utilization. Four of these are identified as system factors and four as client factors. The relationship of these eight themes to the above-identified thematic categories is illustrated in Table 6; and the relationship of the eight themes to the seven domains is illustrated in Table 7.

The system factors are:

- *Insufficiency:* the care system lacks comprehensiveness and capacity
- *Inconvenience:* services are located at multiple sites that are difficult for clients to get to
- *Impersonality:* Some staff treat clients disrespectfully and that the atmosphere in the care settings is unappealing
- *Impediments:* there are features of the care system that obstruct access to services.

The client factors are:

- *Poverty:* clients lead lives of hardship lacking in basic resources
- *Powerlessness:* clients lack agency to act on their own behalf
- *Prioritization:* clients place other individual and family needs before the need for HIV care
- *Privacy:* clients do not use the care system because they fear having their HIV status exposed to members of their community.

Table 6
Palm Beach County HIV Care System
System and Client Themes and Categories

SYSTEM FACTORS	INSUFFICIENCY	INCONVENIENCE	IMPERSONALITY	IMPEDIMENTS
	Lack of ancillary services Long waits at clinics Lack of follow up Interpreter shortage	Services at different sites Some inconvenient locations	Unappealing clinic environment Lack of respect Lack of cultural competence	Cumbersome referral process Red tape Limited clinic hours Some unsafe and insecure locations
CLIENT FACTORS	POVERTY	POWERLESSNESS	PRIORITIZATION	PRIVACY
	Lack of insurance Lack of transportation	Lack of knowledge of disease and treatment Lack of familiarity with health care system Denial/Fear Hopelessness Frustration Non-expression of needs Self-remedies Use of emergency room	Other priorities	Stigma

Table 7
Palm Beach County HIV Care System
System and Client Themes by Domains

DOMAIN THEME	COMPREHENSIVENESS	CAPACITY	INTEGRATION	ACCESSIBILITY	ACCEPTABILITY	TECHNICAL COMPETENCIES	CLIENT HEALTH-SEEKING HAVIORS
INSUFFICIENCY	X	X	X	X			
INCONVENIENCE			X	X			
IMPERSONALITY					X		
IMPEDIMENTS			X	X	X		
POVERTY				X			
POWERLESSNESS						X	X
PRIORITIZATION							X
PRIVACY					X		

The four client factors are closely interrelated; that is, poverty leads to powerlessness and necessitates prioritization of needs; and poverty also leads to privacy concerns since those who have money can buy privacy – i.e., they can attend private clinics where they will not be known or identified as HIV patients – an option that is not available to the poor. Therefore, poverty lies at the root of the overall phenomena of this study.

In conclusion, the HIV/AIDS care system in Palm Beach County faces many challenges in serving Black women. However, the reported experiences of the women in care, which differed quite markedly from those of the women not in care, provide hope for the possibility of positive change.

8 RECOMMENDATIONS

8.1 METHODOLOGY

In April 2005 the entire project team as well as a wide array of community partners participated in a two-day strategic planning process. Before the project team presented the findings publicly, we disseminated results to the advisory committee, broken out by the seven domains under consideration for this initiative. These seven groups, whom we had been working with from the start of the CSAD project, familiarized themselves with the findings arranged by domain. This included findings from each approach (i.e., Document Review, Systems Assessment, and RARE). These groups also facilitated the larger groups in the Strategic Planning Process two-day retreat. The advisory committee was an ad hoc committee that was informally set up by the planning committee within the structure of the Palm Beach County HIV CARE Council. This committee was comprised of consumers, administrators, and key stakeholders. This advisory team invested their personal time into this project and approached this responsibility with gusto.

They met monthly for the first year during the Planning meeting of the CARE Council and afterwards as necessary. As the Strategic Planning retreat approached, the team met weekly for two months to prepare.

The Strategic Planning Retreat developed recommendations for action using the following steps. First, a comprehensive overview of the study findings was presented to the community partners, including HIV+ consumers and providers, county commissioners, and the press, in the Commissioners public chambers. Second, a more in-depth presentation was delivered to those mentioned above with more of an opportunity to present details and open up the process for questions and answers. Third, after the presentation of findings and a robust discussion, the group of about one hundred divided into the seven domain groups and took on the tasks of taking the findings and crafting preliminary recommendations relevant to the domain they were assigned to represent. Fourth, a voting process ensued from the copious amount of recommendations. This allowed the group members to rank by frequency, the prioritized recommendations and actions necessary to accomplish prevailing goals. Fifth, six themes emerged from this process as goals. These six themes/goals appeared in each of the domains and created the foundation for the implementation and action plan. The aim/goals that were constructed from the strategic planning process were: education; single-point of access/entry; confidentiality; treatment adherence; stigma; and cultural beliefs. These goals and their related objectives are presented below. Details of their development, and more comprehensive implementation and action plans are provided in Appendix H.

8.2 RECOMMENDED GOALS AND OBJECTIVES

GOAL I: EDUCATION

To continue to expand the education about HIV/AIDS in terms of prevention and clinical care to 100% of Live AIDS-diagnosed and to 65% of those Live HIV-diagnosed and aware. Reach such individuals through leadership, support and education. Incorporate peer educators as trainers and strive to achieve 100% involvement by Providers in this initiative. Cross-train these individuals together in a team collaborative. Tailor messages to those we intend to reach.

OBJECTIVE I.1 Continue to build an active network of PLWH/A Peer Educators through the Consumer Advisory Committee; neighborhood outreach, and Provider organizations.

OBJECTIVE I.2 Establish a policy and action plan for education about HIV/AIDS education for Community Leaders that is appropriate for them. Advocate for effective educational trainings for community leaders in medical and support services related to HIV/AIDS. Continue to encourage significant progress in the prevention/ education and treatment/education of HIV/AIDS.

OBJECTIVE I.3 Raise the level of awareness by the public regarding the needs of the HIV/AIDS Community in a manner/language the targeted population(s) find acceptable and appropriate.

OBJECTIVE I.4 Develop a Peer Navigator recognition program.

OBJECTIVE I.5 Continue to support special programs that would foster the image of the Planning Council and/ or benefit Title I, Title II and all HIV/AIDS State programs.

OBJECTIVE I.6 Integrate new consumers into the Peer Navigator Committee and thereby continue to build capacity of the Planning Council.

OBJECTIVE I.7 Continue the educational and capacity-building activities of the Planning Council and the HIV/AIDS community as whole, including providers and leaders.

GOAL II: SINGLE POINT OF ENTRY

OBJECTIVE II.1 Provide a comprehensive and detailed description of what the EMA means by ‘Single Point of Entry’. Define this variable and operationalize it with the involvement of the Planning Council, The Community Planning Partnership, and EPICC

OBJECTIVE II.2 Create a strong collaboration with entities that have achieved Single Point of Entry/Access and develop a consortium of interested entities locally to serve the HIV/AIDS Community

OBJECTIVE II.3 Develop a comprehensive and coordinated ‘in-kind’ reimbursement program using skills of those employed at the various Continuum Agencies and by utilizing other ‘in kind’ donations.

GOAL III: CONFIDENTIALITY

To strengthen the mechanism for confidentiality training; comprehensive education and enforcement for all staff at all providers. Accountability will be designed and implemented by quality assurance and performance improvement criteria in achieving EMA standards of care relating to confidentiality and how it’s defined and measured.

OBJECTIVE III.1 Require adherence to minimum standards regarding confidentiality for all providers involved in providing HIV/AIDS services.

OBJECTIVE III.2 Promote consumer empowerment and education programs regarding rights and responsibilities of those receiving services among Title I and Title II services, highlighting the issues of confidentiality.

OBJECTIVE III.3 Conduct evaluations of implementation of confidentiality and enforce these standards by the written policies as designed by the CARE Council.

GOAL IV: TREATMENT ADHERENCE

To maximize Treatment Adherence implementation and utilization by the network of care at 100% for all clients.

OBJECTIVE IV.1 Provide opportunities for providers to craft treatment adherence protocols with the CARE Council.

OBJECTIVE IV.2 Create an implementation protocol and time schedule for roll out of treatment adherence.

OBJECTIVE IV.3 Create Standards of Care relating to Treatment Adherence and monitor such implementation.

OBJECTIVE IV.4 Develop strategies to link treatment adherence protocols with substance abuse and mental health services and primary medical care.

OBJECTIVE IV.5 Require a comprehensive and ongoing training program for all providers relating to treatment adherence.

OBJECTIVE IV.6 Develop a plan to assure that clients have the opportunity to chose their treatment adherence protocols and support the client’s choices regardless of their decisions.

GOAL V: STIGMA

To address the issue of stigma that makes it difficult for individuals to disclose their status and receive care for HIV-spectrum disease. The mechanisms to address stigma will be varied and appropriate for the targeted populations with an emphasis on those special populations that are disproportionately affected by HIV/AIDS.

OBJECTIVE V.1 Develop social marketing techniques to be utilized at faith-based and community events that are culturally appropriate and palatable to the communities most adversely affected by HIV-spectrum disease.

OBJECTIVE V.2 Promote consumer empowerment and education programs regarding stigma at provider agencies. Incorporate rights and advocacy trainings at Title I and II services.

OBJECTIVE V.3 Contribute to the local community by providing open trainings and educational opportunities.

GOAL VI: CULTURAL BELIEFS, PRACTICES, AND BEHAVIORS

To provide outreach and encouragement to populations at risk for HIV/AIDS in Palm Beach County and create the most effective models of HIV/AIDS CARE maintenance among communities that are disproportionately affected by HIV-spectrum disease.

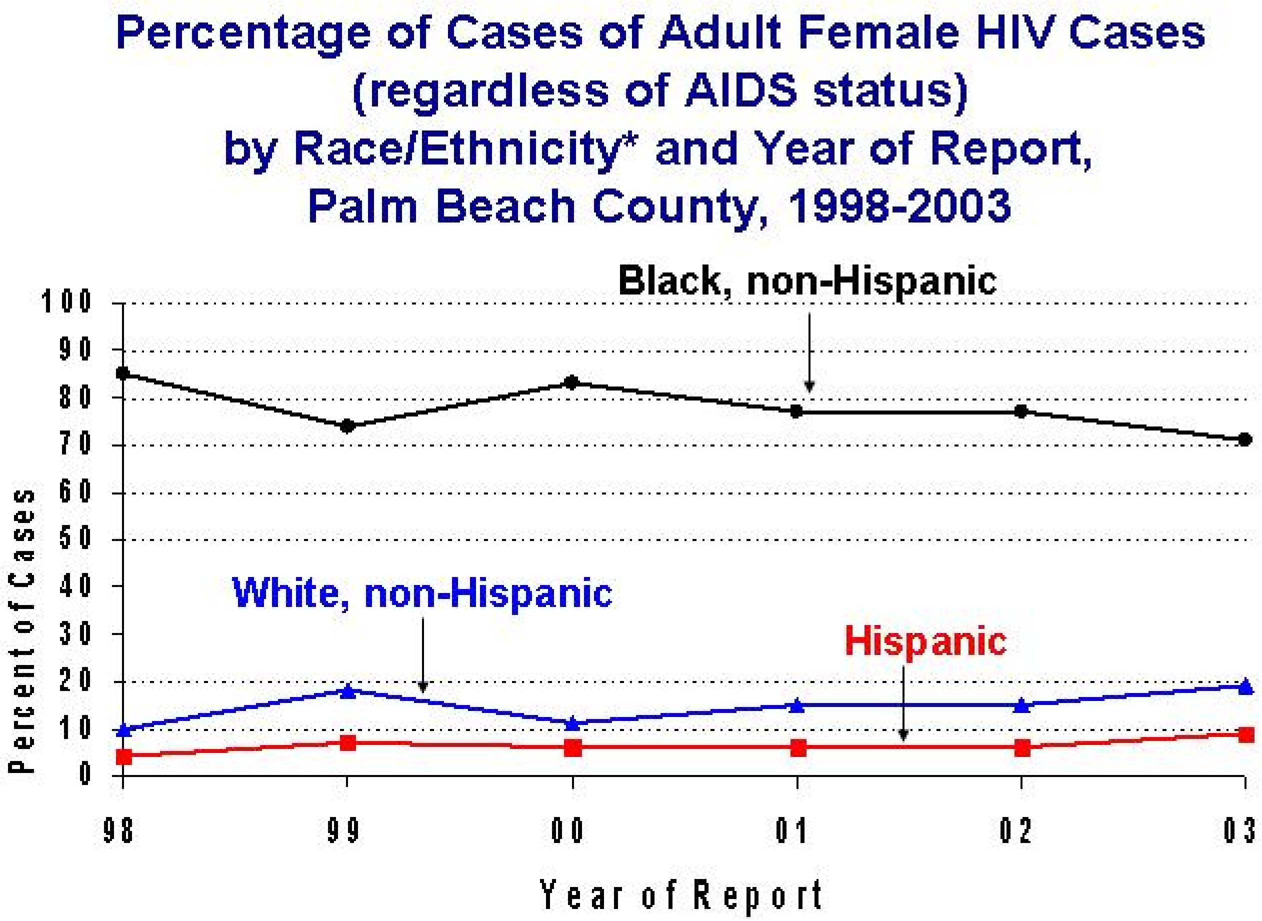
OBJECTIVE VI.1 Identify and work with people in their neighborhoods to devise Outreach Models and CARE Maintenance Interventions that are congruent with those communities' beliefs, practices, and behaviors.

OBJECTIVE VI.2 Actively advocate for the development/ designation of additional funds for community outreach/CARE Maintenance Intervention.

OBJECTIVE VI.3 Explore the need for expanded geographic distribution of these services.

APPENDIX A
EPIDEMIOLOGICAL DATA

Figure 1

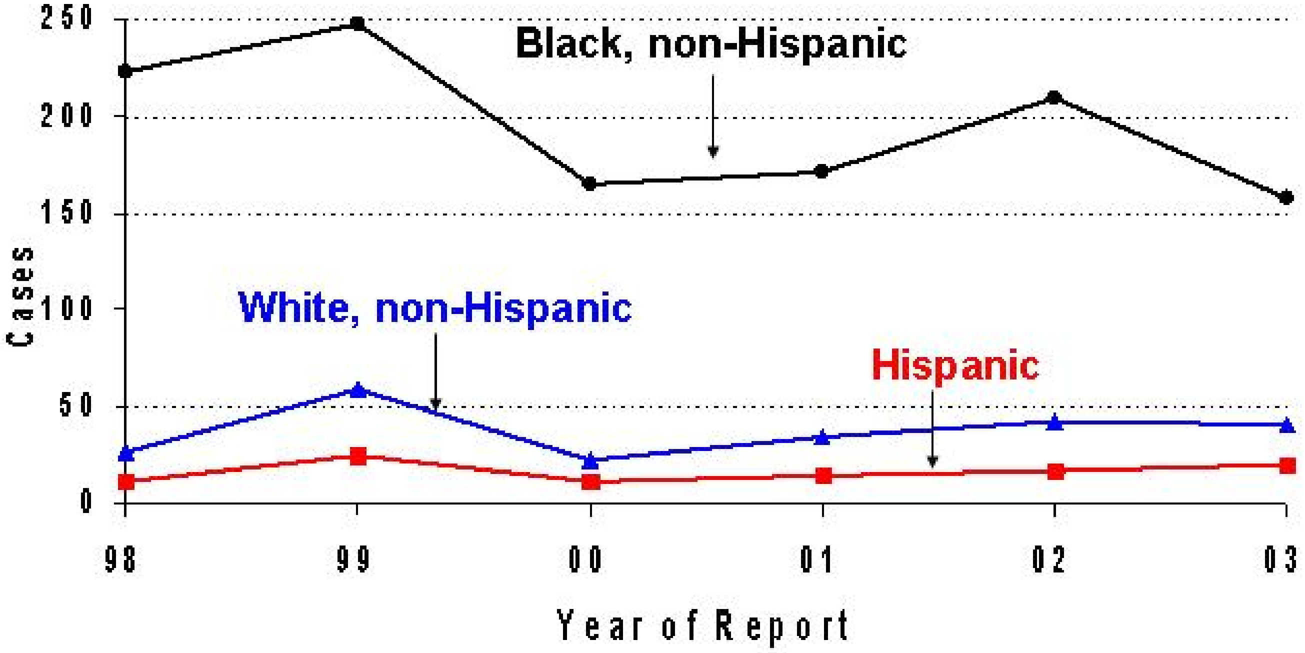


Percentage of Cases of Adult Female HIV Cases (regardless of AIDS status) by Race/Ethnicity* and Year of Report, Palm Beach County, 1998-2003

*Other races represent less than 1% of the cases and are not included.
HIV data includes those cases that have converted to AIDS. These HIV cases cannot be added with AIDS cases to get combined totals since the categories are not mutually exclusive.

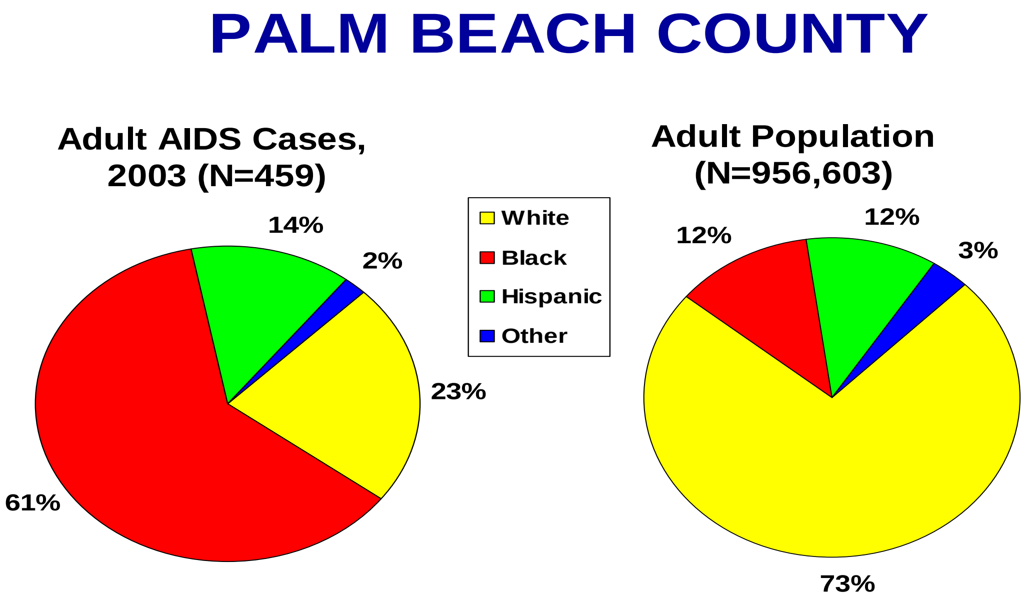
Figure 2

Adult Female HIV Cases (regardless of AIDS status) by Race/Ethnicity* and Year of Report, Palm Beach County, 1998-2003



*Other races represent less than 1% of the cases and are not included.
HIV data includes those cases that have converted to AIDS. These HIV cases cannot be added with AIDS cases to get combined totals since the categories are not mutually exclusive.

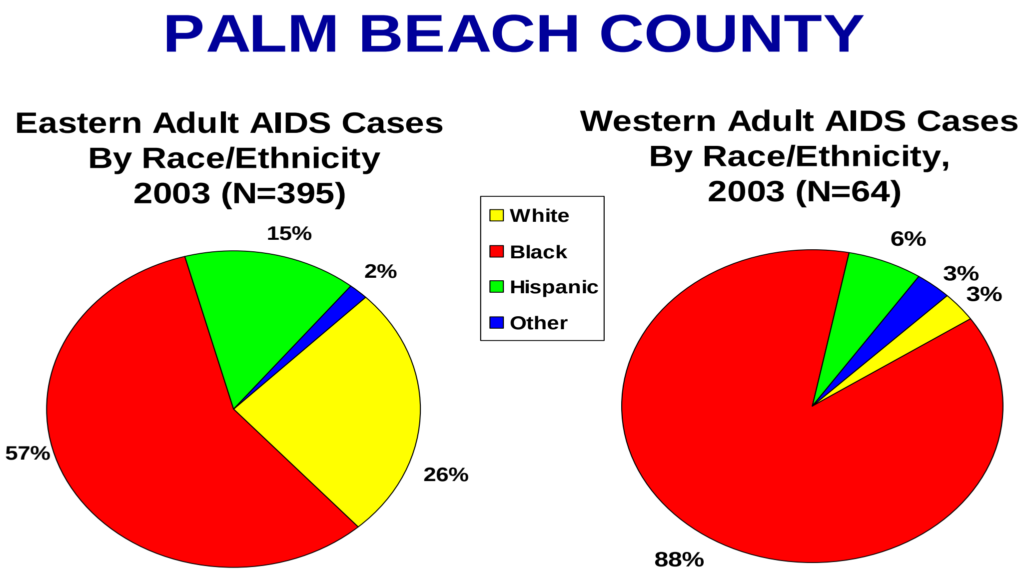
Figure 3



Comment: The racial/ethnic disparity concerning blacks is more pronounced in Palm Beach County than in the state as a whole.

Source: **State of Florida, Department of Health**

Figure 4

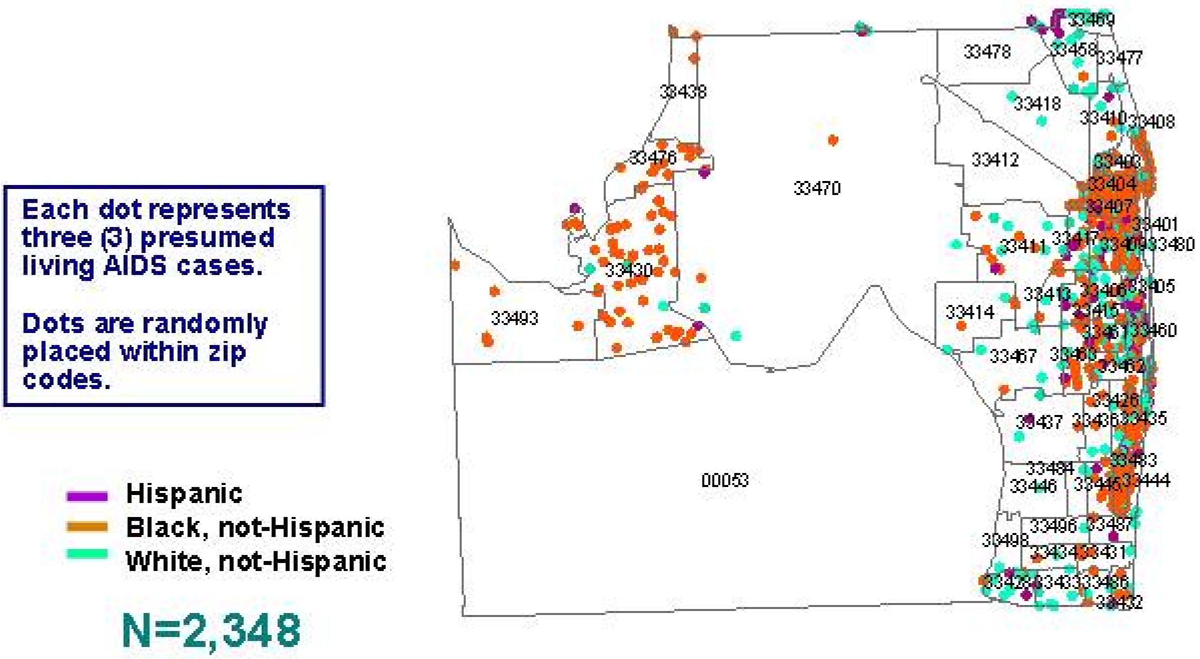


Comment: The demographic AIDS case profiles for eastern and western Palm Beach County are radically different. Though we know there are racial/ethnic disparities in both regions, these cannot be quantified since population data for each are not available by race/ethnicity.

Source: **State of Florida, Department of Health**

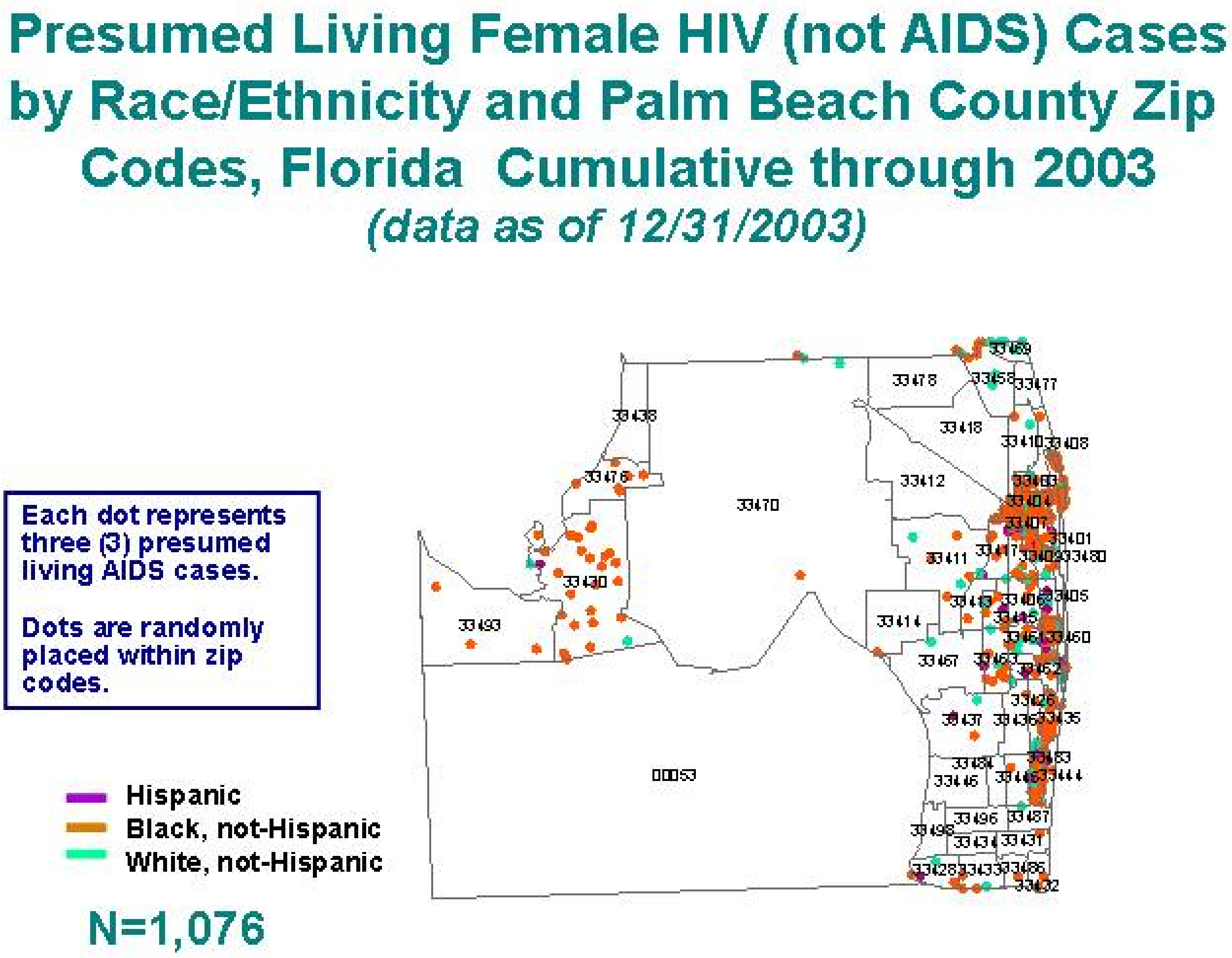
Figure 5

Presumed Living HIV (not AIDS) Cases by Race/Ethnicity and Palm Beach County Zip Codes, Florida Cumulative through 2003*(data as of 12/31/2003)*



Source: State of Florida, Department of Health

Figure 6



Presumed Living Female HIV (not AIDS) Cases by Race/Ethnicity and Palm Beach County Zip Codes, Florida Cumulative through 2003

(data as of 12/31/2003)

Each dot represents three (3) presumed living AIDS cases.

Dots are randomly placed within zip codes.

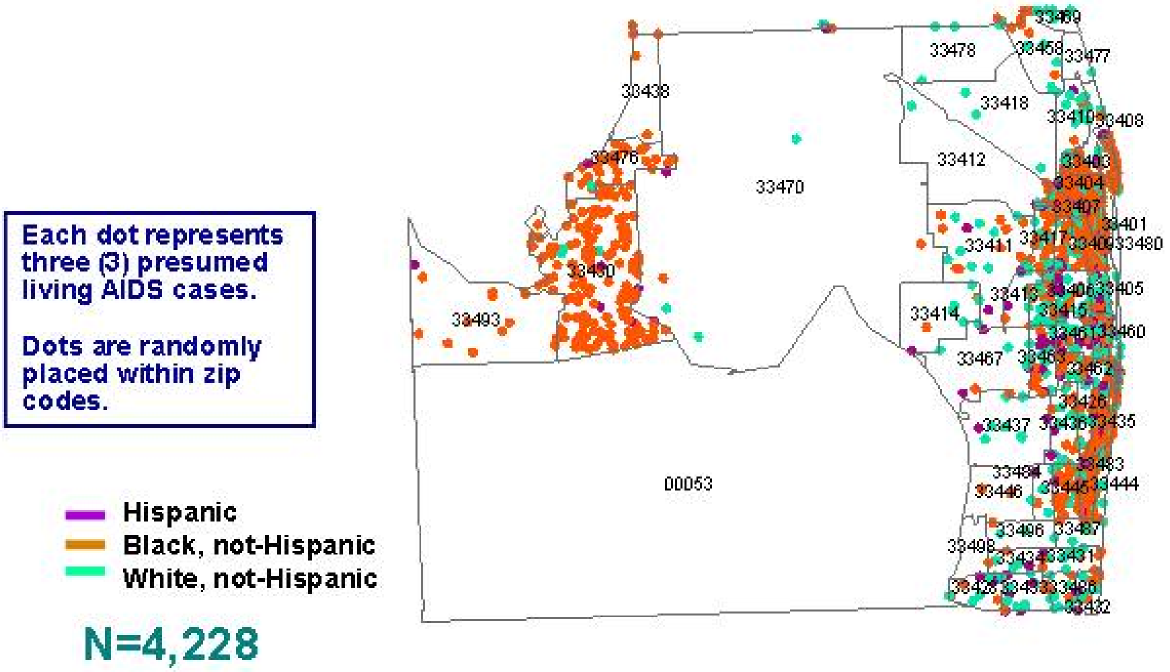
N=1,076

Source**:** State of Florida, Department of Health

Figure 7

Presumed Living AIDS Cases by Race/Ethnicity and Palm Beach County Zip Codes, Florida Cumulative through 2003

(data as of 12/31/2003)



Each dot represents three (3) presumed living AIDS cases.

Dots are randomly placed within zip codes.

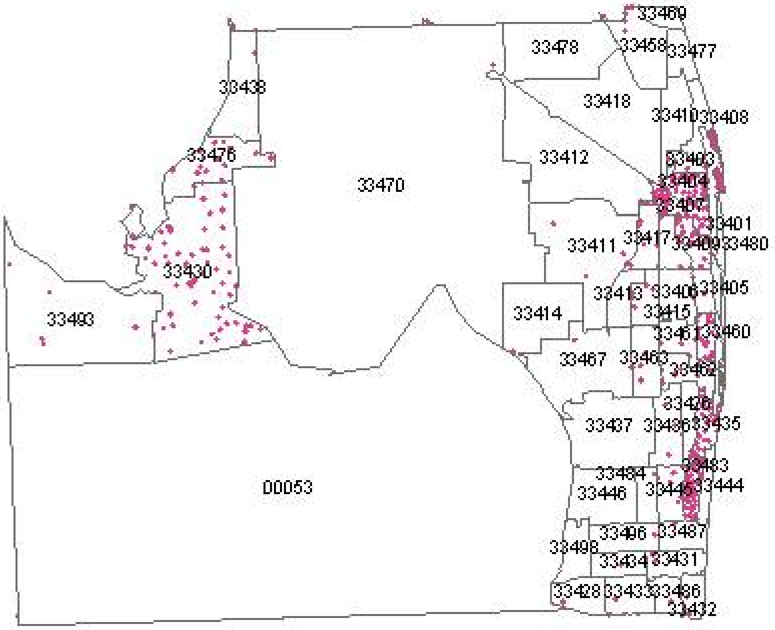
N=4,228

Source**:** State of Florida, Department of Health

Figure 8

Presumed Living Black Female AIDS Cases By Palm Beach County Zip Codes, Florida Cumulative through 2003

(data as of 12/31/2003)



Each dot represents three (3) presumed living AIDS cases.

Dots are randomly placed within zip codes.

N=1,167

- 🟪 **Hispanic**
- 🟧 **Black, not-Hispanic**
- 🟩 **White, not-Hispanic**

Source: State of Florida, Department of Health

APPENDIX B
DOCUMENT REVIEW TABLES

Table B-1
Documents Reviewed by Domain

DOCUMENT/DOMAIN[1]	1	2	3	4	5	6	7
Ryan White Title I Allocations, 2001-2004	X						
Ryan White Title II Allocations, 2001-2004	X						
PBC HIV Care Council Needs Assessment for 2003-2006	X	X					
Patient Care and Network State Funding Allocations, 2001-2004	X						
Housing for Persons with AIDS (HOPWA) Allocations, 2001-2004	X						
PBC HIV Care Council Community Planning Partnership Plan for 2004-2006	X						
Medicaid Reimbursement Rates, 2003	X						
PBC HIV Care Council Prioritization and Allocation Documents		X					
PBC HIV Care Council Comprehensive Plan for 2002-2005		X	X				
Annual Administrative Report, 2000		X					
PBC Ryan White Title I Grant Application, 2004		X					
PBC HIV/AIDS Service Directory			X	X			
Ryan White Title I Grant Applications from service providers[2]			X		X	X	
Map of PBC bus and train routes				X			
PBC HIV Care Council Standards of Care					X	X	
PBC HIV Care Council Summary and Supplemental Reports of the Medical, Social, and Housing Services, 2002-2003						X	
PBC HIV Care Council QA Service Performance Chart Audit External Review Final Report, 2004						X	
PBC RARE Report, 2001							X

Notes:

[1] Domains: 1-Comprehensiveness; 2-Capacity; 3-Integration; 4-Acceptability; 5-Accessibility; 6-Technical Competencies; 7-Client Health-Seeking Behaviors.

[2] Providers: Comprehensive Alcohol Rehabilitation Program; PBC Department of Health; Hope House; Gratitude House; Western PBC Mental Health Clinic; Compass; Haitian Center for Family Services; Legal Aid; PBC Health Care District; Comprehensive AIDS Program; PBC Assisted Living Facility; Children's Place; We Promise to Care; Treasure Coast Health Council.

TABLE B-2
SYSTEM COMPREHENSIVENESS

	Title I Allocation 2001-2004	HOPWA Allocation 2001-2004	State Funding Patient Care 2002-2003	State Funding Network 2002-2003	Medicaid	Other Federal, State, Local Funds	Care Council Needs Assessment* 2003-2006
Ambulatory/ Outpatient Medical Care	√		√	√	√	√ (F,S,L)	72
Local Title I Drug Assistance or Medications Program	√		√				56
State Title II AIDS Drug Assistance Program Contribution						√ (S)	
Dental Care	√		√	√			62
Health Insurance Continuation	√						14
Home Health Care	√						8
Hospice Services		√					6
Inpatient Personnel Costs						√ (L)	27
Mental Health Therapy/ Counseling Services	√		√	√			27
Nutritional Services			√	√			
Rehabilitation Care							14
Substance Abuse Treatment/Counseling	√				√		23
Treatment Adherence/Compliance	√						63
Case Management	√		√	√	√		74
Adoption/Foster Care Assistance/ Permanency Planning	√				√		7
Buddy/Companion Services	√						6
Client Advocacy	√						20
Counseling (Other)	√						48
Day/Respite Care					√		9
Direct Emergency Financial Assistance	√						37
Food Bank/Home Delivered Meals/Nutritional Supplements	√				√		47
Health Education/Risk Reduction	√				√		59
Housing Assistance/Housing Related Services	√	√					41
Outreach/Referral to Primary Care & Related Services	√						64
Transportation	√						45

Service listing from CARE System Assessment Demonstration Project Framework for CARE Service System Assessment, Appendix A

√ - Service is funded

* - Percentage of respondents in needs assessment indicating that they need and use the service

TABLE B-3
SYSTEM CAPACITY

SERVICE[1]	Estimated Consumers in Need[2]	Consumers Served – Title I Funding[3]	Estimated Service Gap Range[4] I	Estimated Service Gap Percentage Range[5]	Funding Priority 2003-2004	2004 Allocation Amount ($)	2004 Allocation Percentage
Ambulatory/Outpatient Medical Care	5925	1947	948-3978	16-67%	1	1,870,599	15.6
AIDS Drug Assistance Program	4187	NA	869	21%	1	861,382	7.2
Dental Care	4582	1054	1501-3528	33-77%	1	337,605	2.8
Health Insurance Continuation	2133	NA	2370	>100%	1	25,000	0.2
Home Health Care	869	158	474-711	55-82%	9	207,643	1.7
Hospice Services	869	NA	316	36%	1	0	0
Inpatient Personnel Costs	2844	NA	711	25%	1	0	0
Mental Health Therapy/ Counseling Services	2765	392	711-2373	26-86%	7	433,175	3.6
Nutritional Services	NA	21	NA	NA	NA	NA	NA
Rehabilitation Care	790	0	790-1659	>100%	NA	NA	NA
Substance Abuse Treatment/Counseling	1106	112	474-994	43-90%	5	500,000	4.2
Treatment Adherence/Compliance	NA	151	NA	NA	NA	NA	NA
Case Management	5372	2944	1264-2428	24-45%	2	3,384,000	28.2
Adoption/Foster Care Assistance/ Permanency Planning	632	265	367-711	58->100%	8	92,117	0.8
Buddy/Companion Services	1106	0	790-1106	71-100%	15	0	0
Client Advocacy	4661	NA	790	17%	2	75,000	0.6
Counseling (Other)	2449	21	1343-2428	55-99%	14	79,281	0.7
Day/Respite Care	948	0	632-948	67-100%	16	0	0
Direct Emergency Financial Assistance	2449	363	2086-2765	85->100%	10	134,223	1.1
Food Bank/Home Delivered Meals/ Nutritional Supplements	4345	1236	1659-3109	38-72%	4	566,552	4.7
Health Education/Risk Reduction	NA	0	NA	NA	1	97,405	0.8
Housing Assistance/Housing Related Services	1659	641	1018-2499	61->100%	3	629,310	5.2
Outreach/Referral to Primary Care & Related Services	4582	0	553-4582	12-100%	1	97,405	0.8
Transportation	2133	990	1143-1659	54-78%	6	213,007	1.8

Data Sources:

[1] CARE System Assessment Demonstration Project Framework for CARE Service System Assessment, Appendix A

[2] Palm Beach County HIV Care Council 2002-2005 Comprehensive Plan, Table 20 (Midpoint Estimates)

[3] Palm Beach County HIV Care Council 2002 Annual Administrative Report

[4] Estimated Service Gap Range is based on a combination of two estimated gaps. Estimated Service Gap I = Column 2 minus Column 3. Estimate II is from the Palm Beach County HIV Care Council 2002-2005 Comprehensive Plan, Table 21 (Midpoint Estimates)

[5] Percentage = Column 4 divided by Column 2.

NA: Data Not Available

TABLE B-4
INTER-AGENCY INTEGRATION

	AGENCY	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15
1	Adopt-A-Family															
2	ALERT															
3	Belvedere Baptist Church															
4	CAP						X					X				
5	Care Ministry															
6	CARP															
7	Catholic Charities															
8	Center for Family Services															
9	CCMO/TOPWA															
10	Community Action Program															
11	Compass													X	X	
12	CROS															
13	DATA															
14	Drug Abuse Foundation															
15	Faith Farm Ministries															
16	Farmworkers Coordinating Council															
17	FAU Student Health Services															
18	FL DCF															
19	FL Institute for Girls															
20	FL Rural Legal Services															
21	Food Stamp Program															
22	Glades Health Initiative															
23	G-d’s Kitchen															
24	Gratitude Guild															
25	Growing Together															
26	Guatemalan-Maya Center															
27	Haitian Center for Family Services															
28	Hanley-Hazelden															
29	Hearts and Hope															
30	A.G. Holley Hospital															
31	Hope House															
32	House of Bread															
33	Infectious Disease Consultants															
34	Jewish Family & Children’s Services															
35	Legal Aid Society															
36	MH Ass’n of PBC															
37	Oakwood Center															
38	Palm Tran Connection															
39	PBC Assisted Living Facility															
40	PBC Division of Human Services															
41	PBC Health Care District															
42	PBC Health Dept.															
43	Planned Parenthood															
44	Pentecostal Church of God															
45	Project AIDS Care															
46	Red Cross															
47	Revitalax															
48	Saint James Missionary Baptist Church															
49	Saint Vincent de Paul Society															
50	Salvation Army															
51	SHIP															
52	Sistah to Sistah Recovery House															
53	The Caring Kitchen															
54	The Children’s Place															
55	The Lord’s Place															
56	The Soup Kitchen															
57	United Deliverance Comm. Resource Ctr.															
58	Wayside House															
59	Western PBC MH Clinic															

X – Formal Inter-Agency Agreement Exists
Data Sources: Palm Beach County HIV/AIDS Service Directory; Ryan White Title I Grant Applications

	AGENCY	16	17	18	19	20	21	22	23	24	25	26	27	28	29	30
1	Adopt-A-Family															
2	ALERT															
3	Belvedere Baptist Church															
4	CAP							X		X			X			
5	Care Ministry									X						
6	CARP									X						
7	Catholic Charities									X						
8	Center for Family Services															
9	CCMO/TOPWA															
10	Community Action Program															
11	Compass			X		X				X			X			X
12	CROS															
13	DATA															
14	Drug Abuse Foundation															
15	Faith Farm Ministries															
16	Farmworkers Coordinating Council															
17	FAU Student Health Services															
18	FL DCF									X						
19	FL Institute for Girls															
20	FL Rural Legal Services												X			
21	Food Stamp Program															
22	Glades Health Initiative															
23	G-d's Kitchen															
24	Gratitude Guild															
25	Growing Together															
26	Guatemalan-Maya Center															
27	Haitian Center for Family Services															
28	Hanley-Hazelden															
29	Hearts and Hope															
30	A.G. Holley Hospital															
31	Hope House															
32	House of Bread															
33	Infectious Disease Consultants															
34	Jewish Family & Children's Services															
35	Legal Aid Society															
36	MH Ass'n of PBC															
37	Oakwood Center															
38	Palm Tran Connection															
39	PBC Assisted Living Facility															
40	PBC Division of Human Services															
41	PBC Health Care District															
42	PBC Health Dept.															
43	Planned Parenthood															
44	Pentecostal Church of God															
45	Project AIDS Care															
46	Red Cross															
47	Revitalax															
48	Saint James Missionary Baptist Church															
49	Saint Vincent de Paul Society															
50	Salvation Army															
51	SHIP															
52	Sistah to Sistah Recovery House															
53	The Caring Kitchen															
54	The Children's Place															
55	The Lord's Place															
56	The Soup Kitchen															
57	United Deliverance Comm. Resource Ctr.															
58	Wayside House															
59	Western PBC MH Clinic															

X – Formal Inter-Agency Agreement Exists

Data Sources: Palm Beach County HIV/AIDS Service Directory; Ryan White Title I Grant Applications

	AGENCY	31	32	33	34	35	36	37	38	39	40	41	42	43	44	45
1	Adopt-A-Family															
2	ALERT															
3	Belvedere Baptist Church															
4	CAP	X				X		X		X			X			
5	Care Ministry															
6	CARP	X				X		X		X			X			
7	Catholic Charities															
8	Center for Family Services									X						
9	CCMO/TOPWA												X			
10	Community Action Program															
11	Compass	X				X		X		X			X	X		
12	CROS															
13	DATA															
14	Drug Abuse Foundation												X			
15	Faith Farm Ministries															
16	Farmworkers Coordinating Council															
17	FAU Student Health Services															
18	FL DCF												X			
19	FL Institute for Girls															
20	FL Rural Legal Services									X						
21	Food Stamp Program															
22	Glades Health Initiative												X			
23	G-d's Kitchen															
24	Gratitude Guild	X				X				X		X				
25	Growing Together															
26	Guatemalan-Maya Center															
27	Haitian Center for Family Services					X		X					X	X		
28	Hanley-Hazelden															
29	Hearts and Hope															
30	A.G. Holley Hospital															
31	Hope House					X				X			X			
32	House of Bread															
33	Infectious Disease Consultants															
34	Jewish Family & Children's Services															
35	Legal Aid Society									X			X			
36	MH Ass'n of PBC															
37	Oakwood Center									X			X			
38	Palm Tran Connection									X						
39	PBC Assisted Living Facility										X		X			
40	PBC Division of Human Services															
41	PBC Health Care District												X			
42	PBC Health Dept.													X		
43	Planned Parenthood															
44	Pentecostal Church of God															
45	Project AIDS Care															
46	Red Cross															
47	Revitalax															
48	Saint James Missionary Baptist Church															
49	Saint Vincent de Paul Society															
50	Salvation Army															
51	SHIP															
52	Sistah to Sistah Recovery House															
53	The Caring Kitchen															
54	The Children's Place															
55	The Lord's Place															
56	The Soup Kitchen															
57	United Deliverance Comm. Resource Ctr.															
58	Wayside House															
59	Western PBC MH Clinic															

X – Formal Inter-Agency Agreement Exists

Data Sources: Palm Beach County HIV/AIDS Service Directory; Ryan White Title I Grant Applications

	AGENCY	46	47	48	49	50	51	52	53	54	55	56	57	58	59
1	Adopt-A-Family														
2	ALERT														
3	Belvedere Baptist Church														
4	CAP		X							X	X		X	X	X
5	Care Ministry														
6	CARP		X							X					X
7	Catholic Charities									X					
8	Center for Family Services									X					
9	CCMO/TOPWA														
10	Community Action Program														
11	Compass					X		X		X					
12	CROS														
13	DATA									X					
14	Drug Abuse Foundation														
15	Faith Farm Ministries														
16	Farmworkers Coordinating Council														
17	FAU Student Health Services									X					
18	FL DCF														
19	FL Institute for Girls														
20	FL Rural Legal Services														
21	Food Stamp Program														
22	Glades Health Initiative														
23	G-d's Kitchen														
24	Gratitude Guild							X		X			X		
25	Growing Together														
26	Guatemalan-Maya Center														
27	Haitian Center for Family Services		X					X							
28	Hanley-Hazelden														
29	Hearts and Hope														
30	A.G. Holley Hospital														
31	Hope House							X		X					
32	House of Bread														
33	Infectious Disease Consultants														
34	Jewish Family & Children's Services									X					
35	Legal Aid Society									X					
36	MH Ass'n of PBC														
37	Oakwood Center														
38	Palm Tran Connection														
39	PBC Assisted Living Facility							X							X
40	PBC Division of Human Services														
41	PBC Health Care District														
42	PBC Health Dept.									X			X		X
43	Planned Parenthood														
44	Pentecostal Church of God														
45	Project AIDS Care														
46	Red Cross	▨													
47	Revitalax	▨	▨												
48	Saint James Missionary Baptist Church	▨	▨	▨											
49	Saint Vincent de Paul Society	▨	▨	▨	▨										
50	Salvation Army	▨	▨	▨	▨	▨									
51	SHIP	▨	▨	▨	▨	▨	▨								
52	Sistah to Sistah Recovery House	▨	▨	▨	▨	▨	▨	▨							
53	The Caring Kitchen	▨	▨	▨	▨	▨	▨	▨	▨						
54	The Children's Place	▨	▨	▨	▨	▨	▨	▨	▨	▨				X	
55	The Lord's Place	▨	▨	▨	▨	▨	▨	▨	▨	▨	▨				
56	The Soup Kitchen	▨	▨	▨	▨	▨	▨	▨	▨	▨	▨	▨			
57	United Deliverance Comm. Resource Ctr.	▨	▨	▨	▨	▨	▨	▨	▨	▨	▨	▨	▨		
58	Wayside House	▨	▨	▨	▨	▨	▨	▨	▨	▨	▨	▨	▨	▨	
59	Western PBC MH Clinic	▨	▨	▨	▨	▨	▨	▨	▨	▨	▨	▨	▨	▨	▨

X – Formal Inter-Agency Agreement Exists

Data Sources: Palm Beach County HIV/AIDS Service Directory; Ryan White Title I Grant Applications

TABLE B-5
INTER-AGENCY INTEGRATION: SUMMARY

AGENCY	SERVICES PROVIDED*	OUTSIDE SERVICES LINKED*												TOTAL LINKAGES
		EI	CM	T	H	MH	SA	A	$	F	TR	S	L	
Adopt-A-Family	$													
ALERT	EI													
Belvedere Baptist Church	F													
CAP	ALL	X	X	X	X	X	X	X	X	X	X	X	X	16
Care Ministry	F						X							1
CARP	T, SA	X	X	X	X	X	X	X	X	X	X	X	X	11
Catholic Charities	F, $				X		X							2
Center for Family Services	MH				X									2
CCMO/TOPWA	T, EI, CM													
Community Action Program	$													
Compass	ALL	X	X	X	X	X	X	X	X	X	X	X	X	17
CROS	F													
DATA	T, SA, EI	X	X	X	X	X	X	X	X	X	X	X	X	2
Drug Abuse Foundation	T, SA	X	X	X	X	X	X	X	X	X	X	X	X	2
Faith Farm Ministries	SA													
Farmworkers Coordinating Cncl.	TCM TRMHEI													
FAU Student Health Services	T													
FL DCF	$	X	X	X	X	X	X	X	X	X	X	X	X	2
FL Institute for Girls	T													
FL Rural Legal Services	L, A	X	X	X	X	X	X	X	X	X	X	X	X	3
Food Stamp Program	$													
Glades Health Initiative	T	X	X	X	X	X	X	X	X	X	X	X	X	1
G-d's Kitchen	F													
Gratitude Guild	SA	X	X	X	X	X	X	X	X	X	X	X	X	13
Growing Together	SA													
Guatemalan-Maya Center	L													
Haitian Center for Family Svcs.	CM, $, EI, T	X	X	X	X	X	X	X	X	X	X	X	X	9
Hanley-Hazelden	SA													
Hearts and Hope	MH													
A.G. Holley Hospital	T													
Hope House	H, EI, T	X	X	X	X	X	X	X	X	X	X	X	X	9
House of Bread	F													
Infectious Disease Consultants	EI													
Jewish Family & Children's Serv.	$				X									1
Legal Aid Society	L	X	X	X	X	X	X	X	X	X	X	X	X	9
MH Ass'n of PBC	MH, A													
Oakwood Center	MH, T	X	X	X	X	X	X	X	X	X	X	X	X	6
Palm Tran Connection	TR				X									1
PBC Assisted Living Facility	H	X	X	X	X	X	X	X	X	X	X	X	X	14
PBC Division of Human Services	$				X	X	X							2
PBC Health Care District	$	X		X	X									2
PBC Health Dept.	EI, T	X	X	X	X	X	X	X	X	X	X	X	X	14
Planned Parenthood	EI, T	X	X	X	X	X	X	X	X	X	X	X	X	3
Pentecostal Church of God	T													
Project AIDS Care	$													
Red Cross	EI, $													
Revitalax	H	X	X	X	X	X	X	X	X	X	X	X	X	3
Saint James Missionary Church	T													
Saint Vincent de Paul Society	$													
Salvation Army	H, F	X	X	X	X	X	X	X	X	X	X	X	X	1
SHIP	S													
Sistah to Sistah Recovery House	H	X	X	X	X	X	X	X	X	X	X	X	X	5
The Caring Kitchen	F													
The Children's Place	H	X	X	X	X	X	X	X	X	X	X	X	X	13
The Lord's Place	H	X	X	X	X	X	X	X	X	X	X	X	X	1
The Soup Kitchen	F													
United Deliverance Comm.	T, EI	X	X	X	X	X	X	X	X	X	X	X	X	3
Wayside House	SA	X	X	X	X	X	X	X	X	X	X	X	X	2
Western PBC MH Clinic	H, MH, SA	X	X	X	X	X	X	X	X	X	X	X	X	4

*EI – Education/Information; CM – Case Management; T – Testing; H – Housing; MH – Mental Health; SA – Substance Abuse Treatment; A – Advocacy; $ - Financial Assistance; TR – Transportation ; S – Support Group; L – Legal; X – Formal Linkage
X – Formal Inter-Agency Agreement Exists
Data Sources: Palm Beach County HIV/AIDS Service Directory; Ryan White Title I Grant Applications

TABLE B-6

PRIMARY MEDICAL CARE SYSTEM TEMPORAL AND LINGUISTIC ACCESSIBILITY

AGENCY	Evening Hours	Weekend Hours	French/Creole	Spanish
HIV/AIDS TESTING SITES				
CAP			√	√
Glades Health Initiative				
PBC Health Dept.			√	√
Planned Parenthood				√
CCMO				
Compass	√	√		√
CARP				
Drug Abuse Foundation	√			
DATA	√			
Farmworkers Coordinating Council			√	√
FAU				
FL Institute for Girls				
Hope House			√	√
Haitian Center			√	
Oakwood Center			√	√
United Deliverance				
PRIVATE PHYSICIANS				
Barry Abrams				√
Floyd Beil				√
Fred Blumenfeld	√	√	√	√
Alexander Carden				
Julio Cardenas				√
FL Lighthouse				√
Beth Frosch		√		
Jacques Guiteau		√	√	
Infectious Disease Ass’n				√
Infectious Disease Consultants				√
Infectious Disease Consultants, Inc.			√	√
John Merey			√	√
Mid-Lake Health Care Center			√	
Kenneth Ness				
Olayemi Osiyemi			√	√
Sacred Heart Family Health Center	√			
Vijay Samant				
Steven Schaeffer				√
Andres Suarez				√
Serge Thys				
Ronald Wagner			√	√
Donald Watren				√
Women’s Health Services			√	√
HOSPITALS/CLINICS				
A.G. Holley	√	√	√	√
Bethesda Memorial	√	√	√	√
Boca Raton Community	√	√		√
PBC Health Dept.			√	√
Columbia	√	√	√	√
Glades General	√	√		√
Good Samaritan	√	√		
JFK Medical Center	√	√		√
Jupiter Medical Center	√	√	√	√
Medical Center of Delray	√	√		
Palm Beach Gardens Medical Center	√	√	√	√
Palms West	√	√	√	√
St. Mary’s	√	√		√
VA	√	√		√
Wellington Regional Medical Center	√	√		√
West Boca Medical Center	√	√		√

√ – Yes.

Data Source: Palm Beach County HIV/AIDS Service Directory

TABLE B-7
ANCILLARY CARE SYSTEM TEMPORAL AND LINGUISTIC ACCESSIBILITY

AGENCY	Evening Hours	Weekend Hours	French/Creole	Spanish
Adopt-A-Family				
ALERT				
Belvedere Baptist Church	√			
CAP			√	√
Care Ministry		√		
CARP				
Catholic Charities			√	
Center for Family Services	√	√		√
Community Action Program				
Compass	√	√		√
CROS				√
DATA	√			
Drug Abuse Foundation				
Farmworkers Coordinating Cncl.			√	√
FL DCF			√	√
FL Rural Legal Services			√	√
Food Stamp Program				
G-d’s Kitchen				
Gratitude Guild				
Growing Together	√	√		√
Guatemalan-Maya Center				√
Haitian Center for Family Svcs.			√	
Hanley-Hazelden	√	√		
Hearts and Hope	√			
Hope House			√	√
House of Bread	√			
Infectious Disease Consultants				√
Jewish Family & Children’s Serv.				
Legal Aid Society				√
MH Ass’n of PBC				√
Oakwood Center	√	√	√	√
Palm Tran Connection				√
PBC Assisted Living Facility				√
PBC Division of Human Services				
PBC Health Care District			√	√
PBC Health Dept.			√	√
Planned Parenthood				√
Project AIDS Care				
Red Cross				√
Revitalax				
Saint James Missionary Church				
Saint Vincent de Paul Society				
Salvation Army	√	√		√
SHIP				
Sistah to Sistah Recovery House	√	√		
The Caring Kitchen				
The Children’s Place	√	√		√
The Lord’s Place	√			
The Soup Kitchen		√		√
United Deliverance Comm.				
Wayside House				
Western PBC MH Clinic	√	√		√

√ – Yes.
Data Source: Palm Beach County HIV/AIDS Service Directory

TABLE B-8
SERVICE ACCEPTABILITY: BARRIERS AND SOLUTIONS

IDENTIFIED BARRIER	AGENCY SOLUTION
HEALTH BELIEFS AND HEALTH-SEEKING BEHAVIORS	
Beliefs regarding medical care; lack of understanding of benefits of accessing care, importance of prevention and early treatment, and efficacy of taking medication; tendency to seek care only in response to symptoms	Culturally/linguistically competent staff
Lack of understanding/adherence to treatment regimens	Patient education; resource center; peer support
Confusion about treatment options; lack of awareness of treatment options	Outreach counselors; patient education
Putting off health care until problem becomes an emergency	None indicated
Competing life priorities such as basic survival needs (employment, child care, housing)	Address non-medical needs
Broken appointments	Follow-up with broken appointments; calling in advance of appointment to confirm; coordinating with case managers
Clients lead full, complex lives lacking in structure	Consistent contact with service provider to provide structure
Perception of AIDS as a disease of homosexuals, IVDUs, prostitutes, and promiscuous individuals	Culturally/linguistically competent staff
Strong association between HIV infection and hopelessness and death	Culturally/linguistically competent staff
Fear of domestic violence when disclosing HIV status to male partner or when seeking services	Culturally/linguistically competent staff
Belief in alternative etiologies of HIV/AIDS; e.g., a curse or an evil spirit sent to those deserving punishment	Culturally/linguistically competent staff
Belief in supernatural powers and their role in health status	Culturally/linguistically competent staff
Belief in alternative health remedies and treatment; i.e., faith healers, herbs, oils, roots, magic	Culturally/linguistically competent staff
Strong sense of self-reliance	Culturally/linguistically competent staff
Fear that disclosure of HIV status will threaten custody of child(ren)	Culturally/linguistically competent staff
Denial of terminal nature of illness and need to plan for future	Educational booklet targeted to client population's reading level
Client low energy and low motivation	In-home services
Unwillingness to enter residential substance abuse treatment due to desire not to be away from family	Include family in treatment plan, enhance family support
CULTURAL/LINGUISTIC BARRIERS	
Mistrust of paperwork, health care system, and persons in authority due to experiences of exploitation and oppression.	Culturally/linguistically competent staff
Fear of being reported to immigration officials	Culturally/linguistically competent staff
Illiteracy, low English proficiency, low level of acculturation resulting in difficulty completing complicated paperwork, following written instructions, knowing about HIV/AIDS care and availability of services, and adhering to treatment	Culturally/linguistically competent staff; peer advocate accompanies client to doctor's appointments; audio tapes; bilingual written materials; use of supportive bilingual family members; contract with translators
Unacceptable foods	Ethnically diverse food selection

--continued--

SYSTEMIC BARRIERS	
Too difficult to get to each separate location for each services	One-stop service center; location of several providers at one site
Service delivery system is intimidating; difficulty understanding complex eligibility rules, enrollment procedures, benefits and limitations of coverage, insurance and cost sharing	Nurse care coordinator to lead clients through system; service coordination meetings; case managers accompany clients through process for obtaining a service
Lack of transportation	Transportation; cab vouchers; services provided in home or other nearby location; multiple service sites; different agencies co-located in one location
Waiting time for approval for state insurance	Payment of private insurance premiums to cover waiting gap
Difficulty selecting qualified health care professional	Referral to qualified professionals; staff training on HIV/AIDS
Waiting list for substance abuse treatment	Contracting with more treatment agencies; streamline entry process
Lack of centralized information	Centralized management information system
Inconvenient operating hours	Expansion of hours
Perception of poor quality of care	In-service training; case review; teleconferencing; continuing education
Clinic located near government immigration office	Move office
Long wait time for walk-in patients	New triage system
Bathrooms distant from pediatric clinic	Locate bathrooms closer
Nursing shortage	Contract with outside agencies for additional nursing services
Confusion about Medicaid reimbursement for specific services	Staff training
Referral problems	More efficient referral mechanism
Provider bias; belief that minority women are less likely to be adherent to treatment	Culturally/linguistically competent staff
Lack of insurance	None indicated
Lack of childcare	None indicated
Ineligibility for public benefits due to immigrant status (legal or illegal)	None indicated
Providers perceived as unknowledgeable about the cultural values and behaviors that affect immigrants' willingness to seek care, the caregivers from whom they seek care, and the type of care they receive	Culturally/linguistically competent staff
Providers' lack of awareness and/or enforcement of federal and state laws requiring access to linguistically appropriate health care	Culturally/linguistically competent staff
Medical services for women have been closely associated with prenatal care; there appears to be less concern for he welfare of the women than that of their children or potential children	None indicated
Unstable housing and frequent relocation	Housing services
Lack of funding	Seek diverse funding sources
Lack of agencies' knowledge of services provided by other agencies	Public relations campaign

Data Sources: Ryan White Title I grant applications. Barriers and solutions are those identified in the grant applications.

TABLE B-9
TECHNICAL COMPETENCY: PHYSICIANS

Physician	Residency	Board Certification	Infectious Disease Fellowship and/or Specialization in HIV/AIDS
TCHC CONTRACTING PHYSICIANS			
1	Family Practice	Family Practice	
2	Unknown	Family Practice	
3	Internal Medicine	Pending	√
4	Unkown	Internal Medicine, Infectious Disease	√
5	Internal Medicine	Internal Medicine, Infectious Disease	√
6	Internal Medicine	Internal Medicine	√
7	Internal Medicine	Internal Medicine, Infectious Disease	√
8	Internal Medicine	Internal Medicine, Infectious Disease	√
9	Internal Medicine	Internal Medicine, Infectious Disease	√
10	Internal Medicine	Internal Medicine, Infectious Disease	√
11	Internal Medicine	Internal Medicine, Infectious Disease	√
PBC HEALTH DEPT.			
12	Internal Medicine	Internal Medicine, Cardiovascular Disease	√
13	Internal Medicine, Preventive Medicine, Public Health	Preventive Medicine, Public Health	√
14	Family Medicine	Family Practice	√
15	General Medicine		
16	Family Practice	Nuclear Medicine Technology	√
17	Pediatrics	Pediatrics	√
18	Pediatrics, Preventive Medicine, Public Health		√
19	Internal Medicine		

Data Sources: CV's of contracting physicians, Treasure Coast Health Council, and staff physicians, Palm Beach County Health Dept., Ryan White Title I Grant Applications.
√ = Yes

TABLE B-10
TECHNICAL COMPETENCY:
PROGRAM ADMINISTRATORS AND CASE MANAGERS

Employee	Bachelor's Degree	Master's Degree	HIV/AIDS Training
CAP			
1	√		√
2	√	√	√
3	√	√	√
4	√	√	√
5	√	√	√
6			√
7	√	√	√
8	√	√	√
9	√		√
10	√	√	√
11	√		√
12	√	√	√
13	√		√
14	√		√
15	√		
16			√
17	√	√	√
18	√		
19	√	√	√
20	√		√
21	√		√
22	√		√
23	√		√
24	√		√
25	√		√
26	√		
27			√
28			√
29			√
30			√
31	√		√
32	√		√
33	√		√
34	√		√
35	√	√	√
36			√
37	√		√
38	√		√
39	√		
40	√		
41	√		√
PBALF			
42	√	√	√
43			√

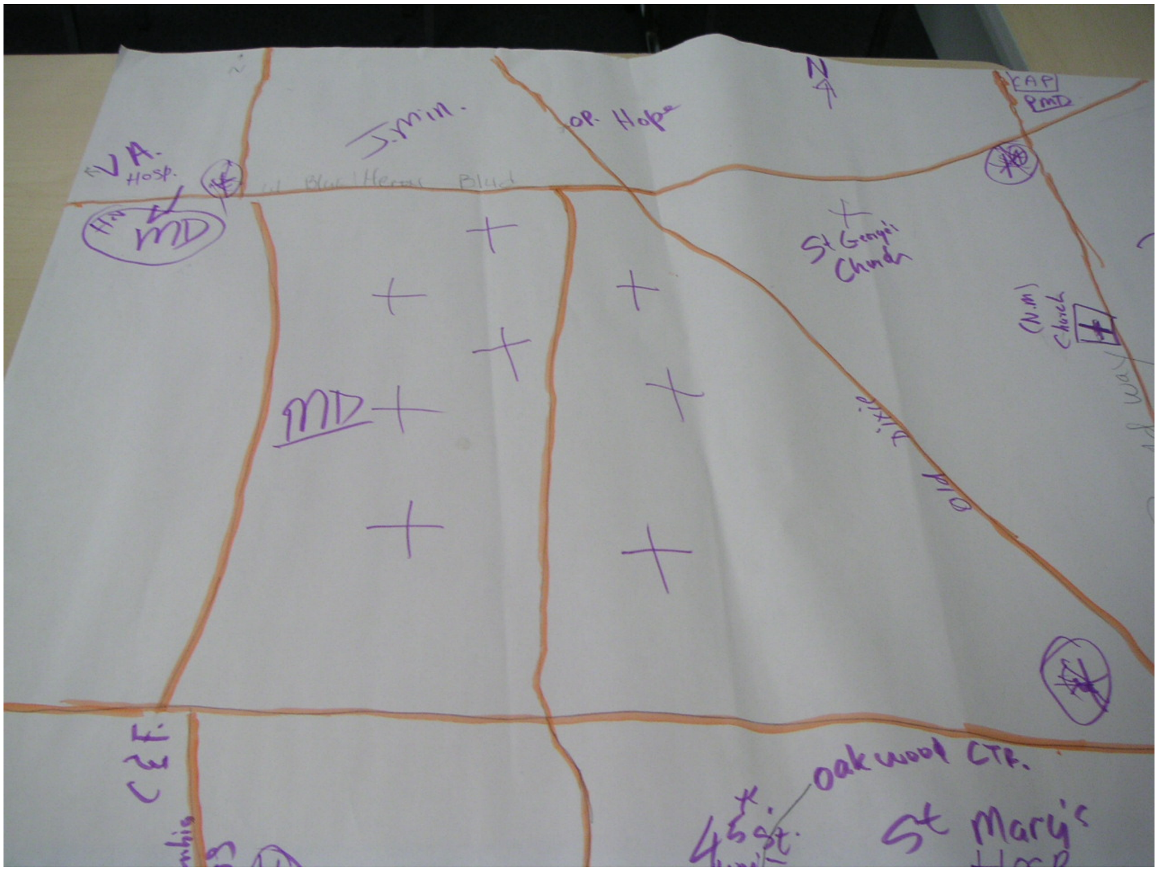
--continued--

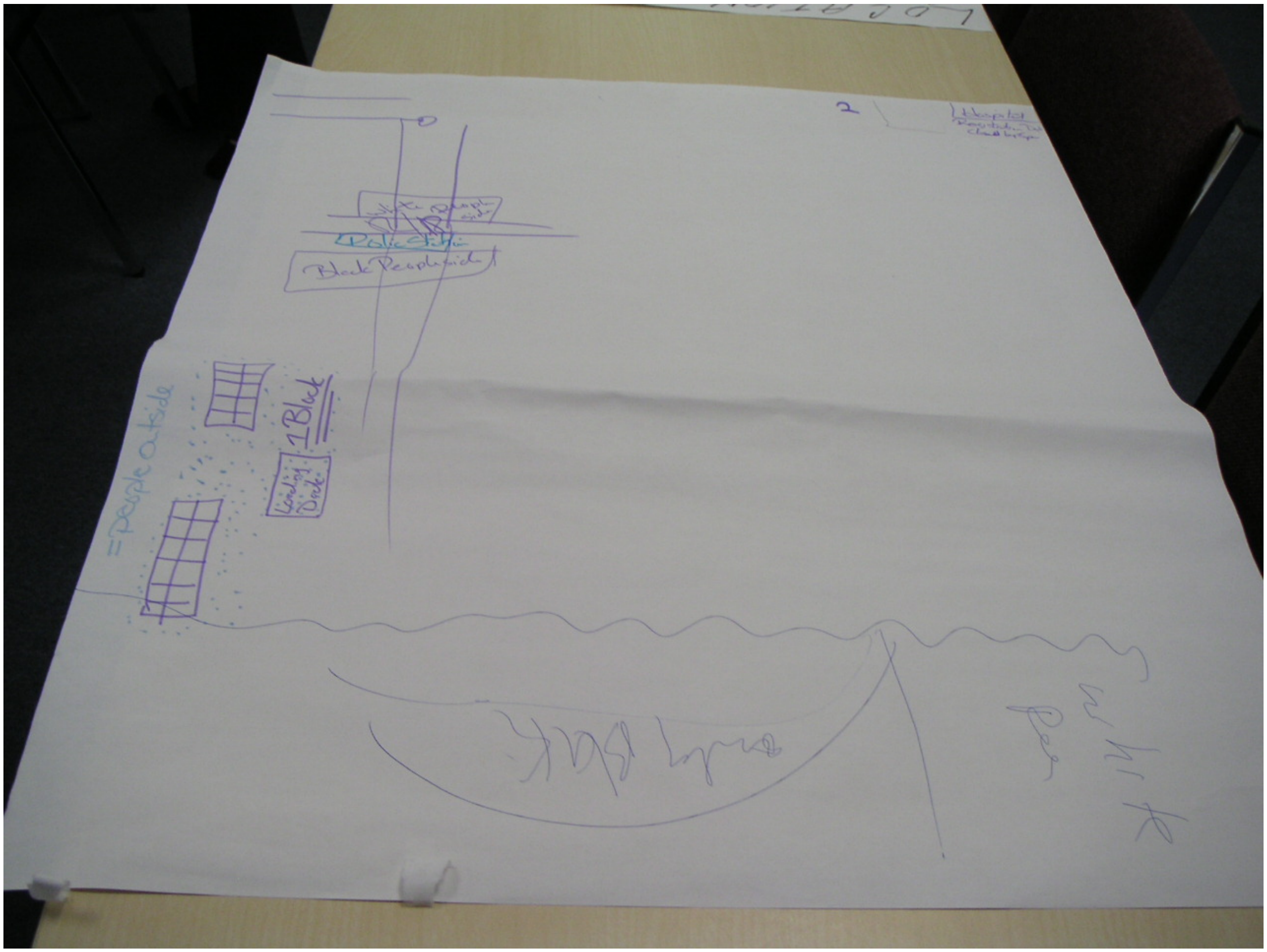
Name	Bachelor's Degree	Master's Degree	HIV/AIDS Training
HAITIAN CENTER			
44	√	√	√
45	√	√	
46	√	√	
47	√	√	
48	√		
HOPE HOUSE			
50	√		√
51	√		
52	√		
GRATITUDE HOUSE			
53	√	√	
54	√	√	
CHILDREN'S PLACE			
55	√	√	
COMPASS			
56	√		√
57	√		
58	√		
59	√		√
60			

Data Sources: Staff résumés in Ryan White Title I grant applications: Comprehensive AIDS Program (CAP), Palm Beach Assisted Living Facility (PBALF), Haitian Center for Family Services, Hope House, Gratitude Guild, Children's Place, Compass.
√ = Yes

APPENDIX C
GEOMAPS

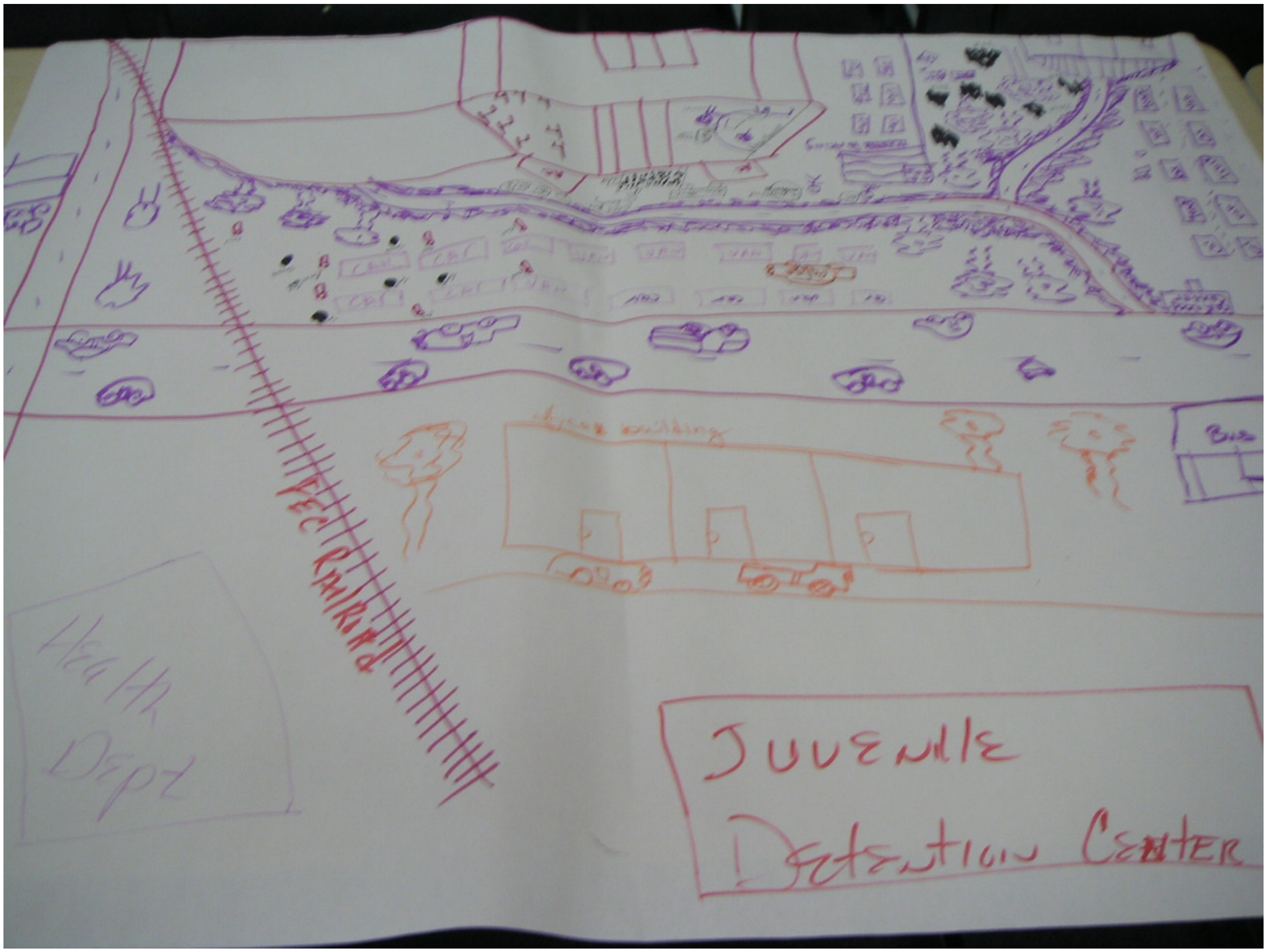
Geo Map of Riviera Beach



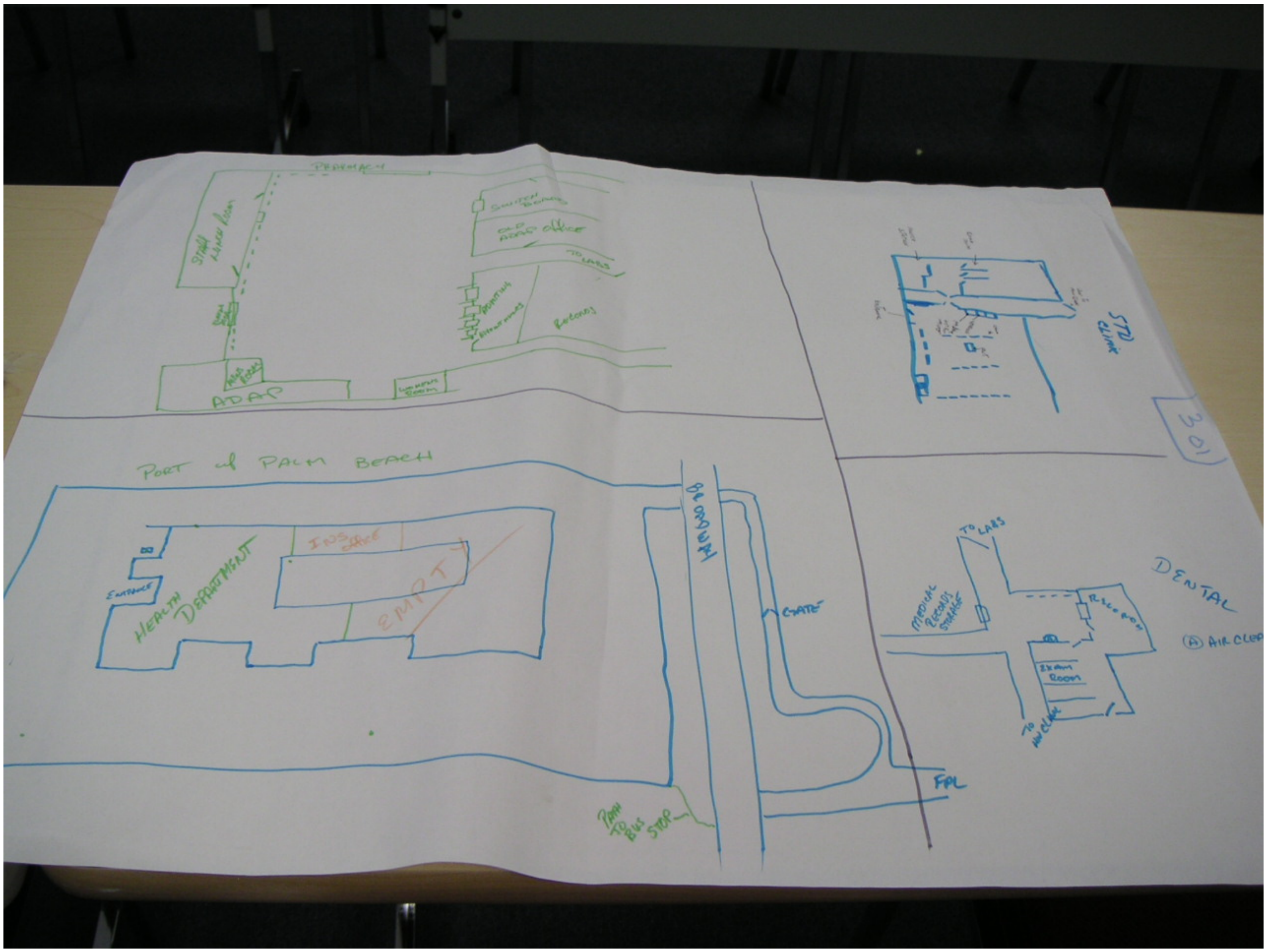

White People side
Police Station
Black People side
= People outside
1 Block
Loading Dock

Belle Glade Hot Spots

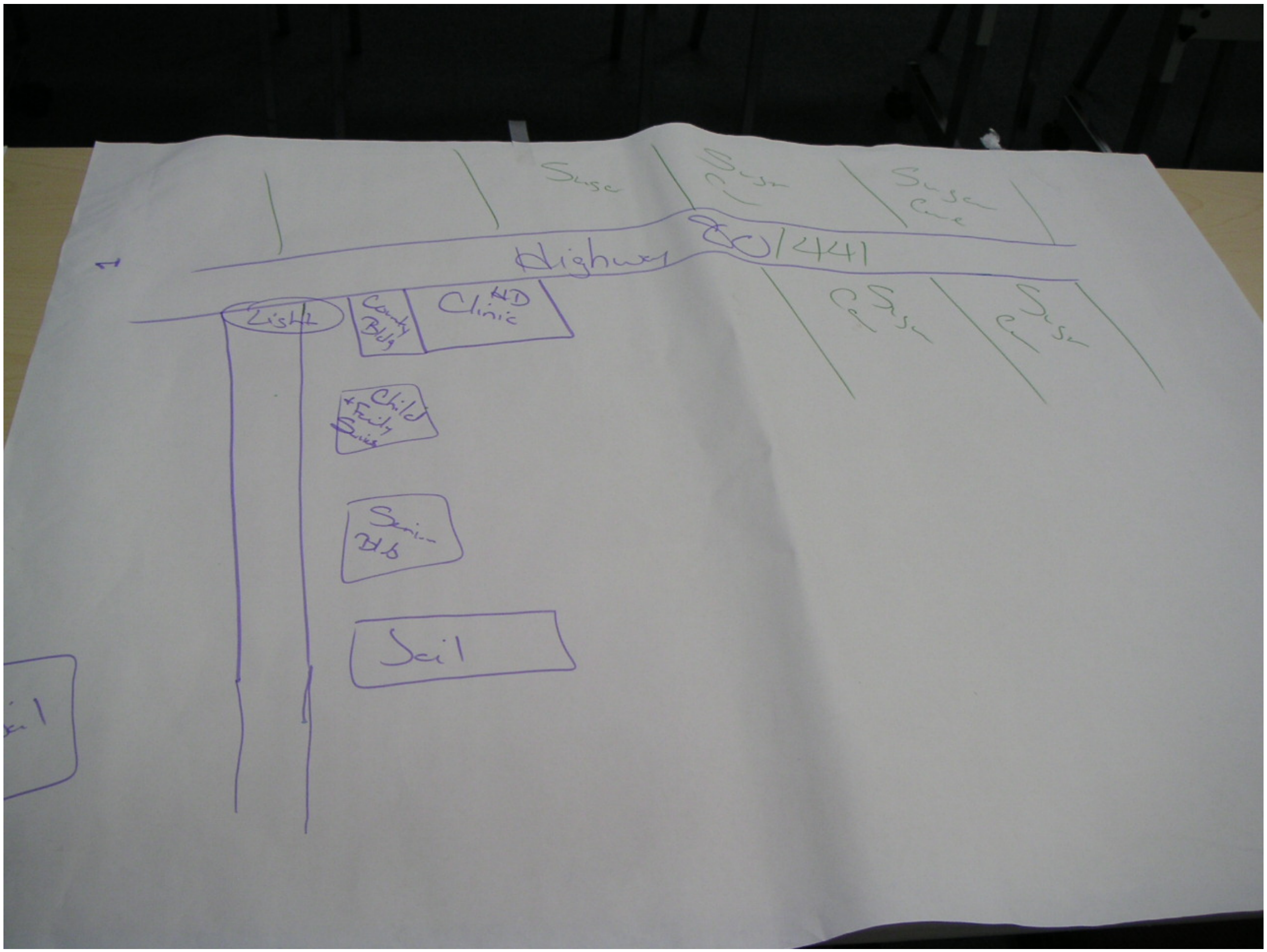
West Palm Beach, 45th Street Health Department Clinic and Vicinity



Riviera Beach, 301 Broadway Health Department Clinic and Vicinity



Belle Glade CL Brumback Health Center and Vicinity



APPENDIX D

RESPONSE FREQUENCIES: SYSTEMS ASSESSMENT PROVIDERS, WOMEN IN CARE, AND FOCUS GROUPS

Note: Frequencies are number of responses (not number of respondents). Respondents often had multiple responses; in some cases respondents had no response.

Demographics of Respondents

	PROV-IDERS		WOMEN IN CARE		FOCUS GROUPS	
AGENCY	n	%	n	%	n	%
Comprehensive AIDS Program	25	28			6	25
Health Department	14	16				
Dept. of Community Services	14	16				
Treasure Coast Health Council	13	15			6	25
Planning Council	7	8				
County Commission	6	7				
Legal Aid	1	1				
Haitian Community Center	1	1				
CMS	1	1				
Housing Partnership	1	1				
Haitian Center for Family Services	1	1				
Bethesda Memorial Hospital	1	1				
Gratitude House			6	100	6	25
Sistah to Sistah					6	25
TOTAL	89	100	6	100	24	100

	PROV-IDERS		WOMEN IN CARE		FOCUS GROUPS	
JOB DESCRIPTION	n	%	n	%	n	%
Case Manager/CM Supervisor/CM Assistant	18	24			6	25
Director/Administrator	9	12				
Planning Committee Member	7	9			6	25
Physician	6	8				
Membership Coordinator/Council Coordinator/Council Staff	5	7				
Contract Administrator	4	5				
County Commissioner	4	5				
Program Monitor	3	4				
Financial Analyst/Fiscal Specialist	3	4				
HIV Testing/Outreach/Counseling	3	4				
Dental Hygienist/Assistant	2	3				
Grantee	2	3				
Planner/Researcher	2	3				
Nurse	2	3				
Administrative Clerk	2	3				
Dentist	1	1				
ADAP	1	1				
Substance abuse residential client			6	100	12	50
TOTAL	74	100	6	100	24	100

	PROV-IDERS		WOMEN IN CARE	
EDUCATION	n	%	n	%
High School	8	11	3	50
Trade School	12	16	2	33
College	25	34	1	17
Graduate School	29	39		
TOTAL	74	100	6	100

Provide 5 reasons why women of color who are HIV positive are not in care.

	PROV-IDERS		WOMEN IN CARE		FOCUS GROUPS	
RESPONSE	n	%	n	%	n	%
Don't want others to know/embarrassment/stigma/shame	46	13	3	16	18	17
Lack of knowledge/information/education/awareness/don't know where to go/don't understand system, how to get care	39	11	1	5	5	5
Denial/Fear	32	9	5	26	13	12
Take care of children first/other priorities – housing, food, child care, husband's needs	27	8			5	5
Lack of transportation	25	7			3	3
No health insurance	23	6			5	5
Use of alternative therapies/folk practices/faith healing/believes illness caused by demons/spell/voudou/punishment from God for sins/Health care not part of culture, never used health care before	19	5			4	4
Poverty/lack of money	19	5			2	2
Substance abuse: don't want to quit, out of touch with reality	15	4	4	21	14	13
Culture/cultural bias/racism/condescension	10	3	2	11		
No time to wait for services/hassle/red tape	10	3			2	2
Mistrust of system/government	9	3				
Husband/boyfriend does not allow her to get care/intimidation/fear of domestic abuse/fear of being left by husband/boyfriend	9	3				
Don't consider self sick/no symptoms	8	2			2	2
Not enough access points/lack of choice in health care	8	2				
Low self-esteem/feel don't deserve care/guilt/hopelessness	8	2	3	16	5	5
Not important to them/just don't care	7	2	1	5	4	4
Language barrier	6	2			1	1
Mental issues	5	1				
Medication side effects	5	1				
Work	4	1				
Immigration status	3	<1				
Prostitution	2	<1				
Instability/homelessness	2	<1				
Too sick/disability	2	<1				
Don't want to know their man is sleeping around	2	<1				
Angry at who gave it to them	1	<1				
Don't want to change lifestyle	1	<1				
Fear of losing children	1	<1				
Think they are only a "carrier"	1	<1			2	2
Believes if her baby seroconverts, she is not HIV+	1	<1				
Newly diagnosed: don't need meds	1	<1				
Hours of service inconvenient	1	<1				
Incarceration	1	<1			1	1
No phone	1	<1				
Regimen too difficult					5	5
Poor relationship with doctor					3	3
Staff attitudes					1	1
Family member died in care					1	1
Change of doctors					1	1
TOTAL	354	100	19	100	108	100

Provide 5 reasons why women of color who are HIV positive dropped out of care.

	PROV-IDERS		WOMEN IN CARE	
RESPONSE	n	%	n	%
Bad experience when received care/distrust/providers don't resemble them	37	11		
Lack of transportation	30	9		
Long wait at clinic/Can't take time off work	25	8		
Fear others finding out/saw people they knew at clinic/shame	24	7	4	21
Children's and other needs come first (e.g., housing, food)	22	7		
Don't care/lack of motivation/hopelessness/depression/low self-esteem/don't take responsibility to follow through	21	6	2	11
Don't feel bad/feel better/virus nondetectable	18	5		
Substance abuse/relapse	15	5	3	16
Process too complex/too many appointments required/frustration	13	4	1	5
Treatment makes them sick	13	4		
Poverty/don't want medical bills	13	4		
Medication regimen too complex	12	4	1	5
Don't qualify for state programs/denied services/difficulty getting appointment/long process to qualify/lack of access to community resources	11	3		
Lack of/loss of insurance	10	3		
Lack of education/information	9	3		
Religion/rituals/faith healing/alternative treatments	8	2		
Feel treatment is not helping	6	2		
Denial/Fear	6	2	5	26
No support	5	2		
Lack of stability/housing issues/homelessness	5	2		
No child care	4	1		
Low self-esteem	3	<1		
Mental issues	3	<1		
Domestic violence	2	<1		
Pushed into care before ready	2	<1		
Go out of state/migrant farmworkers follow work	2	<1		
Relationships/new sex partners	2	<1		
Sick and tired/hopeless	2	<1		
Prostitution	2	<1		
Clinic located next to sheriff's office/immigration office	1	<1		
Don't want to change lifestyle	1	<1	1	5
Poor case management	1	<1		
Incarcerated	1	<1		
Language barrier	1	<1		
Change providers	1	<1		
Racial/ethnic			2	11
TOTAL	331	100	19	100

What services help patients to maintain their health care? How do these services help them maintain their health care?

	PROV-IDERS		WOMEN IN CARE	
RESPONSE	n	%	n	%
Transportation	52	20	1	17
Case Management, Service Coordination, Follow-Up	46	17	1	17
Housing	31	12	1	17
Insurance	19	7		
Medical Care	18	7	2	33
Food/Nutrition	17	6		
Health Education/Prevention	15	6		
Mental Health Treatment	11	4		
Social Support/Buddy Companion/Support Group	9	3		
Better Clinic Locations	7	3		
Child Care	6	2		
Medications/ADAP	6	2	1	17
Financial Assistance	5	2		
Communication/Friendly Staff/Respect/Cultural Competence	4	2		
Dental Care	3	1		
Substance Abuse Treatment	3	1		
Better Clinic Hours	2	<1		
Exercise	2	<1		
Translation Services	2	<1		
Job Skills/Employment	2	<1		
Confidentiality	1	<1		
Legal Assistance	1	<1		
Care in One Place	1			
Accessible Care	1			
TOTAL	264	100	6	100

How long do patients have to wait to see the doctor?

Waiting time for appointment:

	PROV-IDERS	
RESPONSE	n	%
Don’t know/it depends	17	40
3-4 weeks	13	30
1-2 weeks	9	21
3-6 weeks	2	5
6-8 weeks	2	5
TOTAL	43	100

Waiting time in waiting room:

	PROV-IDERS		WOMEN IN CARE	
RESPONSE	n	%	n	%
Don't know/it depends	17	35		
10-15 minutes			1	25
15-30 minutes	1	2		
30-60 minutes	1	2		
1-2 hours	12	25		
2-3 hours	5	10		
4-5 hours	2	4		
All day	5	10		
Timely/reasonable			2	50
Too long			1	25
TOTAL	48	100	4	100

What happens when they have to wait too long to see the doctor? What do they do? How do you think patients feel after they've been told they'll have a long wait?

	PROV-IDERS		WOMEN IN CARE	
RESPONSE	n	%	n	%
Get frustrated, impatient, angry, feel unimportant, discouraged, powerless	68	38	4	44
Leave	46	26	3	33
Sit there, understand	19	11	2	22
Don't make another appointment, give up, go without meds	19	11		
Complain	9	5		
Make new appointment	6	3		
Switch doctors	3	2		
Fear being seen by someone they know	3	2		
Talk to case manager or nurse to expedite, ask where else they can go	2	1		
Fear losing job	2	1		
Afraid of getting sicker	1	<1		
Beg for money for food	1	<1		
Don't know	1	<1		
TOTAL	180	100	9	100

When patients first get into health care for HIV/AIDS, are they referred to other services?

	PROV-IDERS		WOMEN IN CARE	
RESPONSE	n	%	n	%
Yes	43	58	6	100
Sometimes	13	18		
Don't know, they should, hope so, believe so	12	16		
No, probably not	6	8		
TOTAL	74	100	6	100

What services?

	PROV-IDERS		WOMEN IN CARE	
RESPONSE	n	%	n	%
Case management, social services, insurance	34	23	6	100
Mental health counseling, therapy	16	11		
Specialty care	15	10		
Food, nutrition	14	10		
Housing	12	8		
Lab	9	6		
Dental	9	6		
Substance abuse treatment	9	6		
Primary care	7	5		
Pharmacy, meds, ADAP	6	4		
X rays	4	3		
Legal services	3	2		
Transportation	3	2		
Translation services, ESOL	2	1		
GED classes	1	<1		
HIV education	1	<1		
TOTAL	145	100	6	100

Do they go?

	PROV-IDERS		WOMEN IN CARE	
RESPONSE	n	%	n	%
Some	25	44		
Yes	12	21	4	80
No	11	19	1	20
Most	5	9		
Don't know	4	7		
TOTAL	57	100	5	100

If not, explain why you think they don't go.

	PROV-IDERS		WOMEN IN CARE	
RESPONSE	n	%	n	%
Too much effort, hassle, long wait	12	27		
No transportation	5	11		
No follow up from case manager or nurse	5	11		
Uncomfortable, mistrust	4	9		
Stigma, lack of confidentiality	4	9		
Too sick	3	7		
Fear, denial, depression	3	7	1	50
Don't know what to do, don't see importance	2	5	1	50
No child care	2	5		
Don't care	2	5		
No phone	1	2		
TOTAL	44	100	2	100

If patients go to services, explain how satisfied you think they are, or not satisfied.

	PROV-IDERS		WOMEN IN CARE	
RESPONSE	n	%	n	%
Some satisfied, it depends	18	29	2	50
Satisfied	15	24	1	25
Most are satisfied	14	22	1	25
Most not satisfied	11	17		
Don't know	5	8		
TOTAL	63	100	4	100

When patients feel sick, what do they do?

	PROV-IDERS		WOMEN IN CARE	
RESPONSE	n	%	n	%
Go to emergency room	40	33	1	17
Stay in bed, keep working, self remedy, use folk remedies	29	24		
Go to walk in clinic, doctor	19	16	4	67
Call doctor	16	13		
Call case manager	8	7		
Don't know	4	3		
Abuse drugs, get high, overdose on meds	2	2		
Stop taking meds	1	<1		
Call church	1	<1		
Call 911	1	<1		
Go into denial			1	17
TOTAL	121	100	6	100

Describe the last time you provided care to a patient/the last time you observed care being provided to a patient.

	PROV-IDERS	
RESPONSE	n	%
Care was both good and poor/neutral	15	44
Care was good	13	38
Care was poor	6	18
TOTAL	34	100

Has anyone ever come up to you to talk to you about HIV/AIDS health care issues at this health care provider?

	PROV-IDERS		WOMEN IN CARE	
RESPONSE	n	%	n	%
Yes	58	85	5	83
No	10	15	1	17
TOTAL	68	100	6	100

What did they talk to you about? Describe in detail.

	PROV-IDERS		WOMEN IN CARE	
RESPONSE	n	%	n	%
Medications, symptoms, side effects, how to get meds, translate/interpret what doctor said	23	30	1	20
Help with food, housing, family problems, money, how to access services	13	17		
Problem not getting a service, insurance problem, concern about health worker	9	12		
How long will I live?	8	11		
Information on HIV transmission/education/prevention	5	7	4	80
Information about sex	5	7		
HIV testing, where to get tested, have you been tested	3	4		
What will happen to my kids when I die?	3	4		
Confidentiality concerns	2	3		
Happy with their doctor	1	1		
Disclose status	1	1		
Contract work	1	1		
Fear	1	1		
Can I have a child?	1	1		
TOTAL	76	100	5	100

Did you like the way they talked to you? Describe.

	PROV-IDERS		WOMEN IN CARE	
RESPONSE	n	%	n	%
Yes	35	73	5	100
Other	10	21		
No	3	6		
TOTAL	48	100	5	100

Describe what you know about HIV/AIDS.

	PROV-IDERS		WOMEN IN CARE	
RESPONSE	n	%	n	%
Transmission modes, it is preventable	33	31	2	22
Virus that affects immune system, symptoms, it kills you, no cure	32	30	1	11
Treatment, prevention, meds, side effects, can live long time with treatment	25	23	6	66
Broad knowledge	9	8		
High concentration in this area, blacks disproportionately affected	5	5		
Stigma, shame, fear, social effects	2	2		
Funding	1	<1		
Cultural sensitivity	1	<1		
TOTAL	108	100	9	100

What would you like to know about HIV/AIDS?

	PROV-IDERS		WOMEN IN CARE	
RESPONSE	n	%	n	%
When there will be a cure	21	36		
New research, new products and tests, new meds, research on why people are differentially affected and on effective programs	12	20	2	50
Information about meds, side effects, interactions	7	12		
Vaccine information	4	7	1	25
Origin of virus	3	5	1	25
Nothing	2	3		
How long virus takes to show up in system	2	3		
More funding, more providers	2	3		
Information on different strains of virus	2	3		
When will stigma be gone?	2	3		
Information on mental effects	1	2		
How to change cultures	1	2		
TOTAL	59	100	4	100

What is your understanding of case management?

	PROV-IDERS		WOMEN IN CARE	
RESPONSE	n	%	n	%
Provides comprehensive needs assessment and access to needed services	70	100	6	100
TOTAL	70	100	6	100

Have your patients/you seen a case manager?

	PROV-IDERS		WOMEN IN CARE	
RESPONSE	n	%	n	%
Yes	43	96	5	100
No	1	2		
Don’t know	1	2		
TOTAL	45	100	5	100

Describe what happened. What services did they/you get from the case manager?

	PROV-IDERS		WOMEN IN CARE	
RESPONSE	n	%	n	%
Assistance that met their needs, referrals, information	38	27	5	33
Help with housing	19	13	2	13
Help getting food	17	12	4	27
Medical referral	12	9	2	13
Help with transportation	11	8	1	7
Pharmacy, obtain meds	6	4		
Help with insurance	5	4		
Help with bills	4	3		
Support	4	3		
Mental health/substance abuse treatment referral	4	3	1	7
Intake, assessment	3	2		
Fill out paperwork	2	1		
Help getting clothing	2	1		
Legal services	2	1		
Don’t know	2	1		
AIDS education	1	<1		
Help with employment	1	<1		
Help getting eyeglasses	1	<1		
Grief/loss training	1	<1		
Follow-up, aftercare	1	<1		
Explain meds	1	<1		
Accompany to services	1	<1		
Dental care	1	<1		
Translation	1	<1		
Help with immigration	1	<1		
TOTAL	141	100	15	100

What would you like to see a case manager do? Explain.

	PROV-IDERS		WOMEN IN CARE	
RESPONSE	n	%	n	%
Work more closely with clients, follow up, have fewer clients, less paperwork	23	32	1	25
Provide access to comprehensive services	13	18	1	25
Assist with adherence to treatment and meds	7	10		
Promote client independence, empowerment	5	7		
Be empathetic, caring, humble	5	7		
Help client set goals, lead healthy life	5	7		
Keep doing what they do	3	4	1	25
Get training	2	3		
Identify barriers to care, assemble stats and data	2	3		
Prevention	1	1		
Help all who need help, not just those who want it	1	1		
Reach people earlier in disease progression	1	1		
Have more authority and choice in decision-making	1	1		
Explain system	1	1		
Don’t know	1	1		
Help with insurance			1	25
TOTAL	71	100	4	100

What do patients need to maintain their health care? Explain.

	PROV-IDERS		WOMEN IN CARE	
RESPONSE	N	%	n	%
Transportation	8	14	1	13
Housing	7	12	1	13
Food/Nutrition	6	10		
Medical care, keep appointments	6	10	4	50
Medications	6	10		
Case management	6	10	1	13
Desire to live/self-worth	4	7		
Social support	3	5		
Insurance	3	5	1	13
Money	2	3		
Compliance	2	3		
Stop drug use	1	2		
Mental health counseling	1	2		
Patience	1	2		
Don't know	1	2		
Education	1	2		
TOTAL	58	100	8	100

Which health services are too full or hard for patients to get?

	PROV-IDERS		WOMEN IN CARE	
RESPONSE	n	%	n	%
Specialty medical	22	15		
Meds/ADAP	16	11	2	22
Insurance	15	10	1	11
Housing	13	9	1	11
Dental	13	9		
Case management	10	7	1	11
Primary medical	9	6		
Mental health/substance abuse treatment	5	3		
Food/nutrition/food stamps	5	3	1	11
Don't know	5	3	1	11
Massage	4	3		
ER/inpatient treatment	3	2		
Social Security benefits	3	2		
None	3	2	1	11
All of them	2	1		
Home health care	2	1		
Transportation	2	1		
HIV Education	2	1		
Utility assistance	2	1		
Lab	2	1		
Day care	1	<1		
Financial aid	1	<1		
Ryan White	1	<1		
Acupuncture	1	<1		
Support groups			1	11
TOTAL	143	100	9	100

Of all the services offered at this health care provider, which is the most annoying, painful, inconvenient, and/or disappointing for patients? Explain in-depth.

	PROV- IDERS		WOMEN IN CARE		FOCUS GROUPS	
RESPONSE	n	%	n	%	n	%
Waiting	16	16			5	17
Medications/ADAP	10	10	1	17		
Red tape, paperwork, ineligibility for services	9	9	2	34	4	14
OB-GYN	8	8			1	3
Labs	6	6			2	7
Stigma, being seen by others	6	6			1	3
Don’t know	6	6				
Dental	5	5				
Primary care	4	4				
Insurance	3	3				
Invasive procedures	3	3				
Referrals	2	2	1	17		
Transportation	2	2			2	7
Social Services	2	2				
Nutritionist	2	2				
All of them	1	1				
HIV education	1	1				
Utility assistance	1	1				
Lack of money	1	1				
Staff attitudes	1	1			7	24
Social Security	1	1				
Medication side effects	1					
None			2	34		
Poor communication from provider					5	17
Medication side effects					2	17
TOTAL	97	100	6	100	29	100

Of all the services offered at your health care provider, which are the best for patients? Explain.

	PROV-IDERS		WOMEN IN CARE	
RESPONSE	n	%	n	%
Primary medical	17	22	2	25
Case management	14	18	3	36
All of them	7	9		
Dental	6	8		
Medications/ADAP	5	6		
Lab	4	5		
Insurance	4	5		
Don't know	3	4		
Prevention/education	2	3	1	13
Food	2	3		
Hopefulness/acceptance	2	3		
WIC	1	1		
Pediatric care	1	1		
Transportation	1	1		
Mental health treatment	1	1		
Specialty medical	1	1		
Legal	1	1		
Financial	1	1		
Housing	1	1	1	13
Hospice	1	1		
Social atmosphere in waiting room	1	1		
Multidisciplinary clinic	1	1		
TOTAL	77	100	8	100

When patients go to this health care provider, do they get all of the services they need? Describe them.

	PROV-IDERS		WOMEN IN CARE	
RESPONSE	n	%	n	%
Yes	19	26	5	83
No	25	35	1	17
Sometimes/it depends	23	32		
Don't know	5	7		
TOTAL	72	100	6	100

How long does it take patients to get a referral?

	PROV-IDERS		WOMEN IN CARE	
RESPONSE	n	%	n	%
Right away/same day	16	26	1	17
Quickly/a while			2	34
2-4 days	4	6	2	34
1-2 weeks	15	24		
1-3 months	7	11		
It depends	10	16		
Forever			1	17
Don't know	10	16		
TOTAL	62	100	6	100

How long does it take from the referral date to the date the referred service is obtained?

	PROV-IDERS		WOMEN IN CARE	
RESPONSE	n	%	n	%
Right away/next day	3	10		
3-4 days			3	60
1-2 weeks	6	20		
1 month or more	5	17		
It depends	9	30		
Never			1	20
Too long			1	20
Don't know	7	23		
TOTAL	30	100	5	100

Talk about the referral process. If patients have to see a specialist, do they get a referral? Is this an easy/difficult process? Describe it.

	PROV-IDERS		WOMEN IN CARE	
RESPONSE	n	%	n	%
Easy	9	12	4	80
Difficult	10	22	1	20
Both/neither/it depends	24	53		
Don't know	2	4		
TOTAL	45	100	5	100

How easy or difficult is it to go from service to service?

	PROV-IDERS		WOMEN IN CARE	
RESPONSE	n	%	n	%
Easy	25	42	4	66
Difficult	22	37	2	34
Both/neither/it depends	16	27		
Don't know	3	5		
TOTAL	59	100	6	100

Describe how patients get from one service to another service.

	PROV-IDERS		WOMEN IN CARE	
RESPONSE	n	%	n	%
Bus	21	25	4	66
Case manager's help	15	18		
Cab	12	14	1	17
Get ride from friend or family	9	11		
Own car	9	11	1	17
Walk	5	6		
Agency van	5	6		
It's hard/it depends	5	6		
Don't know	3	4		
TOTAL	84	100	6	100

In your opinion, do agencies know and believe in the services they provide and do they have confidence in the services other agencies provide? Talk about your opinion.

	PROV-IDERS		WOMEN IN CARE	
RESPONSE	n	%	n	%
Yes	44	69	3	60
No	7	11		
Sometimes	10	16	2	40
Don't know	3	5		
TOTAL	64	100	5	100

Talk about the barriers blocking disabled clients from getting to services.

	PROV-IDERS		WOMEN IN CARE		FOCUS GROUPS	
RESPONSE	n	%	n	%	n	%
Transportation	26	37	3	60	4	25
Lack of wheelchair access	10	14				
None/there are services available	8	11	1	20	1	6
Language/Sign language	5	7			1	6
Stigma	4	6			3	19
Don't know	4	6				
Too many appointments/red tape	3	4				
No family or support	2	3				
Lack of money	2	3				
Lack of services	1	2	1	20	1	6
No phone	1	2				
Medical	1	2			1	6
Lack of knowledge about services	1	2				
Lack of equipment	1	2				
Lack of insurance	1	2				
Multiple diagnoses, hard to find placement					2	13
Wait for services					2	13
Lack of child care					1	6
TOTAL	70	100	5	100	16	100

Describe the services for people who do not speak English.

	PROV-IDERS		WOMEN IN CARE	
RESPONSE	n	%	n	%
Translators/interpreters available	32	48	2	67
It's hard to get services/Not enough translators/interpreters	28	42		
Don't know	6	9	1	33
TOTAL	66	100	3	100

Describe the services provided for people who do not read English.

	PROV-IDERS		WOMEN IN CARE	
RESPONSE	n	%	n	%
Translators/interpreters available/someone reads to them	24	39		
It's difficult/other	22	36		
Don't know	7	11	2	67
None	4	7		
Agency has written materials in Spanish and/or Creole	4	7	1	33
TOTAL	61	100	3	100

Do you think the staff at this health care provider is properly trained to answer patients' questions?

	PROVIDERS		WOMEN IN CARE	
RESPONSE	n	%	n	%
Yes	33	48	6	100
No	13	19		
Sometimes/maybe	16	23		
Don't know	7	10		
TOTAL	69	100	6	100

What are the problems that people have getting to services?

	PROVIDERS		WOMEN IN CARE		FOCUS GROUPS	
RESPONSE	n	%	n	%	n	%
Transportation	11	46	2	67	2	100
Lack of confidentiality	3	13				
Child care	2	8				
Agency hours	2	8				
Have other priorities	2	8				
If they're too sick, they can't get up	1	4				
Lack of education	1	4				
None	1	4				
Don't know	1	4				
No phone			1	33		
TOTAL	24	100	3	100	2	100

Are business hours convenient?

	PROVIDERS		WOMEN IN CARE		FOCUS GROUPS	
RESPONSE	n	%	n	%	n	%
Yes	19	39	2	67	4	36
No	27	55	1	33	1	9
Other	2	4			6	55
Don't know	1	2				
TOTAL	49	100	3	100	11	100

Is the location convenient?

	PROVIDERS		WOMEN IN CARE		FOCUS GROUPS	
RESPONSE	n	%	n	%	n	%
Yes	23	51	2	67	5	56
No	16	36			2	22
Sometimes/other	5	11	1	33	2	22
Don't know	1	2				
TOTAL	45	100	3	100	9	100

Is confidentiality protected?

	PROV-IDERS		WOMEN IN CARE		FOCUS GROUPS	
RESPONSE	n	%	n	%	n	%
Yes	22	49	3	75	1	
No	14	31			9	
Sometimes/maybe	7	16	1	25	4	
Don't know	2	4				
TOTAL	45	100	4	100	14	100

Is health care provided in a safe and secure area?

	PROV-IDERS		WOMEN IN CARE		FOCUS GROUPS	
RESPONSE	n	%	n	%	n	%
Yes	25	53	2	67		
No	13	28			1	100
Sometimes/maybe	7	15	1	33		
Don't know	2	4				
TOTAL	47	100	3	100	1	100

How are patients being treated by staff at this health care provider?

	PROV-IDERS		WOMEN IN CARE		FOCUS GROUPS	
RESPONSE	n	%	n	%	n	%
Well	25	47	5	100	5	38
Okay/mediocre	4	8				
It depends	11	21			7	54
Badly	10	19			1	8
Don't know	3	6				
TOTAL	53	100	5	100	13	100

Is there a doctor here who specializes in HIV/AIDS?

	PROV-IDERS		WOMEN IN CARE	
RESPONSE	n	%	n	%
Yes	58	83	5	100
No	3	4		
Don't know	9	13		
TOTAL	70	100	5	100

Talk about this doctor.

	PROV-IDERS		WOMEN IN CARE	
RESPONSE	n	%	n	%
Good/well trained	27	84	5	100
Not good/not well trained	3	9		
Other	2	6		
TOTAL	32	100	5	100

What kinds of doctors are patients seeing? Describe.

	PROV-IDERS		WOMEN IN CARE	
RESPONSE	n	%	n	%
Primary care/internal medicine	12	17		
Infectious disease doctor	9	13		
HIV/AIDS doctor	7	10	2	40
Dentist	6	9		
OB-GYN	5	7		
Eye doctor	4	6		
Specialist	3	4		
Cardiologist	3	4		
Psychiatrist	2	3		
Physcian’s assistant	2	3		
Neurologist	2	3		
Kidney doctor	2	3		
Foot doctor	2	3		
Ear, Nose, & Throat Doctor	2	3		
Oral surgeon	1	1		
Cancer doctor	1	1		
Caring, understanding	1	1		
People who do not resemble them	1	1		
Adequate	1	1		
None	1	1		
Foreign doctors without licenses	1	1		
Pediatrician	1	1		
Rheumatologist			1	20
Orthopedist			1	20
TOTAL	69	100	5	100

How are patients treated when in HIV/AIDS health care? Describe their treatment.

	PROV-IDERS		WOMEN IN CARE	
RESPONSE	n	%	n	%
Treated well	13	38	2	40
Okay/Fair/It depends	8	24	2	40
Treated badly	6	18		
Don’t know	4	12	1	20
Other	3	9		
TOTAL	34	100	5	100

Tell me the reason why Black women with HIV/AIDS are not in care.

	PROV-IDERS		WOMEN IN CARE	
RESPONSE	n	%	n	%
Shame/Stigma/Embarrassment	23	19	2	29
Poor treatment/mistrust of system/red tape/lack of access/wait	15	13		
Lack of knowledge	11	9		
Denial	9	7	2	29
Fear	9	7	1	14
Lack of insurance	9	7		
Lack of motivation/low self-esteem/lack of social skills	8	7	1	14
Other priorities	7	6		
Family issues/lack of family support	6	5		
Substance abuse	5	4	1	14
Culture/religion	5	4		
Don’t know status	3	2		
Male partner intimidation/domestic violence	3	2		
Guilt	2	2		
Lack of child care	2	2		
Lack of transportation	2	2		
No symptoms	1	<1		
Language barrier	1	<1		
Don’t know	1	<1		
Poverty	1	<1		
TOTAL	122	100	7	100

Why do patients drop out of care?

	PROV-IDERS		WOMEN IN CARE		FOCUS GROUPS	
RESPONSE	n	%	n	%	n	%
Poor treatment/mistrust/red tape/wait	33	35	1	20		
Shame/stigma	11	11	1	20	1	5
Lack of money/insurance	6	6			2	11
Lack of knowledge of disease	5	5				
Lack of transportation	5	5			1	5
Other priorities	5	5				
Substance abuse	4	4	1	20	2	11
No symptoms/low viral load	4	4			2	11
Low self-esteem	3	3				
Medication side effects/regimen too difficult	3	3			8	42
Denial	2	2				
Various reasons	2	2				
Mental issues	2	2				
Instability/homelessness	2	2				
Lack of family support	2	2				
Lack of child care	2	2				
Religion	2	2				
Intimidation	1	1				
Don’t know	1	1				
Change of case manager	1	1				
No outreach	1	1				
In new relationship	1	1				
Fear	1	1	1	20		
Get disability benefits					1	5
Poor relationship with provider					1	5
Don’t care					1	5
Make wrong choices					1	5
TOTAL	99	100	5	100	19	100

What would it take to get patients back in care?

	PROV-IDERS		WOMEN IN CARE		FOCUS GROUPS	
RESPONSE	n	%	n	%	n	%
Social support/case management	15	17			2	11
Education	14	16			4	21
Easier access/eligibility/shorter wait time	12	14	2	40		
Dedicated staff/friendly care/trust	8	9			3	16
Money	6	7			1	5
Prevention/outreach	4	5	1	20		
Food	4	5			1	5
Housing/stability	3	3				
Transportation	3	3			1	5
Don't know	2	2			2	11
Better clinic environment	2	2				
Child care	2	2			1	5
Insurance	2	2				
Illness	2	2				
Decrease medication burden	2	2				
Support groups	1	1				
Employment	1	1				
Drug treatment	1	1			3	16
Acceptance from community	1	1				
Go to private doctor for confidentiality	1	1				
Change in outlook			2	40		
TOTAL	86	100	5	100	19	100

Do patients know where to get HIV/AIDS care services?

	PROV-IDERS		WOMEN IN CARE	
RESPONSE	n	%	n	%
Yes	35	55	4	66
No	7	11	1	17
Sometimes/other	19	30	1	17
Don't know	3	5		
TOTAL	64	100	6	100

Where?

	PROV-IDERS		WOMEN IN CARE	
RESPONSE	n	%	n	%
Health Department/Clinic	36	53	3	43
Private doctor	19	28	2	29
Community based agencies	12	18	2	29
Friends not medically qualified	1	1		
TOTAL	68	100	7	100

Do patients ever access HIV/AIDS health care services again on the basis of the first experience they had?

	PROV-IDERS		WOMEN IN CARE	
RESPONSE	n	%	n	%
Yes	24	40	6	100
No	11	18		
Sometimes/it depends	19	32		
Don't know	6	10		
TOTAL	60	100	6	100

Describe your first experience giving/getting HIV health care.

	PROV-IDERS		WOMEN IN CARE	
RESPONSE	n	%	n	%
Good	8	47	1	20
Bad	4	24	2	40
Neutral/other	4	24	2	40
Don't know	1	6		
TOTAL	17	100	5	100

Tell me why people who are HIV+ are not in care.

	PROV-IDERS		WOMEN IN CARE	
RESPONSE	n	%	n	%
Shame/stigma	7	15	2	20
Lack of insurance	7	15	1	10
Lack of motivation	5	11	1	10
Denial	4	9	2	20
Red tape/wait/poor treatment experience	4	9		
Other priorities	4	9		
Lack of money	4	9		
Don't know status	3	7		
Don't know	2	4		
Lack of knowledge	2	4	2	20
Fear	1	2	1	10
No symptoms	1	2		
Lack of support	1	2		
Substance abuse	1	2		
Lack of transportation			1	10
TOTAL	46	100	10	100

Do you know of such people?

	PROV-IDERS		WOMEN IN CARE	
RESPONSE	n	%	n	%
Yes	32	68	4	66
No	15	32	2	34
TOTAL	47	100	6	100

Describe the way that your health care provider staff has treated patients.

	PROV-IDERS		WOMEN IN CARE	
RESPONSE	n	%	n	%
Well	19	49	6	100
Okay	3	8		
Poorly	10	26		
It depends	5	13		
Don't know	2	5		
TOTAL	39	100	6	100

Comment on whether or not people of other races, colors, nationalities are treated differently. Describe.

	PROV-IDERS		WOMEN IN CARE	
RESPONSE	n	%	n	%
Yes	26	55		
No	14	30	5	100
Sometimes	4	9		
Don't know	3	6		
TOTAL	47	100	5	100

Describe the feelings you get when you are at this health care provider.

	PROV-IDERS		WOMEN IN CARE	
RESPONSE	n	%	n	%
Good	10	25	4	80
Bad	27	68		
Other	3	8	1	20
TOTAL	40	100	5	100

Is the staff trained to meet patients' needs? Explain.

	PROV-IDERS		WOMEN IN CARE	
RESPONSE	n	%	n	%
Yes	24	60	5	83
No	6	15		
Some	8	20	1	17
Don't know	2	5		
TOTAL	40	100	6	100

Where do people go to get tested for HIV?

	PROV-IDERS		WOMEN IN CARE	
RESPONSE	n	%	n	%
Health Department/Clinic	52	42	5	55
Community based agencies	34	27	1	11
Private doctor	20	16	2	22
Church	5	4		
Hospital	4	3		
Don't know	4	3	1	11
Health fair	3	2		
Mobile testing bus	2	2		
Home test	1	<1		
TOTAL	125	100	9	100

Where do people go to get treated?

	PROV-IDERS		WOMEN IN CARE		FOCUS GROUPS	
RESPONSE	n	%	n	%	n	%
Health Department/Clinic	60	58	5	55	6	46
Private doctor	34	33	4	44	5	38
Emergency room/hospital	6	6			1	8
Home remedies/spiritual/church healing	2	2				
It depends	1	<1				
Community based agency	1	<1			1	8
TOTAL	104	100	9	100	13	100

Describe what people do to get help when they find out they are positive.

	PROV-IDERS		WOMEN IN CARE	
RESPONSE	n	%	n	%
Case management agency	17	24	1	20
Do nothing/denial	16	22	1	20
Family/friend support	11	15		
Health department	8	11	2	40
Doctor	7	10		
Counseling	4	6		
Education	4	6		
Minister	2	3		
Support groups	1	1		
Department of Children and Families	1	1		
Don’t know	1	1		
Get high			1	20
TOTAL	72	100	5	100

Describe how patients feel about being HIV positive.

	PROV-IDERS		WOMEN IN CARE	
RESPONSE	n	%	n	%
Devastated/helpless/hopeless/terrible/upset	27	23		
Ashamed/stigmatized	18	15	4	50
Depressed/sad	16	13		
Scared	10	8	2	25
Shocked/confused/overwhelmed	10	8		
Angry	8	7		
No reaction/denial	8	7	2	25
Don’t know	5	4		
Anxious	4	3		
Many emotions	4	3		
Relieved/happy	2	2		
Disappointed	2	2		
Hurt	2	2		
Alone	2	2		
Guilty	1	<1		
TOTAL	119	100	8	100

What do you think people think of patients being HIV+?

	PROV-IDERS		WOMEN IN CARE	
RESPONSE	n	%	n	%
Dirty/contagious/shun them	28	32	1	20
Condemn them/they deserve it	22	25		
Scared	10	12	4	80
Some are supportive/educated/compassionate	8	11		
Mixed emotions/varies	4	5		
They're stupid for not protecting themselves	3	3		
Don't think about them/don't care	3	3		
Sad	3	3		
Don't know	2	2		
Poor/uneducated	1	1		
Confused	1	1		
They're black, unimportant	1	1		
Disgusted	1	1		
Others don't know	1	1		
TOTAL	88	100	5	100

Do patients' fears of what people think of their HIV+ status affect/influence them in their attempts to get care?

	PROV-IDERS		WOMEN IN CARE	
RESPONSE	n	%	n	%
Yes	62	87	4	80
Sometimes	6	8		
No	3	4	1	20
TOTAL	71	100	5	100

Tell a story about a woman of color in her attempts to get care for HIV/AIDS (Asked of focus groups only)

A. Barriers to Care

RESPONSE	n	%
Paperwork/eligibility	6	22
Don't want family to see meds/stigma	3	11
Poor medical care	2	7
Incarceration	2	7
Doctors don't have space for new patients	2	7
Substance abuse relapse	2	7
Don't know right people	1	4
Denial	1	4
Transportation	1	4
Lack of insurance	1	4
Family problems	1	4
Poor case management	1	4
Lack of knowledge of system	1	4
Immigration status	1	4
Don't want public care	1	4
Don't take responsibility	1	4
TOTAL	27	100

B. Facilitators to care

RESPONSE	n	%
One-site comprehensive care	2	22
Peer advocate	2	22
Good relationship with doctor	2	22
Staff caring/hope	2	22
Met their needs	1	11
TOTAL	9	100

APPENDIX E
RESPONSE FREQUENCIES: RARE WOMEN NOT IN CARE INTERVIEWS AND FOCUS GROUPS

Educational Level

All Sites

Grade	**Number of Response**	**%**
<9	17	23 * With less than grade 9 education
9	10	13
10	10	13
11	16	21
12	22	29

Education by Site

School Grades	**Sites**			**Total**	**Percent**
	Riviera Beach	**Belle Glade**	**Delray Beach**		
	Number	**Number**	**Number**		
<9	7	4	6	17	21
9	3	4	3	10	13
10	3	4	3	10	13
11	3	9	4	16	20
12	7	9	6	22	28
No Response	1	3	1	5	6

Employment

Employment Status	**Sites**				**Percent**
	Riviera Beach	**Belle Glade**	**Delray Beach**	**Total**	
Unemployed	20	31	19	70	88
Employed	5	1	2	8	10
No response				2	3

*Percent total equals 101% due to rounding

Position in Community

Position/Title in Community	Sites			**Total**	**Percent**
	Riviera Beach	**Belle Glade**	**Delray Beach**		
Sex Worker	10	4	6	20	25
Clerk	1	0	4	5	6
Sales	1	1	1	3	4
Food Worker	0	1	1	2	3
Other	0	2	0	2	3
No Response	13	24	10	47	59
Don’t Know	0	1	0	1	1

Reasons Why Women of Color are not in Care/dropped out of care

Reasons	**Sites**			**Total Frequency**
	Riviera Beach	**Belle Glade**	**Delray Beach**	
Fear	8	7	8	23
Shame	6	4	7	17
Anger	6	5	4	15
Denial	29	37	24	90
Don’t Care	12	6	6	24
Drugs	4	12	2	18
Transportation	4	14	6	24

People see you & talk	5	2	8	15
No money	1	6	1	8
Stigma	3	4	0	7
Don’t like the clinic	3	7	3	13
The wait is too long	1	4	5	10
Not enough knowledge of HIV	5	6	3	14
Need social support	4	7	2	13
Care takes too much time	4	10	2	14
No insurance	3	7	3	13
Can’t speak English	0	2	3	5
Too far	0	2	3	5
Location	2	1	1	4
Job and other responsibilities	2	1	1	4
No Child Care	0	3	1	4
Guilt	10	2	4	16
Need Mental Health Counseling	2	2	2	6
High Risk Behavior	12	15	9	36
Don’t like condoms	0	1	0	1

Services that assist with the maintenance of Health Care

Service	**Number**	**Percent**
Medical Services	18	23
No Services	17	21
Transportation	14	18
Testing	11	14
HCD	6	8
Case Management	5	6

How long do you wait to see the doctor?

Area	**Not Long**	**Long Time**	**2 wks – Month**	**> than a month**
Riviera Beach	4	7	2	2
Belle Glade	9	11	0	1
Delray Beach	8	8	0	0
TOTAL	**21**	**26**	**2**	**3**

What Happens When You Have to Wait

Site	**Give Up**	**Leave**	**Go to ER**	**Stays and Waits**
Riviera Beach	5	1	1	3
Belle Glade	7	2	2	2
Delray Beach	2	4	1	3
TOTAL	**14**	**7**	**4**	**8**

How do you feel when you have to wait?

Responses	**Sites**			**Total**	**Percent**
	Riviera Beach	**Belle Glade**	**Delray Beach**		
Discouraged	5	8	2	15	19
Bad	2	2	3	7	9
Disappointed	1	2	1	4	5
Mad/Frustrated	4	1	3	8	10

Hate Self	0	3	1	4	5
Tired/Sick	1	1	2	4	5

Referral to Other Services

Response	**Riviera Beach**	**Belle Glade**	**Delray**	**Total**	**Percent**
No	12	21	14	47	59
Yes	4	5	3	11	14
Total	16	26	17	58	73

Please note: “No response and “don’t know” are not reflected in this table and n = 80.

Did you go to Referred services?

Site	**No**	**Yes**	**Sometimes**
Riviera Beach	10	3	4
Belle Glade	16	6	2
Delray Beach	10	0	3
TOTAL	**36(45%)**	**9 (11%)**	**9 (11%)**

Satisfaction with Services

Response	**Riviera Beach**	**Belle Glade**	**Delray Beach**	**Total**	**Percent**
Satisfied	13	11	7	31	39
Not Satisfied	0	7	4	11	14

When You Feel Sick what do you do?

Responses	**Area**			**Total**	**%**
	Riviera Beach	**Belle Glade**	**Delray Beach**		
Visit Hospital/ER	9	15	17	41	51
Take Care of Self	7	7	0	14	18
Wait until it passes	1	4	0	5	6
Home Remedies	2	0	3	5	6
Go to the Doctor	3	4	1	8	10

How do you feel about your Providers?

Response	**Number**	**Percent**
‘I don’t go to any providers’	24	30
‘Its been a long time”	12	15
‘I was in the hospital	15	19
‘Everything was negative	5	6

N=80. Please note that no ‘responses’ and ‘don’t know’ are not reflected in the above grid.

What did they (Providers) talk to you about?

Responses	**Sites**			**Total**	**%**
	Riviera Bch	**Belle Glade**	**Delray Bch**		
They don’t talk to me	1	14	6	21	26
They talk about HIV	4	3	3	10	13
How you can get HIV	4	3	2	9	12
They explain things	5	1	3	9	12

Do You Like the Way They Talk to You?

Responses	**Riviera Beach**		**Belle Glade**		**Delray Beach**		**Total**	
	#	%	#	%	#	%	#	%
Yes	5	6.2	4	5	8	10	17	21.3
No	4	5	7	9	1	1	12	15

Knowledge of HIV

Response	Sites			Total	
	Riviera Beach	Belle Glade	Delray	#	%
I don't know too much	6	18	0	24	30
People die from it	3	5	6	14	18
I know how you get it	4	3	4	11	14
Its painful	1	2	3	6	8

What would you like to know?

Response	**Sites**			**Total**	
	Riviera Bch	**Belle Glade**	**Delray**	**#**	**%**
A cure	3	4	5	12	15
How it affects people	2	5	1	8	10
Do you have to get it	2	1	4	7	9
To know more about the system	3	4	0	7	9

What is your understanding of Case Management?

Response	**Riviera Beach**		**Belle Glade**		**Delray Beach**		**Total**	**%**
	Frequency	%	Frequency	%	Frequency	%		
No understanding	4		19		11		34	43
Haven't seen one in a long time	11		7		3		21	26
When I go they are helpful	3		0		1		4	5
People caring about me	2		1		4		7	9
No Response	4		0		2		6	13
Don't Know	1		6		1		8	10

Have you seen a case manager?

Response	**Riviera Beach**	**Belle Glade**	**Delray**	**Total**	**%**
No	8	24	14	46	58%
Yes	8	6	7	21	26%
No one referred one to me	1	1	0	2	

What services did you get from case managers?

Response	Riviera Beach	Belle Glade	Delray	Total	%
Nothing	4	17	11	32	40
Don't go	4	8	2	14	18
Everything	2	0	4	6	8
Food	1	1	2	4	5
Housing	2	0	1	3	4
Other	2	2	0	4	5
Rides	2	0	0	2	3
No response	8	5	2	15	19

What services would you like to see case managers provide?

Response	Riviera Beach	Belle Glade	Delray	Total	%
Get me some money	6	3	4	13	16
Help with medical care	1	3	4	8	10
Do more for black people	1	2	2	5	6
Be more compassionate	3	1	0	4	5
Talk to me some more	1	1	1	3	4
Get me housing	1	1	1	3	4

Other	3	1	1	5	6
Don't know	3	9	2	14	18
No response	6	12	7	25	31

NB: Total may exceed 100% due to rounding

What do you need to maintain health care?

Response	**Riviera Beach**	**Belle Glade**	**Delray**	**Total**	**%**
Help to get back into care	8	7	7	22	28
Medical care	3	7	3	13	16
Insurance coverage	2	5	1	8	10
Nothing. I take care of myself	1	1	4	6	8
Get me a job	2	1	2	5	6
Love and understanding	1	1	2	4	5
More interaction with the client	2	0	0	2	3
Don't know	2	2	0	4	5
No responses	2	6	3	11	14
Drug abuse Rx & aftercare	2	2	0	4	5
TOTAL	2	2	0	4	5

What services are too full or hard to get?

Response	**Riviera Beach**	**Belle Glade**	**Delray**	**Total**	**%**
All service	3	4	6	13	16
There are few	1	5	5	11	14
All medical services	5	4	1	10	13
The waiting room at the doc.	0	5	1	6	8
Clinic	1	3	1	5	6
The start and stopping services: eligibility	2	2	1	5	6
ER & Hospital	0	1	2	3	4
Health care district	1	1	1	3	4
Housing	0	1	1	2	3
Annex building is too full	1	1	0	2	3
No response	7	2	1	10	13
Don't know	4	3	1	8	10
Other	0	1	1	2	3

What services are most annoying/painful?

Response	**Riviera Beach**	**Belle Glade**	**Delray**	**Total**	**%**
Waiting	11	12	10	33	41
All Medical	3	6	5	14	18
What I get rejected	2	1	2	5	6
All services are annoying/painful	0	2	3	5	6
No services are annoying/painful	0	4	0	4	5
Myself is the problem	1	1	1	2	3
Other	0	1	1	2	3
Hospital/ER	0	0	1	1	1
Don't know	0	1	0	1	1
No response	8	5	0	13	16
TOTAL				80	100

What services are the best?

Response	**Riviera Beach**	**Belle Glade**	**Delray**	**Total**	**%**
My doctor	4	8	3	15	19

The clinic (HD)	6	4	3	13	16
Don't know	4	5	8	17	21
I like it best when I can go home	0	1	4	5	6
Nothing is good	0	3	1	4	5
Case management	1	2	0	3	4
Jail	0	2	0	2	3
When they explain things to you and talk	1	0	1	2	3
Health Care District	1	0	0	1	1
No response	8	8	2	18	23

Do you get all the services you need?

Response	Riviera Beach	Belle Glade	Delray	Total	%
When I go, yes	7	13	10	30	38
Mostly	2	0	1	13	4
No	2	11	6	19	24
Not at the DOH	1	1	0	2	3
Don't go to services	3	3	2	8	10
You can get tested & a check up. period	1	0	0	1	1
No response	9	3	1	13	16
Don't know	0	1	2	3	4
When you are done (drugged) you cant get help	0	1	0	1	1

How long does it take to get a referral"?

Response	Riviera Beach	Belle Glade	Delray	Total	%
Never got referral	9	13	9	31	39
Not long 3wks/less	4	3	4	11	14
I get it in that day	2	3	2	7	9
A long time	2	2	2	6	8
No time at all, doc uses fax	0	1	0	1	1
Hours	0	1	0	1	1
Don't know	3	7	5	15	19
No response	5	3	0	8	10

Describe Referral Process

Response	Riviera Beach	Belle Glade	Delray	Total	%
Don't know what referral is	4	10	4	18	23
It doesn't take no time	2	2	2	6	8
N/A I don't go to service	0	3	2	5	6
Other	4	2	4	10	13
1hr at my doc. Longer at DOC	0	2	0	2	3
No response	15	14	9	38	48
Case manager do it	0	0	1	1	1

If you need specialist, do you get a referral?

Response	Riviera Beach	Belle Glade	Delray	Total	%
Yes	1	2	2	5	6
NO	2	8	5	15	19
I don't have transportation to get there	1	1	1	3	4

Don't know	1	3	0	4	5
No response	20	18	13	51	64
Other	0	1	1	2	3

How easy it is to get from service to service?

Response	**Riviera Beach**	**Belle Glade**	**Delray**	**Total**	**%**
Easy	5	5	0	10	13
Its hard	12	13	24	39	49
Walks whenever there is no ride	3	2	4	9	11
No transportation	1	2	2	5	6
No response	4	9	1	14	18
Don't know	0	1	1	2	3
Other	0	1	0	1	1

How do you get to services?

Response	**Riviera Beach**	**Belle Glade**	**Delray**	**Total**	**%**
Walks	4	1	3	8	10
Bus Pass/ Vouchers	6	6	6	18	23
My relative takes me	3	1	2	6	8
Friends	1	1	2	4	5
I don't go because I have no way to get there	4	6	4	14	18
I just don't go	5	10	4	19	27
No response	2	7	0	9	11
Don't know	0	1	1	2	3

Do agencies believe in themselves and others?

Response	**Riviera Beach**	**Belle Glade**	**Delray**	**Total**	**%**
Yes	3	3	4	10	13
No	0	4	3	7	9
I think so	2	5	5	12	15
Some of them do	2	1	3	6	8
Don't know	0	1	0	1	1
No response	5	4	1	10	13
I don't know about this	13	15	6	34	43

What are the barriers to the disabled?

Response	**Riviera Beach**	**Belle Glade**	**Delray**	**Total**	**%**
Transportation	5	15	6	26	33
There are no barriers	4	7	2	13	16
They are too sick to go	5	2	7	14	18
No response	3	2	1	6	8
Don't know	7	6	6	19	24

Describe services for those who don't speak English

Response	**Riviera Beach**	**Belle Glade**	**Delray**	**Total**	**%**
They speak other languages at the clinic	9	3	3	15	19
Some Haitian, some Spanish	0	2	4	6	8

They get waited on better and faster	0	2	1	3	4
No response	5	5	3	13	16
Don’t know	5	10	4	19	24
Other	1	1	1	3	4
They get what they need	1	7	2	10	13
They don’t get what they need	4	3	4	11	14

Describe services for those who don’t read

Response	Riviera Beach	Belle Glade	Delray	Total	%
People read for them	9	4	5	18	23
They answer questions for you	2	1	1	4	5
Poor service for those who cant read	4	4	4	12	15
They treat those better who cant read	1	4	0	5	6
No response	4	8	3	15	19
Don’t know	4	12	8	24	30
Other	1	0	1	2	3

Is staff trained to answer questions?

Response	Riviera Beach	Belle Glade	Delray	Total	%
Yes	8	9	5	22	28
No	2	4	2	8	10
Maybe	1	10	5	16	20
No response	7	3	2	12	15
Don’t know	5	4	5	14	18
There is no way to answer this	1	3	2	6	8
They’re supposed to be	0	0	1	1	1
In a way they let you down	1	0	0	1	1

Are business hours convenient?

Response	Riviera Beach	Belle Glade	Delray	Total	%
Yes	13	16	9	38	48
No	4	8	3	15	19
Pretty fair	4	1	2	7	9
When I am not using they are ok	0	0	1	1	1
Transportation is the problem	3	1	1	5	6
No response	1	4	3	8	10
Don’t know	0	3	2	5	6
I don’t go	0	0	1	1	1

What about location?

Response	Riviera Beach	Belle Glade	Delray	Total	%
Good/yes	14	10	10	34	43
Bad/no	7	15	6	28	35
Too far away	0	3	1	4	5
Don’t go to services	0	0	1	1	1
No response	3	2	1	6	8
Don’t know	0	2	3	5	6
Other	1	1	0	2	3

Is confidentiality protected?

Response	Riviera Beach	Belle Glade	Delray	Total	%
Yes	13	20	6	39	49
No	5	7	7	19	24
No response	2	2	5	9	11
Don't go to services	1	1	0	2	3
Don't know	3	3	2	8	10
Other	1	0	2	3	4

Is health care provided in a safe and secure area?

Response	Riviera Beach	Belle Glade	Delray	Total	%
Yes	12	13	13	38	48
No	5	9	0	14	18
No response	6	3	3	13	16
Don't go to services	1	1	3	5	6
Don't know	1	6	2	9	11
Other	0	1	1	2	3

How does staff treat you?

Response	Riviera Beach	Belle Glade	Delray	Total	%
Good	15	13	6	34	19
Bad	1	7	2	10	13
She demand respect	1	0	1	2	3
I'm not being treated	6	10	12	28	35
No response	1	3	0	4	5
Don't know	1	0	0	1	1
Other	0	0	1	1	1

Are you seeing an AIDS doctor?

Response	Riviera Beach	Belle Glade	Delray	Total	%
Yes	4	6	3	13	16
No	13	23	15	51	64
No response	6	3	4	13	16
Don't know	1	1	0	2	3
Other	1	0	0	1	1

Describe your doctor

Response	Riviera Beach	Belle Glade	Delray	Total	%
I don't have a doctor	10	16	10	36	45
A loving or good doctor	7	2	4	13	16
Bad treatment	0	0	2	2	3
I use home remedies	2	1	2	5	6
No response	5	12	4	21	26
Don't know	0	1	0	1	1
Other	1	1	0	2	3

What kind of doctor are you seeing?

Response	Riviera Beach	Belle Glade	Delray	Total	%

Private doctor	1	2	3	6	8
A doctor at the clinic	3	4	1	8	10
My grandmother or other relatives	0	0	1	1	1
A spiritual doctor	1	0	3	4	5
I don't go to the doctor	11	19	6	36	45
HIV doctor	1	1	2	4	5
No response	7	6	5	18	23
Don't know	0	1	1	2	3
12.00	1	0	0	1	1

How are you treated in HIV care?

Response	**Riviera Beach**	**Belle Glade**	**Delray**	**Total**	**%**
Good	14	11	10	35	44
Bad	1	4	0	5	6
Fair	0	4	1	5	6
Not being treated	8	10	9	27	34
No response	1	3	2	6	8
Don't know	0	1	0	1	1
12.00	1	0	0	1	1

Describe your treatment

Response	**Riviera Beach**	**Belle Glade**	**Delray**	**Total**	**%**
Good	3	4	2	9	11
Bad	0	3	1	4	5
Not in any treatment	11	13	9	33	41
They are hard on me	1	3	0	4	5
When I go its okay	2	1	2	5	6
No response	8	9	7	24	30
Don't know	0	0	1	1	1

Are people of other races/ethnicity treated the same?

Response	**Riviera Beach**	**Belle Glade**	**Delray**	**Total**	**%**
Yes	2	0	2	4	5
No	4	0	5	9	11
No response	11	16	10	37	46
Don't know	8	15	5	28	35
Other	0	2	0	2	3

Describe your feelings when you go to your provider

Response	**Riviera Beach**	**Belle Glade**	**Delray**	**Total**	**%**
Good	9	8	7	24	30
Bad	1	3	3	7	9
Fair	0	1	2	3	4
Not in health care	9	13	9	31	39
No response	6	5	1	12	15
Don't know	0	3	0	3	4

Is the staff trained to meet your needs?

Response	**Riviera Beach**	**Belle Glade**	**Delray**	**Total**	**%**

Yes	5	7	5	17	21
No	0	4	2	6	8
She thinks so	2	6	7	15	19
No response	9	6	4	19	24
She don’t know	9	10	4	23	29

Explain what staff does

Response	Riviera Beach	Belle Glade	Delray	Total	%
They give you attitude	1	1	0	2	3
They treat you bad	0	2	0	2	3
They treat you good	1	2	1	4	5
They feed you	0	2	0	2	3
They try to help you	4	2	4	10	13
No response	15	15	12	42	53
Don’t know	4	9	5	18	23

Where do people go to get tested?

Response	Riviera Beach	Belle Glade	Delray	Total	%
Clinics	17	22	17	56	70
Substance abuse facilities	1	0	0	1	1
The doctor	0	3	0	3	4
Case management agencies	5	2	1	8	10
They don’t get tested	1	0	2	3	4
No response	1	2	1	4	5
Don’t know	0	3	0	3	4
Other	0	1	1	2	3

What do people do when they find out that they are HIV positive?

Response	Riviera Beach	Belle Glade	Delray	Total	%
They go the clinic	13	16	10	39	49
They isolate and do nothing	2	4	5	11	14
Call family	1	0	1	2	3
Call a friend	0	3	0	3	4
Call case management agency	3	0	0	3	4
Go to doctor	1	4	1	6	8
They give up and die	1	0	0	1	1
No response	4	4	3	11	14
Don’t know	0	1	2	3	4
Other	0	1	0	1	1

Are you HIV positive and in care?

Response	Riviera Beach	Belle Glade	Delray	Total	%
Yes	5	4	2	11	14
No	16	23	16	55	69
When I’m not using drugs/alcohol	1	0	0	1	1
I go the ER and hospital	0	1	0	1	1
I don’t believe I’m positive	0	1	0	1	1
I don’t need care	3	2	2	7	9
No response	0	1	0	1	1
Don’t know	0	1	1	2	3

Other	0	0	1	1	1

What kind of care are you getting?

Response	Riviera Beach	Belle Glade	Delray	Total	%
She takes care of herself	5	8	2	15	19
Home remedies	1	2	4	7	9
Clinic	2	1	0	3	4
Private Doctor	2	3	0	5	6
Sometimes in care	3	4	7	14	18
She don't think she is positive	2	1	0	3	4
She says she don't care	3	8	3	14	18
No response	4	2	4	10	13
Other	1	0	0	1	1
Case Management	1	1	1	3	4
Hospital/ER	1	3	0	4	5
Doctor & Case Management	0	0	1	1	1

Why are you not in care?

Response	Riviera Beach	Belle Glade	Delray	Total	%
Don't want to go	4	6	3	13	16
Don't think I'm really positive	1	0	0	1	1
Don't have they time/too busy	5	5	2	12	15
Sometime I go	1	3	3	7	9
I'm not sick/don't need care	3	4	5	12	15
No response	10	7	6	23	29
Don't know	0	1	0	1	1
Other	0	1	2	3	4
I'm not afraid	1	3	1	5	6
I got turned down	0	3	0	3	4

Are you in Medical Care?

Response	Riviera Beach	Belle Glade	Delray	Total	%
Yes	5	5	1	11	14
No	14	21	14	49	61
Sometimes	3	4	5	12	15
Don't need it	1	2	2	5	6
No response	2	0	0	2	3
Are you in 10.00	0	1	0	1	1

Tel me why you are not in medical care

Response	Riviera Beach	Belle Glade	Delray	Total	%
Too hard to keep it up	4	3	3	10	13
Meds make her sick	1	2	4	7	9
They are too strict	0	1	0	1	1
Too busy/no time	1	1	1	3	4
No transportation	0	1	0	1	1
Drugs/alcohol	6	4	2	12	15
No response	7	11	7	25	31
Other	1	0	2	3	4
She's too afraid	0	3	3	6	8

She don't believe in health care	2	3	0	5	6
She feels fine	3	2	0	5	6
She gets turned down	0	2	0	2	3

How do you feel about being HIV positive?

Response	Riviera Beach	Belle Glade	Delray	Total	%
Sad	2	2	2	6	8
Mad	1	2	3	6	8
Punished by sins/God	3	0	0	3	4
It's a curse	1	2	3	6	8
Hatred	0	2	1	3	4
I'm not accepting I'm HIV+	0	2	4	6	8
She's too sick	3	1	3	7	9
Shame/guilt	4	2	2	8	10
No response	5	14	3	22	28
Don't know	1	2	0	3	4
Scarred	3	2	1	6	8
Other	2	2	0	4	6

How do you think others think about you being HIV positive?

Response	Riviera Beach	Belle Glade	Delray	Total	%
The don't care	3	10	4	17	21
They afraid of you	2	3	3	8	10
They avoid you	3	1	2	6	8
Judgmental	2	2	5	9	11
Don't want to know	0	1	2	3	4
They deny you	2	2	0	4	5
No response	6	8	3	17	21
Don't know	3	2	2	7	9
Other	3	0	0	3	4
They think they cant get it	0	1	1	2	3
They don't know	1	3	0	4	5

Does your fear of what others think of you keep you from care?

Response	Riviera Beach	Belle Glade	Delray	Total	%
Yes	11	9	5	25	31
No	5	12	6	23	29
Kind of	1	4	3	8	10
I wont pick up my results	2	1	3	6	8
She don't care when she is high	2	1	1	4	5
No response	3	5	4	12	15
Other	1	0	0	1	1
11.00	0	1	0	1	1

Tell us more about HIV positive women of color

Response	Riviera Beach	Belle Glade	Delray	Total	%
They want nothing	4	2	2	8	10
No education	0	2	3	5	6
Drugs/alcohol	1	2	2	5	6
I feel bad for their ignorance	0	3	2	5	6

It makes me feel bad	4	3	1	8	10
It hurts me	1	4	1	6	8
I/They don't care	0	4	1	5	6
No response	8	8	4	20	25
Other	1	0	1	2	3
They are scared to get help	4	3	2	9	11
They're afraid of their confidences being exposed	2	1	1	4	5
The women need group treatment adherence information	0	1	2	3	4

APPENDIX F
RARE METHODOLOGICAL TRIANGULATION CHARTS: FINDINGS BY DATA COLLECTION STRATEGIES, DOMAINS, AND THEMES

Table F-1
Belle Glade Methodological Triangulation Chart

DOMAINS & THEMES	**Data Collection Strategies**				
	Focus Group	**Observation**	**Cultural Consensus**	**Interviews**	**Geo Mapping**
Client Health Seeking Behavior					
Substance abuse	Yes	Yes	Yes	Yes	Yes
Inconvenience (Barriers such as lack of transportation)	Yes	Yes	Yes	Yes	No
Impersonality	Yes	No	No	No	No
Impediments (long waiting, long appointments, etc.)	Yes	No	Yes	Yes	No
Lack of insurance	Yes	No	Yes	No	No
ER Utilization	No	No	Yes	Yes	No
Hopelessness/ Powerlessness	Yes	No	Yes	Yes	No
Prioritization	Yes	No	Yes	Yes	No
Abusive Spouse	Yes	No		Yes	No
Shame	Yes	No		Yes	No
Faith Healing	Yes	No	Yes		No
Privacy (concerns regarding confidentiality)	Yes	No	Yes	Yes	No
Accessibility	**Focus Group**	**Observation**	**Cultural Consensus**	**Interviews**	**Geo Mapping**
Inconvenience (location and or hours of operation)	Yes	Yes	Yes	Yes	No
Lack of insurance	Yes	No	Yes	No	No
Impediments (long waiting, long appointments, etc.)	Yes	Yes	Yes	No	No

DOMAINS & THEMES	***Data Collection strategies***				
Capacity	**Focus Group**	**Observation**	**Cultural Consensus**	**Interviews**	**Geo Mapping**
Impediments (long waiting, long appointments, etc.	No	Yes	Yes	No	No
Inconvenience (Barriers)	No	Yes	No	No	No
Integration	**Focus Group**	**Observation**	**Cultural Consensus**	**Interviews**	**Geo Mapping**
Referral Process	Yes	No	Yes	Yes	No
Provider Mix	Yes	No	No	No	No
Privacy (concerns regarding confidentiality)	No	Yes	No	No	No
Technical Competency	**Focus Group**	**Observation**	**Cultural Consensus**	**Interviews**	**Geo Mapping**
Lack of confidence in Provider(including potential breach of confidentiality)	Yes	No	Yes	Yes	No
Comprehensiveness	**Focus Group**	**Observation**	**Cultural Consensus**	**Interviews**	**Geo Mapping**
Types and number of services available	Yes	Yes	Yes	Yes	No
Knowledge of available services	Yes	No	Yes	Yes	No
Acceptability	**Focus Group**	**Observation**	**Cultural Consensus**	**Interviews**	**Geo Mapping**
Loss of social network	No	No	Yes	Yes	No
Quality of care	Yes	No		Yes	
Quality of provider services and acceptance	Yes	No	Yes	Yes	No

Table F-2
Delray Beach Methodological Triangulation Chart

DOMAINS & THEMES	**Data Collection Strategies**				
	Focus Group	**Observation**	**Cultural Consensus**	**Interviews**	**Geo Mapping**
Client Health Seeking Behavior					
Substance abuse	Yes	Yes	Yes	No	Yes
Inconvenience (Barriers such as lack of transportation)	Yes	Yes	No	Yes	No
Impersonality	Yes	No	No	Yes	No
Impediments (long waiting, long appointments, etc.)	No	Yes	No	Yes	No
Lack of insurance	Yes	No	Yes	Yes	No
ER Utilization	No	No	Yes	Yes	No
Hopelessness/ Powerlessness	Yes	No	No	Yes	No
Prioritization	No	No	Yes	Yes	No
Abusive Spouse	No	No	Yes	Yes	No
Shame	Yes	No	Yes	Yes	No
Faith Healing	Yes	No	Yes	Yes	No
Privacy (concerns regarding confidentiality)	Yes	Yes	Yes	Yes	No
Accessibility	**Focus Group**	**Observation**	**Cultural Consensus**	**Interviews**	**Geo Mapping**
Inconvenience (location and or hours of operation)	No	Yes	Yes	No	Yes
Lack of insurance	No	Yes	No	Yes	No
Lack of Confidentiality	Yes	No	Yes	Yes	No

DOMAINS & THEMES	***Data Collection strategies***				
Capacity	**Focus Group**	**Observation**	**Cultural Consensus**	**Interviews**	**Geo Mapping**
Impediments (long waiting, long appointments, etc.	Yes	No	Yes	Yes	No
Inconvenience (Barriers)	Yes	No	Yes	Yes	Yes
Integration	**Focus Group**	**Observation**	**Cultural Consensus**	**Interviews**	**Geo Mapping**
Referral Process	Yes	No	Yes	Yes	No
Provider Mix	No	Yes	Yes	No	No
Privacy (concerns regarding confidentiality)	Yes	Yes	Yes	No	No
Technical Competency	**Focus Group**	**Observation**	**Cultural Consensus**	**Interviews**	**Geo Mapping**
Lack of confidence in Provider(including potential breach of confidentiality)	Yes	No	No	Yes	No
Comprehensiveness	**Focus Group**	**Observation**	**Cultural Consensus**	**Interviews**	**Geo Mapping**
Types and number of services available	No	No	Yes	Yes	No
Knowledge of available services	No	No	No	Yes	No
Acceptability	**Focus Group**	**Observation**	**Cultural Consensus**	**Interviews**	**Geo Mapping**
Loss of social network	Yes	No	No	Yes	No
Quality of care	Yes	No	Yes	Yes	No
Quality of provider services and acceptance	Yes	No	Yes	Yes	No

Table F-3
Riviera Beach Methodological Triangulation Chart

DOMAINS & THEMES	**Data Collection Strategies**				
	Focus Group	**Observation**	**Cultural Consensus**	**Interviews**	**Geo Mapping**
Client Health Seeking Behavior					
Substance abuse	No	Yes	Yes	No	Yes
Inconvenience (Barriers such as lack of transportation)	No	Yes	No	Yes	No
Impersonality	Yes	No	No	Yes	No
Impediments (long waiting, long appointments, etc.)	No	Yes	No	Yes	No
Lack of insurance	Yes	No	No	Yes	No
ER Utilization	No	No	Yes	Yes	No
Hopelessness/ Powerlessness	Yes	No	No	Yes	No
Prioritization	No	No	Yes	Yes	No
Abusive Spouse	No	No	Yes	Yes	No
Shame	Yes	No	Yes	Yes	No
Faith Healing	Yes	No	Yes	Yes	No
Privacy (concerns regarding confidentiality)	Yes	Yes	Yes	Yes	No
Accessibility	**Focus Group**	**Observation**	**Cultural Consensus**	**Interviews**	**Geo Mapping**
Inconvenience (location and or hours of operation)	No	Yes	Yes	No	Yes
Lack of insurance	No	No	No	No	No
Lack of Confidentiality	Yes	No	Yes	Yes	No

DOMAINS & THEMES	***Data Collection strategies***				
Capacity	**Focus Group**	**Observation**	**Cultural Consensus**	**Interviews**	**Geo Mapping**
Impediments (long waiting, long appointments, etc.	Yes	No	Yes	Yes	No
Inconvenience (Barriers)	Yes	No	Yes	No	Yes
Integration	**Focus Group**	**Observation**	**Cultural Consensus**	**Interviews**	**Geo Mapping**
Referral Process	Yes	No	Yes	Yes	No
Provider Mix	No	Yes	Yes	No	No
Privacy (concerns regarding confidentiality)	Yes	Yes	Yes	No	No
Technical Competency	**Focus Group**	**Observation**	**Cultural Consensus**	**Interviews**	**Geo Mapping**
Lack of confidence in Provider(including potential breach of confidentiality)	Yes	No	Yes	No	No
Comprehensiveness	**Focus Group**	**Observation**	**Cultural Consensus**	**Interviews**	**Geo Mapping**
Types and number of services available	No	No	Yes	Yes	No
Knowledge of available services	No	No	No	Yes	No
Acceptability	**Focus Group**	**Observation**	**Cultural Consensus**	**Interviews**	**Geo Mapping**
Loss of social network	Yes	No	No	Yes	No
Quality of care	Yes	No	Yes	Yes	No
Quality of provider services and acceptance	Yes	No	Yes	Yes	No

APPENDIX G
RESPONSE FREQUENCIES:
CULTURAL CONSENSUS SURVEY

Cultural Consensus Survey
Questionnaire for HIV+ Black Women Not in Care

The following questions need you to give a one word answer.

Most people I know don't get HIV Care because of_____________________.
I know at least ______________________positive people who are not in care.
On a scale of 1 to 5 (5 being the highest knowledge, 1 being the least knowledge), I rank my knowledge of HIV care at___________________________________.
I won't get HIV care until I____.
I know at least____________places to go to get HIV care if I need it.
Most of the people in my immediate family **don't know/know** I'm positive.
My ethnicity is____.
My sexual orientation (Hetero,Homo, Bi, Nothing, Other).* Circle one
I've not been in HIV care because I've been in jail__________
My age is__________________________
I live in the South, North or Western portion of the County.* Circle one
My sexual and drug-related risk behaviors include:

The Following Questions can be answered **true** or **false**:
It is difficult to get health care in this county:
I don't wish to get health care in my community
I don't want people to know I'm positive
I'm ashamed of being positive
If my man finds out I've been to the Clinic he'll beat me up
If I have a health problem other than HIV my doctor won't treat it. (Examples of other Women's' health problems are: Ovarian or breast cancer or Hepatitis C
Pharmacies give out shots for HIV, so I'm in care for HIV.
Most people can get healed of HIV if they pray and get healings
I'm not HIV if the babies I give birth to are negative
If I'm not feeling sick I'm not HIV
If I'm a 'Carrier'of HIV so, I'm not really HIV positive
I don't have any HIV symptoms so I'm not HIV
I get sick through a spell from my enemies so, I'm not really HIV
I don't take meds because they make me sick
I treat myself for HIV with home remedies
I don't believe I'm HIV so I go back to get to tested to see if results change
I don't believe the HIV test results, so I'm not positive
My viral load is undetectable so I don't have HIV
I would go back to HIV doctor if I could get drug/alcohol treatment
I can get a miracle from God and not have the virus
The reason I won't go to clinic is that they treat be wrong
I don't need HIV CARE because I only have sex with a small group of friends I've known my whole life
My babies are born or turn HIV-negative so, I'm HIV-negative
I only have sex with educated people so, I don't have to worry about catching HIV
I trade sex for stuff for me and my kids so I can't go for HIV care; they'll find out, and I won't have anyone to take care of us anymore
I'm a member of the Black middle class. I have a job, a family and money. This means I'm not at risk for HIV and don't need to wear a condom, get tested or even be worried about HIV
I don't ask nobody about their HIV and I don't tell about my HIV
I don't reach for condoms because this makes sex real
I'm too sick to get HIV care so, I stay away and try to deal on my own
I'll get treated for HIV when I'm sick enough to go to the Hospital
I've never been in any Health care so I'm not going for HIV
I go to Emergency room if I'm sick

Getting Health care is not what my people do
I need to care for my husband and kids. There's no time for me
If I go into care for HIV I have to stop using drugs/alcohol
I dropped out of HIV care because I went to jail

This is for those that have dropped out of CARE for HIV.

The following questions can be answered **Yes** or **No**.
I dropped out of care because I have no symptoms
My kids come first so I don't have the time to go to HIV care
My man will hurt me if he finds out I go for HIV treatment
My faith will heal me so I don't need medical care
My drinking/drug use prevents me from getting HIV medical care
I have a hard time getting to doctors appointments because of work
The providers are nasty, so I won't go for help
They hurt me when I go, so I don't go
The providers are too far to get to
They tell my business, so I won't go
I go to the ER when I feel sick
I just stay at home until I feel better than carry on
There is no one to help me with my children so I stay away

I dropped out of care becauseI'd go back into HIV care if____

The following questions can be answered **True** or **False**:
It is difficult to get HIV Medical care in my community
My community don't go to the doctor or clinic for medical care
I'm not responsible for the 'virus' so, I'm not dealing with it
I'm tired from hiding all the medicines from everybody so I dropped out of HIV care
The wait times are too long so, I'm not going to the doctor any more
I feel better now so I don't need the doctor no more
I'm tired of lying to everybody about where I go to get care so, I dropped out of care
I dropped out of care because the medicines made me too sick
I look good so I don't need no medical care
I need to work and that's more important than going to the doctor
I take care of my self with natural remedies
I go to the Voodoo Healers and they take the spell off me
I got the healing from the Believers so I'm not sick no more
The clinic takes a whole day. I'm not doing that
I'm too ashamed of being HIV to go to clinic or HIV doctor
I don't want to make my family embarrassed so, I dropped out of care
I'm being punished from God. Medicine won't do any good.
The people at the clinic/doctor are too nasty. I'm not going back
The people at the clinic/doctor will tell my business. I'm not going back
I'm using drugs/alcohol and that comes first before the HIV care
I don't have insurance so, it's too hard to get the eligibility for the doctor/clinic
The ADAP Nazis at the clinic are nasty and have too many rules, so I dropped out of care
I don't want my employer to find out I'm positive so I won't go back to clinic/doctor
I'm just too tired of doing everything that it takes to stay healthy. I've got burnout from all I got to do
It's too hard for me to get to clinic/doctor. I'm not going back

Cultural Consensus Survey
Questionnaire for Providers
Response Frequencies for Providers and Women not in Care

Note: Number of respondents = 14 providers, 28 women not in care. Questions shown are those for providers; analogous questions asked of women as per preceding questionnaire.

1. Why do you think most women of color don't get HIV care?

	Providers		Women	
Response	n	%	n	%
Denial	2	14	2	7
Stigma	2	14		
No time/work	2	14		
Put family first	2	14		
Don’t care	1	7	1	4
Shame	1	7	12	43
Not enough information	1	7	4	14
Lack of awareness of services	1	7		
Side effects	1	7		
No response	1	7		
Addiction			3	11
Fear			6	21

2. I know at least _______ positive people who are not in care.

	Providers		Women	
Response	n	%	n	%
0	5	36	1	4
1-2	1	7	1	4
3-4	1	7		
5-10	1	7	4	14
> 10	5	36	22	79
No response	1	7		

3. On a scale of 1 to 5 (5 being the highest knowledge, 1 being the least knowledge), I rank my knowledge of HIV care at:

	Providers		Women	
Response	n	%	n	%
1	0	0		
2	0	0	1	4
3	1	7	1	4
4	7	50	6	21
5	5	36	20	71
No response	1	7		

4. Generally, women of color won't get HIV care until:

	Providers		Women	
Response	n	%	n	%
They get or feel sick	7	50	3	11
Get AIDS	2	14		
They get tested	1	7	1	4
No response	1	7	4	14
Get pregnant	1	7		
Get over shame	1	7		
They are dying	1	7	2	7
Stop being scared			5	19
Get a real diagnosis			5	19
Believe it’s true			6	22
Know information is safe			2	7

5. How many places do you know of that provide HIV care?

	Providers		Women	
Response	n	%	n	%
1			2	7
2	1	7	7	25
3	2	14	5	19
4	2	14	12	43
5	2	14	2	7
6	1	1		
> 6	5	36		
No response	1	7		

6. Do most of the people in the immediate family of HIV+ women of color not know/know they're positive?

	Providers		Women	
Response	n	%	n	%
They don’t know	8	57	14	50
They know	2	14	12	43
Some of them know	2	14		
No response	2	14	1	4
Don’t know			1	4

7. What is the predominant ethnicity of your HIV+ women of color?

	Providers		Women	
Response	n	%	n	%
African-American	7	50	15	54
Haitian	6	43	12	43
Caucasian			1	4
No response	1	7		

8. What is the predominant sexual orientation (e.g., Hetero; Homo; Bi, Nothing; Other) of your women of color who are HIV+?

	Providers		Women	
Response	n	%	n	%
Heterosexual	13	93	17	61
Lesbian			1	4
Bisexual			2	7
Celibate			6	21
No response			2	71
Don't know	1	7		

9. My gender is:

	Providers	
Response	n	%
Woman	11	79
Man	3	21

10. How often do you hear that women of color are not in HIV care because they've been in jail?

	Providers		Women	
Response	n	%	n	%
Yes	10	71	2	7
No	3	21	12	43
No response	1	7	14	50

11. Please describe the sexual and drug-related risk behaviors that your patients describe to you:

	Providers		Women	
Response	n	%	n	%
Unprotected sex	5	36	2	7
No response	5	36	11	40
Sex for drugs	2	14	5	18
Substance abuse	2	14	1	4
Sex for commodities			1	4
Sex for drugs and money			2	8
Don't know			1	4
Staying safe			2	7
Other			2	7

12. Do you suggest to your patients that certain sexual behaviors are safer than others?

	Providers	
Response	n	%
Yes	3	21
No	2	14
No response/don't work with patients	9	65

13. Do you talk about secondary prevention with your patients?

	Providers	
Response	n	%
Yes	7	50
No response/don't work with patients	7	50

14. Do you explain the importance of starting and maintaining HIV pharmaceuticals?

	Providers	
Response	n	%
Yes	7	50
No response/don't work with patients	7	50

15. Women of color drop out of care because:

	Providers		Women	
Response	n	%	n	%
Difficult regimen/side effects	3	21		
Lack of knowledge	2	14		
No insurance	1	7	9	32
No transportation	1	7		
Shame, guilt, embarrassment	1	7		
Fear	1	7		
It's too much hassle	1	7		
Confidentiality	1	7	4	15
Denial	1	7		
Not sick	1	7		
Lack of child care	1	7		
Substance abuse/prostitution			8	29
Don't like doctor			3	11
No response			4	16

16. Women of color would go back into HIV care if they:

	Providers		Women	
Response	n	%	n	%
Symptoms change, get sick	2	14		
Perceived advantages of care	2	14		
Got disability income	2	14		
Didn't get the run around	1	7		
Were dying	1	7		
Had transportation	1	7	5	19
Had easier drug regimen	1	7		
Had knowledge of available services	1	7		
Had time off work	1	7		
Had child care	1	7		
Had help with paperwork			1	4
Had reliable people to depend on			2	8
When I feel safe			1	4
When people stop talking			4	14
If I get the right doctor/have choice of doctor			3	12
If I get my kids back			1	4
If I get substance abuse treatment			1	4
No response	1	7	4	18

	Providers		Women	
Item	Yes n	Yes %	Yes n	Yes %
Is it difficult to get health care in this county?	5	36	13	46
Do women of color wish to get health care in this community?	13	93	17	61
Do women of color avoid HIV medical care because they don't want people to know they are positive?	12	86	15	54
Do women of color feel ashamed of being positive?	13	93	17	61
If the man (husband, boyfriend, John, partner) of a woman of color finds out the 'woman' has been to the Clinic he'll beat the woman.	2	14	8	29
Do you treat health problems other than HIV?	8	57	8	29
Do Pharmacies give out shots for HIV?	2	14	8	29
Most people can get healed of HIV if they pray and get healings.	2	14	17	61
Have you heard women of color say "I'm not HIV if the babies I give birth to are negative?	5	36	7	25
Have you heard women of color say "If I'm not feeling sick I'm not HIV?	10	71	8	29
Have you heard women of color say "I'm a 'Carrier' of HIV so I'm not really HIV positive"?	5	36	11	39
Have you heard women of color say "I don't have any HIV symptoms so I'm not HIV"?	11	79	4	14
Have you heard women of color say "I get sick through a spell from my enemies so I'm not really HIV?"	7	50	4	14
Have you heard women of color say "I don't take meds because they make me sick?	13	93	13	46
Are you aware of women of color treating themselves for HIV with home remedies?	8	57	9	32
Are you aware of women of color suggesting "I don't believe I'm HIV so I go back to get to tested to see if results change"?	8	57	13	46
Have you heard women of color say "I don't believe the HIV test results, so I'm not positive?"	9	65	3	11
Have you heard women of color say "if a viral load is undetectable I don't have HIV?"	11	79	5	18
Have you heard women of color say "I would go back to an HIV doctor if I could get drug/alcohol treatment?"	2	14	14	50
Have you heard women of color discuss that they can get a miracle from God and not have the virus?	8	57	23	82
Have you heard women of color say "the reason I won't go to clinic is that they treat me wrong?"	5	36	16	57
Have you heard women of color say "I don't need HIV CARE because I only have sex with a small group of friends I've known my whole life?"	2	14	5	18
Have you heard women of color say "My babies are born or turn HIV-negative, so I'm HIV negative"?	4	29	6	21
Have you heard women of color say "I only have sex with educated people, so I don't have to worry about catching HIV"?	1	7	0	0
Have you heard women of color mention "I trade sex for stuff for me and my kids so I can't go for HIV care; they'll find out, and I won't have anyone to take care of us anymore"?	4	29	3	11
Have you heard women of color say "I'm a member of the Black middle class. I have a job, a family and money. This means I'm not at risk for HIV and don't need to wear a condom, get tested or even be worried about HIV?"	5	36	6	21
Have you heard women of color discuss in general, "I don't ask anybody about their HIV and I don't tell about my HIV"?	8	57	16	57
In general, have you heard women of color say, "I don't reach for condoms because this makes sex real"?	2	14	4	14
Have you heard women of color say, "I'm too sick to get HIV care, so I stay away and try to deal on my own"?	4	29	7	25
Have you heard women of color say, "I'll get treated for HIV when I'm sick enough to go to the Hospital"?	9	64	12	43
Have you heard women of color say, "I've never been in any health care so I'm not going for HIV"?	5	36	12	43
Have you heard women of color say, "I go to the Emergency room if I'm sick"?	11	79	25	89
Have you heard women of color say, "Getting Health care is not what my people do"?	3	21	4	14
Have you heard women of color say, "I need to care for my husband and kids. There's no time for me to go to HIV care"?	6	43	26	93
Have you heard women of color say, "If I go into care for HIV I have to stop using drugs/alcohol"?	4	29	24	86
Have you heard women of color say, "I dropped out of HIV care because I went to jail"?	6	43	2	7

Women of color DROP OUT OF CARE because:

	Providers		Women	
Item	Yes n	Yes %	Yes n	Yes %
They have no symptoms	13	93	6	21
Their kids come first so they don't have the time to go to HIV care	11	79	12	43
Their man will hurt them if he finds out she goes for HIV treatment	7	50	14	50
Her faith will heal her, so she doesn't need medical care	9	64	15	54
Her drinking/drug use prevents her from getting HIV medical care	10	71	15	54
They have a hard time getting to doctors' appointments because of work	11	79	6	21
They say the providers are nasty, so they won't go for help	4	29	18	64
They say the providers hurt them when they go, so they don't go	4	29	13	46
They say providers are too far to get to, so they don't access care	6	43	17	61
They say the providers tell their business, so they won't go	7	50	17	61
They say they go to the ER when they feel sick	12	86	23	82
They just stay at home until they feel better	9	64	12	43
They say there is no one to help them with their children so they stay away	10	71	7	25

	Providers		Women	
Item	True n	True %	True n	True %
It is difficult to get HIV medical care in the Black community.	3	21	16	57
The Black community doesn't go to the doctor or clinic for medical care.	2	14	12	43
The Black Community believes that they are not responsible for the 'virus,' so they're not dealing with it.	2	14	8	29
Women of color are tired of hiding all the medicines from everybody, so they drop out of HIV care.	9	64	7	25
The wait times are too long, so women of color do not go to the doctor any more.	9	64	12	43
When women of color feel better, they believe they don't need the doctor any more and drop out of care.	12	86	7	25
Women of color get tired of lying to everybody about where they go to get care, so they drop out of care.	11	79	12	43
Women of color drop out of care because the medicines made them too sick.	12	86	12	43
Women of color believe that when they look good they don't need medical care.	10	71	8	29
Women of color need to work and that's more important than going to the doctor.	12	86	6	21
Women of color take care of themselves with natural remedies.	9	64	4	14
Haitian women go to the Voodoun Healers to take the HIV spell off them.	11	79	4	14
Women of color get the healing from the Believers so they're no longer sick.	9	64	11	39
Women of color report that the clinic takes a whole day, and they're not doing that.	12	86	16	57
Black women are too ashamed of being HIV to go to the clinic or HIV doctor.	11	79	12	43
Black women don't want to make their family embarrassed, so they drop out of care.	10	71	3	11
Black women believe that they are being punished by God. They believe that medicine won't help them.	7	50	4	14
Black females say that the people at the clinic/doctor are too nasty. They say they're not going back.	5	36	9	32
Women of color are worried that the people at the clinic/doctor will tell their business, so they're not going back.	9	64	11	39
Some women of color use drugs/alcohol and that comes first before the HIV care.	11	79	8	29
Some women of color don't have insurance so it's too hard to get the eligibility for the doctor/clinic.	9	64	16	57
The ADAP Nazis at the clinic are nasty and have too many rules, so some women of color have dropped out of care.	8	57	15	54
Women of color don't want their employers to find out they're positive so they won't go back to the clinic/doctor.	11	79	8	29
Some women of color are just too tired of doing everything that it takes to stay healthy. They've got burnout from all they have to do.	13	93	10	36
It's too hard for some women of color to get to the clinic/doctor. They're not going back.	10	71	14	50

APPENDIX H
STRATEGIC PLANNING RECOMMENDATIONS: PLANNING PROCESS AND IMPLEMENTATION PLAN

4152 West Blue Heron Boulevard, Ste. 228
Riviera Beach, Florida 33404

Dear Chairman Masilotti, March 21, 2005

Palm Beach County has had a unique project taking place within the past two years. We were selected as one of three sites nationally for a Special Project of National Significance (SPNS) study to determine why people who are aware of their HIV status are not in regular medical care. In 2003, the HIV/AIDS Bureau, in conjunction with the Office of HIV/AIDS Policy in the U.S. Department of Health and Human Services, chose Palm Beach County as a study participant because of the quality of our plan to discover why many black women living with HIV in our county are not seeking care. Our rate of 740 AIDS cases per 100,000 population is unusually high, and it includes a very high percentage of women of color (70%-85% of affected women), as shown in the chart below, which works out to approximately 2,000 black females in the county who are HIV/AIDS-infected. It was later determined that about 900, or nearly half, of these women are not receiving primary medical care for HIV/AIDS.

The Special Project of National Significance is called the CARE System Assessment Demonstration Project (CSADP). We have reserved your large conference room, the McEaddy room, on the 12th floor for April 19th and 20th of April, 2005, from 9:30 a.m. to 3:00 p.m., to present the findings of the CSADP and to begin broadly participatory strategic planning to address the project's findings. We would like to present our findings and recommendations to the Commissioners on the 20th of April, 2005. We can be available for the 15 minutes we are requesting for this presentation any time on April 20th between 10 a.m. and 3 p.m. We would prefer a time-certain appointment if that is at all possible. Commissioners Koons and Greene have already provided their support for this presentation.

The CSADP initiative has been a collaboration among Federal, State, County and non-profit (i.e., Treasure Coast Health) entities. The Federal Government will be represented by Christopher Bates, Acting Director of OHAP; Johanne Messore, Southeastern Branch Chief, Division of Service Systems in the HIV/AIDS Bureau of the Health Resources and Services Administration (HRSA); and Dr. Richard Conviser, Senior Health Scientist in the HIV/AIDS Bureau and originator of the project. The State will be represented by Dr. Jean Malecki; Dr. Vikas Virkud, Dr. Mitchell Durant, and Paul Moore from the Department of Health and Dr. Miriam Potocky-Tripodi from Florida International University. The County will be represented by Mr. Edward Rich and Ms. Gayle Corso from Community Services, Dr. Ronald Wewora and Mr. Michael Greene from the Health Care District, and Mrs. Barbara Jacobowitz and Dr. Karen Dodge from the TREASURE COAST HEALTH COUNCIL, INC. Also in attendance will be Leah Kedar, the principal investigator for the project; Dr. Miguel Vasquez, project analyst; and Dr. Luis Mejia, project evaluator. We are not requesting any accommodation from your budget. We are requesting only your time and attention to this effort to assess the impact of the HIV epidemic in our community and how we can address it more effectively.

We will be succinct in our presentation illustrating findings and recommendations to address them. We are seeking your support as Commissioners because you are uniquely positioned to promote broad spectrum public education in our County.

Thank you in advance for the use of the McEaddy room. We would deeply appreciate your giving us an opportunity to present our findings and recommendations to the commissioners. Please let us know if and when you would allow us to present for 15 minutes on the 20th of April.

Sincerely,

Karen Dodge, PhD, Treasure Coast Health Council: HIV/AIDS Planner Ryan White Title I

Cc: Mary McCarty; Warren Newell; Jeff Koons; Addie Greene; Karen Marcus; Burt Aronson; Robert Weissman

The large Strategic Planning group crafted the following preliminary recommendations in their small groups that had broken out by domains. These groups met in the late morning and afternoon of the first day. Large writing boards and magic markers were provided so that group members could call out their ideas in a brainstorming activity and the facilitators wrote down their responses. The facilitators had the written results of each approach (i.e., document review; systems assessment, and the RARE report), ready to refer to if there were questions or need for clarification.

DOMAINS

I. Comprehensiveness

Preliminary Recommendations

1. There needs to be an evolution of the services continuum
2. Are all of the services listed on the Continuum of Care
3. What is needed today?
4. Are other services needed?
5. How do we pull in more than the "usual suspects?"
6. What do we do with the reduction of Ryan White funding?
7. How do we balance the needs of maintaining people in care with the needs of the newly infected?
8. There needs to be a better evaluation of eligibility
9. Know that Ryan White is the payer of last resort. Everyone thinks they are the payer of last resort. Who truly holds this position?
10. One on one development of trust
11. Use a community person as a navigator
12. Locate, train and pay HIV+ individuals willing to be mentors
13. Improve basic transportation
14. What incentives can we use to get females into care?
15. Confidentiality needs to be preserved
16. Address fear of being seen at the Doctors offices/clinics/pharmacies
17. Don't submit information to insurance
18. Better monitoring of eligibility. RW payer of last resort
19. Develop incentives to get women into care
20. How is transportation defined?
21. Medical appointments are not the only transportation need
22. Broaden the understanding of confidentiality
23. Address the issues of being seen at the pharmacy
24. We can't continue to conduct business as usual
25. Require 1-1 minority navigators
26. Resurrect the buddy/companion category

After general presentations of ideas about recommendations were written on the boards within each domain group, a vote was taken by placing dots by the recommendations that were most highly considered by each and all individual members of all domain groups. The results of the votes related to each domain are displayed below after the general recommendations associated with each domain are exhibited.

Recommendations	Votes
1. Need one to one minority navigators as the new buddy /companion category	19
2. Comprehensiveness involves more than just the 'usual Suspects'	11
3. Balance between those already in care and the newly infected Address levels of need (acuity)	16
4. Develop incentives to get women into care	24
5. Better monitoring of eligibility status	5

II. Capacity

Preliminary Recommendations

1. Single Point of Entry/ eligibility and one-stop shopping/think outside of system
2. More Funding to agencies and staff
3. Financial Assistance for Clients
4. Increase knowledge of services to the Community
5. Peer education/Buddy system
6. Increase knowledge of HIV/AIDS services outside of the system
7. Change attitudes so that people want to get help
8. Better links between medical and case management
9. Housing
10. Improve access by improving transportation to medical providers
11. More competent pharmaceutical providers and medical providers and more choices in these categories

Recommendations	Votes
1. Single Point of Entry a. 1 stop shopping b. better linkage c. housing access	14
2. Funding a. financial assistance b. housing c. transportation d. more providers	30
3. Education a. increase knowledge of services available to the community b. peer education/buddy system c. hotline d. increase knowledge of services	26

outside the system
e. change attitudes to encourage people to seek help (ie. train providers in customer relations)
f. provide continuing training to providers re: HIV/AIDS

III. Integration

Preliminary recommendations

1. Share eligibility across agents/Computerize eligibility profile across all services (i.e., food, housing Medicaid, transportation)
2. Assure that this universal eligibility is user friendly
3. Enhance Direct Emergency Assistance Funding with Local Funding this would require non-HRSA funds
4. Develop a mechanism to inform HIV-workers about non-HIV funded resources and services
5. Develop a strong advocacy organization
6. Embrace in a combined manner; policy and practice (e.g., MOA's and referrals)
7. Operationalize Policies and Practices
8. Create an accountability system between and within policy and practice
9. Where, Whom, What and How do we have control?
10. Define treatment(s)
11. What does having a client-driven system mean? Define.
12. What would need to happen for the system to be more client-driven?
13. How do we become more accountable to the clients?
14. Develop incentives for referrals and f/u (linkage)
15. Utilize Factors as Single Eligibility determinant and for documentation And monitoring
16. Fund Treatment Adherence programs. Integrate them into primary care; case management and pharmacy

Recommendations	Votes
1. Improve Eligibility System	32
2. Client-driven system Including Adherence	17
3. Enhance Funding for Emergency Services	5
4. Incentives for referrals and linkages	4
5. Develop a Strong Advocacy System	14

IV. Accessibility

Preliminary Recommendations

1. Covered Bus Stops
2. Cab Vouchers
3. Gas Cards
4. Shorten process for disability eligibility bus pass

5. Palm Tran Connection information
6. Inform about church/other locations for bus passes
7. Contract with churches to use buses and/or other forms of transportation
8. Mobile health van
9. Cab card
10. Address stigma and address (geographic) stigma
11. Reduce barriers through minimizing paperwork
12. Centralized computer networking for eligibility criteria for RW providers
13. Openness/willingness to identify status in community

Recommendations	Votes
1. Acceptance of HIV/AIDS Status	22
2. Informing the Consumer/patient	11
3. Utilize storefronts	16
4. Utilize central IT system for eligibility (all RW clients)	29

V. Acceptability

Preliminary Recommendations

1. Treatment Adherence Groups
2. Train Providers about treatment adherence
3. Mandatory provider documentation of adherence issues (put in client/patient file
4. Internal System in place for customer service and front line staff
5. Confidentiality training across all providers and administrators at all staffing levels
6. Stigma
7. To eliminate stigma put services where other services are also provided (wrap around services)
8. Education, education, education
9. Outreach by churches and other faith-based organizations
10. Make choices available for the people;
11. Enhance capacity by encouraging minority providers to apply for funding
12. Provide TA to such organizations before they fall into hot water
13. Have providers resemble the people
14. Acceptance of HIV status
15. Educate all media venues
16. Shift/share priorities for social services
17. Have entertainment instead of HIV tapes run at the clinic
18. Literacy classes
19. Informing the consumer needs to be a priority
20. Use storefronts/churches/local physicians offices

Recommendations	Votes
1. Treatment Adherence	16
2. Customer Service and Confidentiality training	27
3. Address Stigma with all providers of service not	

just HIV/AIDS providers	19
4. Education/Outreach by Faith-based CBO's	7

VI. Technical Competencies

Preliminary recommendations

1. Produce different methods of education to and for clients, providers, and community leaders
2. Get local churches involved
3. Get rid of the stigma
4. Use peer counselors to educate the community
5. Create community Health Centers (CHC's)

Recommendations	Vote
1. Produce different methods of education to and for clients, providers and Community leaders	40
2. Get local churches involved	36

VII. Client Health Seeking Behaviors

Preliminary recommendations
1. Beliefs and education
2. Confidentiality and trust in the system
3. Denial…Retesting
4. Provide options for medical care
5. Education about using patience and compassion
6. Address religious and cultural beliefs of both consumers and providers
7. Help providers better understand the culture, ideology and perceptions of the consumers
8. Teach the HIV patient to put their health (including mental), first. Posit this by suggesting that it would be difficult to take care of your family if you got really sick and couldn't get out of bed. You can't take care of the needs of others if you aren't healthy physically and mentally, emotionally, spiritually and socially
9. Change system to engender trust
10. There need to be consequences for violating confidentiality
11. Stigma… Combat through public education; speak to how disease is spread. Don't just emphasize drug users; gay men; prostitutes; Haitians; and Bi-sexual. Make it real for middle of the road, ordinary folks
12. Fear…This is exacerbated through segregation of services. A remedy would be to integrate or mainstream all services

Recommendations Votes

1. Beliefs	18
2. Fear/Stigma	28
3. Denial	3
4. Confidentiality	26

Recommendations Displayed by Voted Upon Frequency

Highlighted Recommendations collapsed across domains and collective recommendations

I. Education

What:
- Educate providers think outside of the box
- Educate community leaders in the language of the people
- Develop Peer educators and utilize the language of the people
- Tailor the message to the audience
- Increase consumer information

Who:
- EPICC;
- DOH: Robb Scott
- RMAC (regional minority AIDS coordinator)
- Peer educators
- Volunteers affiliated and not affiliated with the Volunteers at DOH
- Community Stake holders
- Churches
- Storefronts

How:
- By requiring 4 hour certificate
- Construct speaker data base
- Create a network of peer educators by establishing an agency that does this task exclusively
- Create alternative funding/non-service
- FIGS= Filling in the GAPS with a volunteer force
- Identify and train community stakeholders/ involve the communities

When:
- Quarterly interagency educational training
- Set up two peer educators within the next year
- Recruit three Volunteers within next year
- Identify and train two community stakeholders within the next year
- All participants will have time-limited commitments

II. Single Point of Entry

What: Acceptance of system by State and Federal programs

Who: Project Access
Benefits Bank
DOH
Palm Beach County Health Care District,
Medicaid,
Medicare
WIC,
DCF

Where: Undetermined at this point

How: Investigating collaborations with entities that have achieved Single Point of Entry or Access, locally
Identify Comprehensive System serving entities
Set up client navigators that can help similar other negotiate the entire system
Set up 'in kind' payment system
Consider State liability package
Collaborate with Community Services, the Palm Beach County Department of Health, the Palm Beach County Health Care District, Medicaid, Medicare WIC, DCF, to get a full system-wide single Point of entry/access system

When: These are all on-going processes
Review progress every 6 months

III. Confidentiality

What: This issue revolves primarily around the training of all staff at all providers regardless of their focus (e.g., private physicians, non-HIV providers; HIV-providers, Labs, Insurance companies etc…), about confidentiality related to HIV/AIDS. All service providers need to produce a combined effort to accomplish this.
Who: 1. All staff particularly front line staff
2. All Funding sources
3. Leadership at all levels need to be trained in this issue and taught about enforcement and consequences

How:
1. Hold all staff accountable this needs to be enforceable by written documents signed by employees and kept in their contracts
4. Reassure clients/patients of existing confidentiality laws
5. If breach occurs consequences need to transpire
6. Empower the client
7. Agency needs to post this new philosophy or verbally convey it in the 3 languages
8. Files need to be maintained in a confidential manner; Lock them up immediately
9. Receptionists need immediate training on how to keep confidentiality

10. A system needs to be in place for hard files in the MIS/IT system at the State and local levels
11. Phone lines need to be secured and unidentifiable. Restrictions need to be in place
12. Signage: Signing of signatures need to be minimal
13. Service integration needs to occur
14. Put confidentiality guarantee and consequences in each providers contract

When
1. ASAP for all recommendations
2. The trainings need to occur every 6 months
3. Accountability needs to be in place throughout employment
4. Confidentiality clauses need to be reviewed at hire and at regular intervals throughout employment
5. Files need to be locked up immediately after use

IV. TREATMENT ADHERENCE

What: This concept needs to be generalized and then implemented across services; for example mental health, substance abuse maternal/Child Health. This is important in light of the serious, unacceptable and deleterious side effects.

Who: Anyone of the sundry of suppliers providing services for our Consumers or a narrowly and specifically defined job description could be created to accommodate this need.

Where: At the DOH, Private physicians offices, Dentists, Pharmacists,
Nursing appointments, Lab appointments, at case management offices, etc…

How: Education; Peer Navigators or treatment adherence specialists will provide an enhanced treatment adherence at any/every given point in the visiting schedule of the identified client. Improve cognitive functioning of clients vis a vis substance abuse tx. and mental health counseling. Discuss the uncertainty of side effects and the importance of continuing despite being uncomfortable. Distinguish between real “effects’ and the “threat of effects”. Mention treatment Holidays and the management of side effects. Address issues of memory, addiction, and mental health (i.e., depression). Design a pt. /provider connection that is 2-way and is a open discussion about methods of providing treatment in a way that is acceptable to the client. Design an intervention that uses role-play, trials, buddy-system, that facilitates client commitment. Provide non-judgmental support to a patient’s decision to make a choice about treatment and adherence to their choice.

When: At all points in the primary medical care process. To utilize each patient/doctor contact as an opportunity to provide enhanced treatment adherence by a Tx. Adherence specialist or by case managers; doctors and/or nurse care coordinators.

Objectives:

I. Communication and building a relationship that is productive
   1. Improve cognitive functioning
   2. Develop 2-way communication and commitment (pt. and provider)
   3. Echo pts. beliefs by following their treatment decisions (use role play, treatment navigators).
   4. Provide group dynamics, patient adherence training and education, buddies, individualized treatment
   5. Set up feasible times for clients
   6. Use multiple points in treatment process to educate and encourage clients
   7. Educate providers on their participation in the dominant paradigm And cultural sensitivity and the importance of teamwork
   8. Negotiate with clients about their role in their treatment
   9. Ensure that clients have the opportunity to choose their own role in their health

II. Enhance the Patients beliefs in their own ability to follow through on Their treatment decisions
   1. Practice trials
   2. Buddies who model behavior will be used as Peer Supports/ navigators
   3. Help patients/consumers recognize and overcome barriers

III. People should be readied for adherence before adherence is expected
   1. Improve Patients/consumers cognitive functioning
   2. Remain respectful of addicts/alcoholics and not deny treatment because of limitations and provide substantial support to help them remember to attend appointments and take medications
   3. Provide mental health services
   4. Do not allow people with cognitive impairments to fall through The substance abuse/mental health cracks
   5. Use memory devices
   6. Provide reminder calls from clinic/social services
   7. Simplify medication regimens to fit into the consumers lives

V. STIGMA

What: To address the societal stigma that makes it difficult for someone to Come forward and seek help for their HIV-spectrum disease

Who: Social Marketing needs to occur that develops PSA's to disseminate to various media venues. For example: PSA" s need to address the changing of Public Relations; Marketing services; reframe HIV and its labeling to a more positive focus; provide a new direction (i.e., go back to school; get a job); contribute to society; train churches to embrace their HIV members instead of distancing them and punishing church members; Use Big Sisters/Big Brothers to reach those needing care; Provide peer navigators/buddy companions that are defined by the clients needs; Use family members to be beacons of support to their family members and to other families dealing with the same thing; construct gender-sensitive support groups; Introduce these concepts to the CARE Council to garner their support for funding issues

Where: Churches; CARE Council; Media venues; Big Brother/Big Sister; Schools; Case management and Clinics and Primary Care Centers; Community Centers; Marketing venues

How: Address misconceptions

1. Discuss this as how the press portrays it, “ An ugly disease”
2. It need not be portrayed as a death sentence
3. People Living with HIV disease need not be defined by the Disease
4. Being on mood and mind altering drugs to deal with HIV is Not mandatory in fact, this philosophy can be harmful
5. HIV-spectrum disease need not be marketed and viewed as an “immoral” disease
6. Redefine HIV-spectrum disease as a chronic disease similar to Diabetes or Heart Disease or Cancer. Recall Cancer being called The big “C”.
7. Social Marketing is required to reframe cognitions of providers And consumers and the general population to mainstream the Concept of HIV/AIDS as merely just another disease
8. Change the preconceived notions held about HIV/AIDS through Education
9. Work with the family of the HIV+ individual to help them better Understand the disease and related myths. This might help to Normalize their behavior towards the infected family member
10. Create educational programs and provide affiliative support groups
11. Involve churches and construct relevant spiritual education and acceptance programs

VI. Cultural Beliefs

What: Outreach: Identify and work with ideas held by the populations under consideration to craft the most effective models for outreach and meet the people where they are

Who: Use people from the community that are trained/have knowledge of How to engage the people appropriately

Where: Engage the people in their neighborhoods

How:
1. Questions need to be asked such as 'How do we educate?'; 'How do we know of beliefs?'; 'How do you meet the people?'; 'Where do we meet the people?'; 'How do we develop trust?'
2. Bring back peer advocates, buddy/companions
3. Clone the diehards (eg. Shirley; Lorenzo; Mary Jane; Annette)
4. Partner with churches that hold the same beliefs as the targeted pops.
5. Partner with community organizations that hold the same beliefs as the targeted populations
6. Demonstrate an interest in this population
7. Conduct sensitivity trainings relevant to the population that is target
8. Recruit more culturally diverse medical providers.
9. Help with comfort level between providers/clients
10. Dialog sessions: Get an understanding of how the people feel and think and behave
11. Develop ideas on where to go and when to meet the people

IMPLEMENTATION PLAN

GOAL I: Education

To continue to expand the education about HIV/AIDS in terms of prevention and clinical care to 100% of Live AIDS-diagnosed and to 65% of those Live HIV-diagnosed and aware. Reach such individuals through leadership, support and education. Incorporate peer educators as trainers and strive to achieve 100% involvement by Providers in this initiative. Cross train these individuals together in a team collaborative. Tailor messages to those we intend to reach.

OBJECTIVE I.1 Continue to build an active network of PLWH/A'-Peer Educators through the Consumer Advisory Committee; neighborhood outreach and Provider organizations.

#	*ACTION*	*RESPONSIBLE PARTIES*	*IMPLEMENTATION DATE*	*STATUS AS OF September 1, 2005*
1	Recruit and advocate and encourage PLWH/A'S to participate in Consumer activities and to become Peer Navigators.	Consumer Advisory/ Planning Council in concert with CBO'S and Provider Organizations	Ongoing	Council Administration working with local CBO to increase consumer participation.
2	Communicate with consumers to encourage their participation in the Peer Education Program. (i.e. Peer Navigators)	Consumer Advisor/ Planning Council and the PLWH/A's informal networks	Ongoing	Continues on a one-to-one basis. No organized efforts at this time.
3	Reach out to the infected/affected consumer communities	Consumer Advisory/ Planning Council; CBO'S, Providers and informal networks	Ongoing	Not being done in any organized fashion.
4	Continue ongoing, regularly scheduled meetings to discuss treatment advances, advocacy and other important issues with Peer educators and outreach workers	Consumer Advisory committees and the newly formed Peer Navigators	Ongoing	This committee meets on a monthly basis. Additional Consumer group meetings for other populations will begin in November, 2005
5	Re-examine communication tools for outreach and information dissemination	Consumer Advisory/ Client Services/ Council Administrator	2005	To date has not been done
6	Actively work to form a functioning Consumer/Peer Navigator Advisory Committee	Consumer Advisory/ Planning Council	2005	Ongoing process w/ local CBOs & Council Administrator
7	Communicate with providers to encourage participation in Consumer/Peer Navigator Advisory Committee	Consumer Advisory/ HIV Service Coordinator/ Council Administrator	Ongoing	To date has not been done.
8	Tailor educational messages to the targeted populations	Consumer Advisory/ Planning Council	Ongoing	Fliers disseminated for sessions but no organized efforts.

9	Publish a Consumer/Peer Navigator/Education committee's newsletter on a quarterly basis	Consumer Advisory/ Council Administrator/ HIV Services Coordinator	2005	To date has not been done.

OBJECTIVE 1.2: Establish a policy and action plan for education about HIV/AIDS education for Community Leaders that is appropriate for them.

Advocate for effective educational trainings for community leaders in medical and support services related to HIV/AIDS. Continue to encourage significant progress in the prevention/ education and treatment/education of HIV/AIDS.

#	*ACTION*	*RESPONSIBLE PARTIES*	*IMPLEMENTATION DATE*	*STATUS AS OF September 1, 2005*
1	Maintain a visible presence at local faith-based and state and national functions of direct concern to the HIV Planning Council. These functions are important in terms of training and updating	Planning Council/ Council Administrator	Ongoing	Contact is maintained via email but travel has been limited due to lack of manpower hours.
2	Continue to participate in the Statewide Coordinated Statement of Need project	Planning Council/ Council Administrator	Ongoing	Contact is maintained via email but travel has been limited due to lack of manpower hours.
3	Continue to participate in the statewide HIV prevention planning group (Note: Providers and Stakeholders are involved in these functions).	Planning Council and CPP Planning Groups	Ongoing	Member of the Council sits on this committee. No monthly reports or summaries are received at this time.
4	Participate in any newly created relevant local educational forum related to HIV/AIDS. Build-in a 4-hour certificate program for these trainings	Planning Council/ Council Administrator	Ongoing	To date, none have been created.
5	Continue to provide a community forum to inform Planning Council members, providers and community stakeholders of recent developments concerning HIV/AIDS-related issues	Council Administrator	Ongoing	Updates are distributed during monthly meetings and via email depending on time sensitive data.
6	Establish semi-annual meetings for networking	Executive Committee/ Council Administrator	2005	
	Consider the formation of	Executive Committee/		TA from HRSA to

7	an Integrated Planning Committee, which will coordinate all HIV/AIDS services within the County.	Council Administrator/ Grant Administrator/EPICC	2005	beginn in September 2006 for reorganization of Council.

OBJECTIVE I.3 Raise the level of awareness by the public regarding the needs of the HIV/AIDS Community in a manner/language the targeted population(s) find acceptable and appropriate

#	***ACTION***	RESPONSIBLE PARTIES	IMPLEMENTATION DATE	***STATUS AS OF*** September 1, 2005
1	Publicize the results of important research by the Planning Council such as Needs Assessment, Unmet Need, Special Studies, etc., in a manner comprehendible to the people	Executive Committee/ Council Administrator	Ongoing	Needs Assessment Update to be approved by Council July, 2006. Unmet Need began in 2003 and continues to be updated.
2	Publicize and make accessible all meeting minutes of the Planning Council and its committees	Council Administrator	Ongoing	All minutes and sub-committee minutes are posted on the web-site within 7 days of the meeting.
3	Re-evaluate and maintain the Planning Council website	Executive Committee/ Council Administrator	Ongoing	Website has been redesigned to be more consumer friendly.
4	Develop relationships with Latino community/ social organizations to expand access and communication to this population	HIV Services Coordinator/ Council Administrator/ Planning Council	2005	To date, this has not been done.
5	Build relationships with African American community/ social organizations to enhance access and communications with communities of color	HIV Services Coordinator/ Council Administrator/ Planning Council	2005	To date, this has not been done.
6	Enhance access to the Planning Council via printed materials, the internet, personal contact & outreach	Planning Council/ Council Administrator/ Executive Committee	2005	
7	Reevaluate & maintain the 800-number. Construct a speaker data-base	Client Services/ HIV Service Coordinator	2005 & ongoing	To date, this has not been done.
8	Build relationships with the gay, lesbian, bi-sexual & transgender community to publish realistic sensitive & consistent messages & thus bring more PLWH into services	HIV Service Coordinator/ Council Administrator/ Planning Council	2005	

OBJECTIVE I.4 Develop a Peer Navigator recognition program

#	***ACTION***	RESPONSIBLE PARTIES	IMPLEMENTATION DATE	***STATUS AS OF*** September 1, 2005
1	Develop and maintain a structured and formal commemorative for deceased Peer Navigator members.	Executive/ Council Administrator/ World AIDS Day Committee	December 2005 and annually thereafter	
2	Develop and implement a recognition program for accomplished and productive Peer Navigators.	Executive/ Membership/ Council Administrator	November 2005 and annually thereafter	

OBJECTIVE I.5 Continue to support special programs that would foster the image of the Planning Council and/ or benefit Title I, Title II and all HIV/AIDS State programs.

#	***ACTION***	RESPONSIBLE PARTIES	IMPLEMENTATION DATE	***STATUS AS OF*** September 1, 2005
1	Continue to host events in conjunction with World AIDS Day.	Executive/ Planning Council/ World AIDS Day Ad Hoc/ Council Administrator	Annually	Ongoing basis.
2	Assist and support faith-based organizations in the endeavors to reduce risk among and develop outreach programs for their constituents.	Executive Committee/ Council Administrator/ Planning Council	Ongoing	To date, not being done.

OBJECTIVE I.6 Integrate new consumers into the Peer Navigator Committee and thereby continues to build capacity of the planning Council.

#	***ACTION***	RESPONSIBLE PARTIEIS	IMPLEMENTATION DATE	***STATUS AS OF*** September 1, 2005
1	Continue a one-on-one personal outreach program for the purpose of Peer Navigator recruitment and advocacy	Consumer Advisory/ Membership/ Planning Council/CBO'S/Neighborhood outreach	Ongoing	Being done w/out an organized plan.
2	Provide skills building activities for the Peer Navigator Advisory Committee	Consumer Advisory/ Council Development	2005 and ongoing	TA in conjunction with Council reorganization to begin in September, 2005.

3	Provide ongoing nurturing and support to all members of the Peer Navigator Advisory committee	Council Development/ Consumer Advisory/ Planning Council/Peer Navigator	Ongoing	To date, this has not been done. Part of reorganization efforts.
4	Develop a Mentoring Program to assist new Peer Navigators as they begin to take an active role in their work	Council Development/ Peer Navigators	March 2005	On hold till reorganization effort begun in September, 2005 completed
5	Review and update Peer Navigators Training Manual	Council Development/Peer Navigators Development	Annually	To date, this has not been done. Part of reorganization efforts.

OBJECTIVE I.8 Continue the educational and capacity-building activities of the Planning Council and the HIV/AIDS community as whole; including providers and leaders.

#	***ACTION***	RESPONSIBLE PARTIES	IMPLEMENTATION DATE	***STATUS AS OF*** September 1, 2005
1	Continue Planning Council education/ information training through the "Planning Council" moment	Council Development	Ongoing	On hold. HRSA TA begun September, 2005
2	Develop and provide semi-annual education workshops based on the training guidelines established by HRSA.	Council Development	2005	
3	Develop an advocacy training for members	Council Development	2005	
4	Develop training/ advocacy guide for mentors, community stakeholders, providers and local power brokers	Council Development/ Council Administrator	2005	

Additional ideas:

PROVIDE SUFFICIENT FUNDING TO CONDUCT A COUNTY-WIDE PUBLIC AWARENESS CAMPAIGN THAT REACHES ALL OF THE TARGETED POPULATIONS INCLUDED IN THIS STUDY. THIS CAMPAIGN SHOULD BE CONDUCTED IN ENGLISH, SPANISH, SEVERAL MAYAN INDIAN DIALECTS, CREOLE AND FRENCH TO ADDRESS HIV/AIDS CLINICAL CARE ISSUES.

Strategies:

1). Encourage a partnership between the State of Florida, local cultural organizations, private enterprises and the Public Health system to fund and infiltrate the media with information about HIV/AIDS.
2). Recruit Latino, Guatemalan and Haitian Volunteers, emphasizing the church, to deliver radio, television and written and drawn messages relating to HIV/AIDS.
3).Increase funding or utilize available sources to provide educational outreach to our county's public school system, prison systems, substance abuse treatment facilities, Mental health agencies, foster care and other child welfare systems and local government officials.
4). Present HIV/AIDS as the health threat that it is; underscoring the upward trend towards increases in STD'S; AIDS incidence and teen pregnancies.

DEVELOP A MEDIA BLITZ THAT EMPHASIZES THAT MINORITY PERSONS WHO ARE AT RISK OF HIV AND AIDS INFECTION SEEK TESTING.
1).Place posters in key places in targeted neighborhoods to educate community members about HIV and direct those individuals to community-based testing and referral sites.
2).Sex workers, Johns, Substance Abusers and Drug distributors to receive "104".
When any of the above are arrested, we recommend that they be required to get education on HIV (i.e., "104", the designation of the standard course on AIDS required by Palm Beach County Health Workers).
3).Distribute and publicly play audio tapes containing messages on prevention of HIV and the accompanying testing and referral information. The tradition of sending and receiving audio cassettes has potential as a vehicle for disseminating public service announcements.
4).Place condoms and needle/syringe sets in zones where the assessment teams worked. Additionally, provide information where individuals can be tested for HIV and referred for services.

DEMONSTRATE THAT THE COUNTY OF PALM BEACH HAS A CONTINUED COMMITMENT TO HIV CLINICAL CARE ACTIVITIES BY TAKING A LEADERSHIP ROLE IN IDENTIFYING AND SECURING ADDITIONAL FUNDING TO ADDRESS AND IMPLEMENT THESE RECOMMENDATIONS.
1). Commit and/or provide through the county, the mechanism to secure additional funding to support harm reduction and HIV care/outreach initiatives, including but not limited to:
 The dissemination of wound care items
 Water and condom distribution
 Syringe/needle kits
 Expanded HIV/AIDS, STD and Family Planning counseling and testing and referral services HIV Primary care, case management and other supportive services
2).Dedicate and/secure funding through the city of West Palm Beach and the County of Palm Beach to serve as HIV liaisons within the mayor's and county commissioners offices.
3). Support mechanisms to provide technical assistance to organizations targeting high-risk populations around capacity building so that they are able to obtain future resources.

GOAL II: SINGLE POINT OF ENTRY

OBJECTIVE II.1: Provide a comprehensive and detailed description of what the EMA means by 'Single Point of Entry'. Define this variable and operationalize it with the involvement of the Planning Council; The Community Planning Partnership and EPICC.

#	*ACTION*	*RESPONSIBLE PARTIES*	*IMPLEMENTATION DATE*	*STATUS AS OF July 1, 2005*
1	Assure adequate resources are available to support the defining of this concept and that there is sufficient support within the HIV/AIDS Continuum of Care to further this endeavor. Begin the operationalization process within the Planning Committee	Needs Assessment/ Planning Committees of HIV CARE Council/CPP/EPICC	Ongoing	The Planning Committee has undertaken this in the past and will continue as it has reemerged.
2	Update a Consumer and provider inventory of information on SPOE/A functions and resources related to the Public Health or Social Services with a user friendly information gathering and reporting tool	Needs Assessment/ Planning Council/ Council Administrator/CPP/DOH/HCD	Ongoing	Ongoing
3	Provide informational updates of all population and service categories relating to Single Point of Entry/Access	Needs Assessment/ Planning Council/ Administrator	Ongoing	Rich data available in updated Needs Assessment, Comprehensive Plans; Grant applications. Additional information being used from Special Studies.
4	Conduct Client and Provider Town Meetings on Single Point of Entry/Access to determine if there is sufficient community interest	Assessments designed in the Planning Committee/ Council Administrator	Ongoing	Begin this data gathering in Fall of 2005.Need to consider outside sources for conducting FY05 information gathering
5	Conduct a Public forum	Planning Committee Assessments / World AIDS Day Adhoc/ Council Administrator	Annually	

OBJECTIVE II.2 Create a strong collaboration with entities that have achieved Single Point of Entry/Access and develop a consortium of interested entities locally to serve the HIV/AIDS Community

#	*ACTION*	RESPONSIBLE PARTIES	IMPLEMENTATION DATE	*STATUS AS OF* September 1, 2005
1	Identify providers/provider systems either currently implementing or interested in implementing a single point of entry system in Palm Beach County Florida to recommend appropriate actions to the Council.	Planning Committee/Client Services representatives	Begin in Fall of 2005	Beginning in July, 2005
2	Continue to identify working Single Point of Entry Systems; ask for literature and recommendations	Planning Committee	Ongoing	Beginning in July, 2005.
3	Promote a literature review of Single Point of Entry/Access	Planning Committee	Ongoing	Planning Committee to resume this in Fall of 2005
4	Ask for assistance from Project Access	Grant Administrator	2005 and 2006	Fall of 2005

OBJECTIVE II.3 Develop a comprehensive and coordinated ‘in-kind’ reimbursement program using skills of those employed at the various Continuum Agencies and by utilizing other ‘in kind’ donations.

#	*ACTION*	RESPONSIBLE PARTIES	IMPLEMENTATION DATE	*STATUS AS OF* September 1, 2005
1	Advocate for the development of ‘in kind’ programs for hard to get services for the purposes of linking hard to serve clients with hard to get services	Client Services/ Consumer Advisory/Support Services/Medical Services	2005	To date, this has not been done.
2	Continue collaborative/educational forums that include targeted discussions on how to get services from providers outside the RW realm	Support Services/Medical Services/ Funders/Grant Administrators	Ongoing	To date, Support Services has not hosted any forums but these could be part of the Capacity Development Program as a funded service category.
3	Collaborate with faith-based and Providers outside the HIV/AIDS Community for more effective linking to services that other entities offer (e.g., ADM, CARP, Oakwood, Food Stamps, etc...).	Planning Council/ Council Administrator/ HIV Services Coordinator	2005	Include Directors of local Projects by Fall of 2005
4	Collaborate with non-HIV specific groups for more effective outreach to Migrants at risk for HIV/AIDS	Planning Council/ Council Administrator/ HIV Services Coordinator	2005	Ongoing
5	Evaluate the need for and advocate	Needs Assessment/		Ongoing

	for the development of support for this initiative	Support Services/ Planning Council/ Council Administrator	2005	

Additional ideas:

ESTABLISH TARGETED FUNDING TO ADDRESS THE HIV/AIDS BARRIERS UNCOVERED IN THE PALM BEACH COUNTY CDADP REPORT RELATING TO MINORITY COMMUNITIES. THIS TARGETED FUNDING SHOULD BE USED TO FUND MINORITY ORGANIZATIONS IN ORDER TO ADDRESS HIV PATIENT CARE NEEDS WITHIN THE SINGLE POINT OF ENTRY ENVIRONMENT.

1). Encourage collaboration between established HIV/AIDS providers, Public Health, Community-Based organizations and emerging minority agencies.

2).Provide adequate funding for HIV single point of entry education and
collaboration for providers.

3).Form a collaborative of minority organizations that can construct and apply for grants on a unified basis. Have a buy in from well established agencies that will provide data upon request.

CONSTRUCT PATIENT CARE SERVICE WITH SINGLE POINT OF ENTRY STRUCTURE IN MIND; WITHIN THE TARGETED COMMUNITIES. FURTHER CONSIDER NEEDS THAT CSAD PROJECT RESPONDENTS HAVE INDICATED WHEN THEY ARE PRACTICING HIGH RISK BEHAVIORS.

1).To avoid stigma attached to AIDS-only venues and services, provide venues and services that are health-generic. Offer these services in places associated with generic health concerns.

2). Develop and sustain satellite community-based services in neighborhoods where high-risk behaviors occur. Staff these offices with trained members of the surrounding indigenous communities.

3).Outreach agents need to be available to provide services at hours when clientele are receptive to services and education.

4). Utilize the Risk-related to Time information gathered from this project to guide construction of intervention time schedules and other needs.

DESIGN A PLAN TO EVALUATE THE IMPLEMENTATION OF THE SINGLE POINT OF ENTRY RECOMMENDATIONS BY THE CSAD PROJECTS' ADVISORY COMMITTEE.

1).Include the outcomes of the CSAD Project and attendant recommendations in the Comprehensive Plans of the local Community Planning Partnership and the Palm Beach County HIV CARE Council.

2).Conduct a Secondary Analysis with the data collected by the Comprehensive Three Year Needs Assessment to determine whether or not the qualitative data collected in the CSAD Project is congruent with the HRSA required analysis of HIV/AIDS need in Palm Beach County. Utilize information relevant to the zip codes explored by the Field Teams.

3).Analyze data on the number of positive tests, negative tests, and posttest counseling rates relevant to sites ands the imminent testing/counseling/referral needed in the County.

4).Compile a list of minority community-based organizations applying for and receiving HIV prevention dollars through federal, state, local and private funding.

5).Collect the number of new testing sites given to minority organizations.

GOAL III: CONFIDENTIALITY

To strengthen the mechanism for Confidentiality training; comprehensive education and enforcement for all staff at all providers. Accountability will be designed and implemented by quality assurance and performance improvement criteria in achieving EMA standards of care relating to Confidentiality and how it's defined and measured.

OBJECTIVE III.1 Require adherence to minimum standards regarding Confidentiality for all Providers involved in providing HIV/AIDS services

#	*ACTION*	RESPONSIBLE PARTIES	IMPLEMENTATION DATE	***STATUS AS OF*** September 1, 2005
1	Revision of the Standards of Care including Outcome objectives for Confidentiality across all services and providers. Specialty Medical Providers need to adhere to these standards, too.	Support Services/Medical Services/ Grant Administrator	2005	Standards need to be completed & approved by Council. Outcome measures have not been developed.
2	Revision of the Standards of Care for all other service categories to reflect confidentiality inclusions	Client Services/ Grant Administrator	2005	Ongoing
3	Re-examine how confidentiality trainings are provided and required for all providers; recommend revisions and make this mandatory	Client Services	2005 and annually thereafter	Training requirements will be presented to Council in October, 2005 for adoption.
4	Collaborate with Providers in the EMA in an effort to develop a mechanism to make an HIV/AIDS Confidentiality specialist a preferred position within a designated provider. Such an individual needs credentials, experience and established demonstration of success with PLWA/H's.	Planning Council/ Council Administrator/ SCSN Task Force	2005 until goal is accomplished	To date, this has not been done.

OBJECTIVE III.2 Promote consumer empowerment and education programs regarding rights and responsibilities of those receiving services among Title I and Title II services.; highlighting the issues of confidentiality.

#	*ACTION*	RESPONSIBLE PARTIES	IMPLEMENTATION DATE	***STATUS AS OF*** September 1, 2005
1	Promote innovative programs to educate and encourage	Support Services/Medical	2005	To date this has not been done.

	consumer empowerment and education re: confidentiality	Services/ Consumer Advisory		HRSA TA could begin September, 2005
2	Re-evaluate the mechanism to address client's grievances beyond the agency level relating to issues of confidentiality	Client Services/CARE Council	2005	To date, this has not been done. HRSA TA begun September, 2005

OBJECTIVE III.3 Conduct evaluations of implementation of confidentiality and enforce these standards by the written policies as designed by the CARE Council

#	***ACTION***	RESPONSIBLE PARTIES	IMPLEMENTATION DATE	***STATUS AS OF*** September 1, 2005
1	Continue evaluation via QA on confidentiality discrepancies and gaps at all service providers	CARE Council and QA specialist/Confidentiality Specialist	Annually	Ongoing.
2	Enforce policies designed to address breaches of confidentiality. Review provider reports to assist in determining emerging needs and confidentiality problems	CARE Council/ QA and Confidentiality Specialists/Grant Administration	Ongoing	On going.

Additional ideas:
REQUIRE THAT ALL DEPARTMENT OF HEALTH EMPLOYEES AND COMMUNITY - BASED ORGANIZATION STAFF AND VOLUNTEERS PROVIDING SERVICES TO CLIENTS IN ANY PROVIDER AGENCY; RECEIVE CONFIDENTIALITY TRAINING. THE TRAINING NEEDS TO BE INCORPORATED IN EMPLOYEE ORIENTATION.
1).Encourage a partnership between Palm Beach County and Florida universities to educate incoming students via confidentiality. Likewise, cultivating a relationship with colleges and universities in the Caribbean may yield similarly beneficial results.
2).Require that all state HIV/AIDS contracts have a staff training component requiring confidentiality training, implementation and adherence , which includes standards.The agency must conform to all requirements set by the Center for Disease Control and the State of Florida.
3).Recruit Guatemalan, Spanish, and Haitian workers to provide HIV/AIDS Confidentiality training to their respective neighborhoods in a culturally appropriate manner.

GOAL IV: TREATMENT ADHERENCE

To maximize Treatment Adherence implementation and utilization by the network of care at 100% for all clients.

OBJECTIVE IV.1 Provide opportunities for providers to craft treatment adherence protocols with the CARE Council

#	***ACTION***	RESPONSIBLE PARTIES	IMPLEMENTATION DATE	***STATUS AS OF*** September 1, 2005
1	Encourage providers to share information and to utilize the Council's Public Forum and the HIV Service Coordinator's monthly meeting to disseminate important information including changes in agency policies, documentation, personnel, etc.	Planning Council/ Executive Committee/ HIV Services Coordinator	Ongoing	Need to reevaluate this type of information in the Public Forum of the meeting.
2	Facilitate interactions between community-based organizations; AIDS service organizations and faith-based organizations, which will act as a catalyst for dialogue and the exchange of ideas among all involved.	Planning Council/ Executive Committee/ HIV Services Coordinator	2003	To date, there is limited participation from various groups at the HIV Provider's Network meeting.
3	Develop a quarterly bulletin that highlights/ updates changes in providers, policies and staff.	HIV Services Coordinator/ Council Administrator	2004	To date, this has not been don.

OBJECTIVE IV.2 Create an implementation protocol and time schedule for roll out of treatment adherence.

#	***ACTION***	RESPONSIBLE PARTIES	IMPLEMENTATION DATE	***STATUS AS OF*** September 1, 2005
1	Establish an inter-agency task force of providers and consumers to explore and create an appropriate TX. adherence intervention for the EMA	Executive/ Needs Assessment/ Client Services/ Council Administrator	2005	Development done, first meeting being organized.
2	Develop written recommendations for TX. Adherence	Needs Assessment/ Planning/Capacity Development Ad Hoc	2005	
3	Organize and host a regional TX. Adherence summit	Executive Committee/ Adhoc Task Force	2005 & bi-annually	Done as part of Capacity Building in 2005.

OBJECTIVE IV.3 Create Standards of Care relating to Treatment Adherence and monitor such implementation

#	***ACTION***	RESPONSIBLE PARTIES	IMPLEMENTATION DATE	***STATUS AS OF*** September 1, 2005
1	Update and continue work on provider inventory re: TX. Adherence	Needs Assessment/Planning/ Council Administrator	2005 and ongoing	Phase I complete. Follow-up to be done by January, 2006
2	Update the analysis protocols and monitoring protocols for TX. Adherence	Needs Assessment/Planning Council Administrator	Ongoing	To date this has not been done.

3	Conduct an actual Inventory and evaluation of TX. Adherence in the EMA and identify client usage pattern	Needs Assessment/ Planner/Grant Administrator	Ongoing	To date this has not been done.
4 4	Begin to collect service utilization data from the monthly provider's reports	Needs Assessment/Planner HIV Services Coordinator/ Grantee	Ongoing	Information obtained via Grant Administration.

OBJECTIVE IV.4 Develop strategies to link treatment adherence protocols with Substance Abuse and Mental Health services and Primary Medical Care

#	***ACTIONS***	RESPONSIBLE PARTIES	IMPLEMENTATION DATE	***STATUS AS OF*** September 1, 2005
1	Conduct mini surveys to obtain targeted information on specific information on how ETOH and MH use TX. Adherence services	Needs Assessment/Planner HIV Service Coordination/ Council Administrator	2005	Targeted and additional surveys need to be done to update this information to reevaluate the process.

OBJECTIVE IV.5 Require a comprehensive and ongoing training program for all providers relating to treatment adherence.

#	***ACTION***	RESPONSIBLE PARTIES	IMPLEMENTATION DATE	***STATUS AS OF*** September 1, 2005
1	Provide training strategies that case managers and medical providers can employ to empower consumers and inform and improve TX. Adherence	Client Services/Planner HIV Service Coordinator	2005 and ongoing	To date this has not been done.
2	Provide training strategies to enhance provider's communication skills, particularly in the areas of client choice, and how to support a TX. Adherence	Client Services/ Planner/HIV Service Coordinator	2005 and ongoing	Trainings need to be offered through Capacity Development Committee and during the Provider

	Plan constructed by the client.			Network meetings. Mandatory attendance needs to be enforced
3	Provide training programs in substance abuse interventions, harm reduction & identification of substance users	HIV Services Coordinator/Planner/Grantee	2005 & ongoing	To be done by Capacity Development and Provider Network meetings.

OBJECTIVE IV.6 Develop a plan to assure that clients have the opportunity to chose their treatment adherence protocols and support the clients choices regardless of their decisions.

#	***ACTION***	RESPONSIBLE PARTIES	IMPLEMENTATION DATE	***STATUS AS OF*** September 1, 2005
1	Explore alternate systems of other models of TX. Adherence	Client Services/ Planner/HIV Service Coordination	2005	To date this has not been done.
2	Link Title I and non-Title I case management, Medical Services in the EMA in relation to TX. Adherence	Client Services/ HIV Service Coordination	2005	Not being done
3	Develop TX. Adherence case conferencing sessions for communication and networking among front-line providers, which includes access to data, & interagency communication.	HIV Service Coordinator/Planner/Grantee	2005 & ongoing	Not being done

Additional ideas:
INCREASE THE AVAILABILITY AND ACCESS TO TREATMENT ADHERENCE SERVICES FOR SUBSTANCE ABUSERS PARTICULARLY, INJECTION DRUG USERS WITHIN THE SPECIFIED RISK POCKETS.
1). Produce and implement substance abuse TREATMENT ADHERENCE interventions that can be introduced and sustained at the street level, based on these ethnographic and epidemiologic trends. These interventions need to focus on the hidden and target populations living in or frequenting these risk pockets without diluting current county-wide efforts.
2). Make treatment adherence services available through organizations who have a proven track record with the populations examined in this CSAD project. Services must be targeted to the behaviors occurring in the neighborhoods represented in this report. These services need to be formally linked with opportunities for HIV primary medical care.
3).Explore implementing a pilot program of Harm Reduction to include a needle exchange designed to combat the spread of HIV through intravenous drug abuse.
4). Establish minority-based substance abuse treatment programs with an outreach component to address HIV and substance abuse among minority clients in urban and rural settings.

Additionally, interventions need to be constructed to meet the needs of Guatemalan, Haitian, and Latino substance abusers.

RAISE AWARENESS AND EDUCATE INDIVIDUALS ABOUT THEIR HIV STATUS AND TREATMENT ADHERENCE PROTOCOLS AND ATTENDANT RISKS RELATED TO THEIR CHOICES IN THEIR OWN LANGUAGES IN THEIR OWN COMMUNITIES WITH INDIGENOUS PEOPLE.
1).Expand and implement HIV treatment adherence education into Palm Beach County, and establish a formal linkage to the Regional Community Planning Partnership.
2).Produce culturally appropriate treament adherence protocols and messages and services including messages transmitted by radio and posters utilizing art-messages for those who are unable to read.
3).Expand current messages to include individuals who may not necessarily receive treatment adherence messages and interventions (e.g., teens, women, the drug addicts).
4). Deliver messages by sources respected and understood by individuals engaging in the identified risk behaviors.

URGE LOCAL PLANNERS, PROVIDERS, COLLEGES, UNIVERSITIES AND POLICY MAKERS TO UTILIZE THE FINDINGS OF THIS REPORT WHEN DEVELOPING AND IMPLEMENTING PROGRAMS TO DESIGN TREATMENT ADHERENCE INTERVENTIONS.
1).Establish an advisory group to develop and/or review national and local programs that provide treatment adherence training and support.
2). Form research collaboration with colleges and universities to explore and examine HIV/AIDS Literature, interventions, policy and analyses relating to treatment adherence.
3). Provide local treatment adherence training on a quarterly basis for all involved in HIV/AIDS service provision at a local collage and/or university. Offer class credits or credentials.
4). Disseminate the findings of this ethnographic report to local educational institutions for buy in and feed back.

GOAL V: STIGMA

To address the issue of Stigma that makes it difficult for individuals to disclose their status and receive care for HIV-spectrum disease. The mechanisms to address stigma will be varied and appropriate for the targeted populations with an emphasis will be put on those special populations that are disproportionately affected by HIV/AIDS.

OBJECTIVE V.1 Develop social marketing techniques to be utilized at faith-based and community events that are culturally appropriate and palatable to the communities must adversely affected by HIV-spectrum disease.

#	***ACTION***	RESPONSIBLE PARTIES	IMPLEMENTATION DATE	***STATUS AS OF*** September 1, 2005
1	Disseminate HIV information at Big Brothers/Big Sisters; Area Churches; and various media venues. Hire a Public	Client Services/CARE Council Coordinator/ Grant Administrator Work with EPICC and CPP	2005	Develop marketing mechanisms by 2005.

	Relations Specialist.			
2	Reframe HIV prevention messages to be more positive and help provide a new direction for those infected	Client Services/ CARE Council Coordinator/Grant Administrator	2006	Nothing being done at this time
3	Identify and use family members in disproportionately affected communities to reach out to other families	Client Services/CARE Council Coordinator	2005 and annually thereafter	Nothing currently being done.
4	Have community forums to discuss why the press portrays this as an ugly disease. Reframe the message in community groups. Provide revised messages to local media venders.	Planning Council/ Council Administrator/EPICC/CPP SCSN Task Force	2005 until goal is accomplished	To date, this has not been done.

OBJECTIVE V.2 Promote consumer empowerment and education programs regarding stigma at provider agencies. Incorporate rights and advocacy trainings at Title I and II services.

#	***ACTION***	RESPONSIBLE PARTIES	IMPLEMENTATION DATE	***STATUS AS OF*** September 1, 2005
1	Promote innovative programs to encourage consumer empowerment and education relating to reversing stigma in their respective communities	Client Services/ Consumer Advisory/ CARE Council Coordinator	2005	To date this has not been done. HRSA TA begin September, 2005
2	Re-evaluate the mechanism to address client's understanding of stigma and how it affects them and their communities	Client Services/CARE Council Coordinator	2005	To date, this has not been done. HRSA TA needs to be requested.

OBJECTIVE V.3 Contribute to the local community by providing open trainings and educational opportunities.

#	***ACTION***	RESPONSIBLE PARTIES	IMPLEMENTATION DATE	***STATUS AS OF*** September 1, 2005
1	Continue inviting members of the community to attend CARE Council functions	CARE Council Coordinator	Monthly	Ongoing.
2	Appeal to Providers to do community-open trainings	CARE Council Coordinator	Ongoing	To begin in Fall 2005

Additional ideas:
CREATE MENTOR PROGRAMS AND ENHANCE INFORMATION AND GATHER IDEAS FROM MINORITY COMMUNITY-BASED ORGANIZATIONS THAT PROVIDE INFORMATION ON HIV/AIDS. INCLUDE LOCAL COLLEGES WHEN CONSIDERING INTERNSHIP PROGRAMS.

INCLUDE DISCUSSIONS ON STIGMA AND THE REDUCTION OF STIGMA ASSOCIATED WITH THE DISEASE.

1).Ensure that HIV/AIDS training in the Department of Health includes more material on stigma associated with HIV/AIDS, being a teen with HIV/AIDS, and how to get support as parents of HIV positive kids.

2).Expand and restructure service delivery system to include individuals from the targeted risk areas, including sex workers and substance abusers. Provide incentives in a Harm Reduction format introducing a Model of Change Philosophy to Palm Beach County.

3).Recruit Natural Helpers from the CSADP participating neighborhoods to spread messages against HIV/AIDS stigma. Owners of local businesses, pimps and drug pushers all share vested interests in preserving the health of their customers to yield profit. Use every opportunity to promote healthy prevention interventions even non- traditional methods of intervention.

DESIGN SPECIFIC STRATEGIES TO HELP REDUCE OR ELIMINATE HIV/AIDS STIGMA IN PERSONS WHO TEST NEGATIVE BUT CONTINUE TO PRACTICE HIGH RISK BEHAVIORS.

1). Form support groups for high-risk individuals (i.e., prostitutes, drug addicts, minority bisexual and homosexual males, sexually active teens). Provide incentives for attendance and creative risk reduction behaviors and suggestions.

2). Consider supplying high-risk individuals with an arts-based, Harm Reduction intervention. Include ideas from neighborhoods and local Arts High Schools.

3). Provide a one-stop-shop for risk reduction education and stigma.

4).Earmark funding that allows the purchase of food items to encourage individuals to seek testing, counseling and referrals in local markets, community centers, churches, schools, pharmacies, etc...in an effort to increase community involvement and reduce stigma.

EDUCATE PALM BEACH COUNTY COMMUNITY HEALTH AGENCIES , NON- HIV SERVICE PROVIDERS, AND THE COUNTY AND CITY COMMISSIONERS ABOUT THE TARGETED AT-RISK COMMUNITIES AND THEIR INHABITANTS WITH REGARD TO HIV/AIDS STIGMA AND ITS BARRIERS TO THE RECEIPT OF CARE. DISSEMINATE INFORMATION RELATING TO STIGMA AND CLINICAL CARE TO CREATE SYSTEMIC AND SYSTEMATIC CHANGE.

1).Construct a round table, hands-on forum for the County commissioners and the city commissioners from the community to allow participation and exchange information and solutions with the CSADP ethnographers, the Department of health and all HIV-related service providers in an effort to reduce stigma through community cooperation.

2).Integrate ongoing HIV/AIDS care and prevention education related to reduction of stigma into Palm Beach County's community health agencies and other city and county agencies who provide services to the targeted populations at-risk for contracting HIV disease. Begin with the City of West Palm Beach Community Development office; the grantees for HOPWA, the Palm Beach County Board of Education, The Palm Beach County Sheriff's Office and the Palm Beach County Mental Health Board.

3).Issue a county 'Call for action on HIV/AIDS stigma elimination and provision of medical care' that demands partnerships between community service providers and city, county, state, federal partners.

GOAL VI: CULTURAL BELIEFS, PRACTICES AND BEHAVIORS

To provide outreach and encouragement to populations at risk for HIV/AIDS in Palm Beach County and create the most effective models of HIV/AIDS CARE maintenance among communities that are disproportionately affected by HIV-spectrum disease.

OBJECTIVE VI.1 Identify and work with people in their neighborhoods to devise Outreach Models and CARE Maintenance Interventions that are congruent with that communities beliefs, practices and behaviors

#	***ACTION***	RESPONSIBLE PARTIES	IMPLEMENTATION DATE	***STATUS AS OF*** September 1, 2005
1	Encourage community members to produce a community gathering to discuss and about their communities beliefs, practices and behaviors related to HIV/AIDS. Incorporate science-based intervention strategies relating to outreach and CARE Maintenance Interventions with cultural and religious beliefs, practices and behaviors of special populations that are targeted. Utilize the help of the CARE Council Coordinator's monthly meeting to disseminate important information to community.	Planning Council/ Executive Committee/ HIV Services Coordinator	Needs to be Ongoing	Need to reevaluate this type of information in the Public Forum of the meeting.
2	Facilitate interactions between community-based organizations; AIDS service organizations and faith-based organizations, which will act as a catalyst for dialogue and the exchange of ideas among all involved to create this community outreach and CARE Maintenance Intervention.	Planning Committee/ Executive Committee/ HIV Services Coordinator	This needs to be ongoing	To date, there is limited participation from various groups at the HIV Provider's Network meeting regarding outreach and CARE Maintenance Intervention

OBJECTIVE VI.2 Actively advocate for the development/ designation of additional funds for community outreach/CARE Maintenance Intervention.

#	*ACTION*	RESPONSIBLE PARTIES	IMPLEMENTATION DATE	***STATUS AS OF*** September 1, 2005
1	Establish an inter-agency task force of providers to explore outreach and CARE Maintenance Intervention opportunities in terms of a new service category available in the EMA	Executive/ Needs Assessment/ Client Services/ Council Administrator/Planning Committee/Priorities and Allocations	2005	Development needs to be done than first meeting to be being organized.
2	Develop recommendations for new Outreach and CARE Maintenance Intervention. Operationalize this service category	Needs Assessment/Planning Priorities & Allocations	2005	Not Currently in place
3	Organize the request of the funds for this service category	Executive Committee/ Ad hoc Task Force/Planning/P & A	2005 & bi-annually	Done as part of Capacity Building in 2005.

OBJECTIVE VI.3 Explore the need for expanded geographic distribution of these services

#	*ACTION*	RESPONSIBLE PARTIES	IMPLEMENTATION DATE	***STATUS AS OF*** September 1, 2005
1	Update and continue work on this service category in terms of a zip code analysis and inventory	Needs Assessment/ Planning/Council Administrator	2005 and ongoing	Follow-up to be done by January, 2006
2	Update the analysis of the continuum of care regarding these service categories	Needs Assessment/Planning Council Administrator	Ongoing	To date this has not been done.
3	Provide Outreach and CARE Maintenance Intervention is accordance with the need demonstrated by distribution of new HIV/AIDS cases in PB County zip codes	Needs Assessment/Planning Grant Administrator	Ongoing	To date this has not been done.

Additional Ideas:

ESTABLISH A FUNDING SOURCE TO IDENTIFY ADDITIONAL TARGETED SPECIFIC GEOGRAPHIC AREAS WITH HIGH CONCENTRATIONS OF INDIVIDUALS ENGAGING IN HIGH RISK BEHAVIORS.

STRATEGY:

1. INCREASE FUNDING OR MAKE OPPORTUNITIES AVAILABLE TO IMPLEMENT THE CSADP METHODOLOGY IN OTHER RISK POCKETS IN PALM BEACH COUNTY.
2. PROVIDE ADDITIONAL FUNDS TO INCREASE PROGRAMS THAT PROVIDE CAPACITY BUILDING TO EXPAND THE PALM BEACH COUNTY MINORITY NETWORK, COMMUNITY-BASED ORGANIZATION TRAINING AND TECHNICAL ASSISTANCE THAT ASSIST COMMUNITIES TO INCREASE THEIR LOCAL FUNDING.
3. IDENTIFY AND ENCOURAGE COLLABORATION BETWEEN PRIVATE SECTOR AND PUBLIC HEALTH RELATING TO AUGMENTATION OF CURRENTLY AVAILABLE HIV/AIDS FUNDING SOURCES.

INCREASE THE AVAILABILITY OF AND ACCESS TO HIV PREVENTION AND MEDICAL CARE FOR AFRICAN AMERICAN, LATINO, GUATEMALAN AND HAITIAN BISEXUALS AND HOMOSEXUALS WITHIN THE IDENTIFIED RISK POCKETS.

Strategies:

1). Develop and sustain street level interventions which are based on epidemiologic and ethnographic trends. Evaluate these interventions on an on-going basis. These interventions must concentrate on hidden populations living in or frequenting the CSADP-identified risk pockets.

2).Contact, establish and/or make services available through African American and Latino Gay organizations which are targeted to the behaviors occurring in the risk pockets as well as the ‘risk behavior initiation points’ that are identified in this report. These services need to be formally linked with opportunities for HIV testing and counseling.

3). Mobilize HIV prevention and medical outreach services. Services must be provided in non-traditional settings and at non-traditional hours (not just 9-5) to better reach targeted populations in their geographic pockets.

DEVELOP STRATEGIES TO INCLUDE THOSE INDIVIDUALS WHO ARE ENGAGED IN HIGH-RISK BEHAVIOR AND/OR THOSE WHO CURRENTLY WORK WITH INDIVIDUALS (E,G., COMMUNITY OUTREACH WORKERS), IN POLICY MAKING DECISIONS.

1).Recruit indigenous, natural leaders in risk sites to develop and participate in interventions. People living to the places where the risk occurs have expressed their willingness to help, including RARE team members. It is important that natural community receive training and modest material support to help protect their neighborhoods.

2). Conduct a quarterly meeting involving county health departments, AIDS service organizations, community-based organizations, and faith-based organizations to share successes , barriers, and strategies in reaching communities being served.

3).Extend treatment teams to include other disciplines such as mental health workers, substance abuse counselors, nutritionists, and community stakeholders. All providers need to be certified and given credentials to provide services.

CONSTRUCT SPECIFIC STRATEGIES FOR REDUCING THE RISK OF HIV AND AIDS IN THE COMMUNITIES INCLUDED IN THE CSAD PROJECT, EMPHASIZING MINORITY NEIGHBORHOODS.
1). Provide continual funding for the Black Leadership Conference on HIV/AIDS and the Hispanic Summit on HIV/AIDS to allow minority agencies to exchange ideas.
2). Fund innovative health services, including the reconsideration of health service vehicles, that place outreach at risk locales, and/or satellite community-based services in the identified risk pockets.
3).Conduct micro-interventions in risk locales, such as condom distribution and HIV testing on strolls. This includes providing condoms to individuals engaged in sex trade and on-site HIV-testing. This also includes the provision of condoms to substance abusers and distributions of other HIV prevention materials.

UTILIZE RARE METHODOLOGY TO EVALUATE THE NEEDS OF THOSE BELIEVED NOT TO BE IN CARE , THOSE THAT RECEIVE CARE OUTSIDE OF THE TRADITIONAL SYSTEM , THE NEEDS OF AT-RISK GROUPS, AND HARD TO REACH POPULATIONS.
1).Continue and extend the process of CSAD to other frequently yielding reported HIV-risk zip codes.
2). Recognize that this methodology enabled us to discover aspects of HIV in Palm Beach County that we heretofore were unaware of. We now know how much we need to further discover about the HIV epidemic in the affected neighborhoods.
3). The CSAD technique has the potential to identify scores of opportunities for appropriate, targeted interventions and the further ability to identify, test and refer people to HIV services in a manner that they themselves have created.
4).Make available resources to train a group of assessment specialists to identify new areas of acute need.
5). Palm Beach County needs to incorporate ongoing assessments into its master plan and the community prevention plan.

DESIGN AND ENSURE THAT PERSONS WHO TEST POSITIVE FOR HIV/AIDS ARE PROVIDED WITH ACCESS TO CLINICAL CARE AND SECONDARY PREVENTION.
1).Improve access to HIV primary medical care for those who test positive for HIV.
2). Continue to provide outreach efforts to those who have tested positive yet are resistant to services in an attempt to prevent the spread of the disease and provide medical care to ensure continued health of those who are positive.
3). Insure that Palm Beach county community health agencies and other county health agencies who provide services to the targeted at risk populations, develop and implement mechanisms to integrate HIV/AIDS/STDS and Family Planning prevention and medical care education within services to the CSAD targeted neighborhoods either directly or in collaboration with programs funded to provide HIV/AIDS/STDS Family Care education.
4). Create plans of action/continuity relating to HIV/AIDS testing and referral. Explore, develop and implement culturally sensitive methods for delivering results of HIV tests. Consider provision of incentives and construct efforts with the CSAD-targeted populations in mind.
5). Create a better transportation system.
6).Establish linkage and follow-up from emergency rooms, crisis centers, Hot Lines to local health departments.