

FY 2010 RYAN WHITE NEEDS ASSESSMENT: EXECUTIVE SUMMARY REPORT

Adopted: November 3, 2010



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WHO WE ARE

The health councils were created in 1983 by Florida Statute to identify, address and resolve health care issues of local concern. Each health council is a private, non-profit organization governed by a Board of Directors. The Board members are appointed by County Commissioners to represent the concerns of health care consumers, providers and purchasers.

The Health Council of West Central Florida, Inc. (HCWCF) serves Hardee, Highlands, Hillsborough, Manatee and Polk counties. The Suncoast Health Council, Inc. (SHC) serves Pasco and Pinellas counties. The two councils share staff to optimize resources and to coordinate services across planning districts. Working together as The Health Councils, Inc. “we make health care better” for area residents. Collaboration and cooperation are critical to the success of our mission.

We have three strategic goals: (1) support the accessibility of health care and social support systems through *comprehensive health planning*; (2) obtain and provide *education* about essential community health challenges and solutions; and (3) participate as collaborative partners to address current and emerging health issues to develop and sustain efficient and cost effective *service delivery* systems.

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I. BACKGROUND

The Ryan White Care Council conducts an annual needs assessment for the purpose of gathering service need data. The results are utilized in conjunction with other information to prioritize and allocate Ryan White funding throughout an eight-county service area. Covered counties include Hardee, Hernando, Highlands, Hillsborough, Manatee, Pasco, Pinellas and Polk.

The needs assessment is a three-year process and consists of multiple components updated at periodic intervals. The following components were utilized in the FY2010 assessment and the year the component was completed is noted in parentheses:

- ▶ Case Manager/Expert Survey (2008)
- ▶ Client Focus Groups (2006)
- ▶ Client Survey (2007 completed, 2010 analysis in progress)
- ▶ Epidemiologic Profile (2010)
- ▶ Funding Stream Analysis (2008)
- ▶ Resource Analysis (2010)
- ▶ Unmet Need Estimate (annual)
- ▶ EIIHA (Early Identification of Individuals with HIV/AIDS)

II. METHODOLOGY

The needs assessment utilized a variety of techniques to gather information from relevant sources. The specific methodology for each component of the process completed during the last three years is explained below.

A. Case Manager/Expert Survey (2008)

The Case Manger/ Expert Survey involved surveying case managers who serve people living with HIV/AIDS (PLWHA) and surveying experts. Experts were defined as members of the Care Council and/or its nine standing committees (both voting and non-voting) and former Care Council members.

Surveys were distributed to all attendees at two mandatory case manager training sessions in January 2008. A total of 69 surveys were completed. Surveys were also mailed to 100 'expert' individuals in March 2008 with postage paid return envelopes. A total of 46 were completed and returned.

The survey requested that each individual respond regarding the needs of **all** people living with HIV/AIDS (PLWHA) for their respective county. Individuals that served more

than one county were asked to complete a separate survey for each county served. Respondents were provided with a copy of the Health Resources and Services Administration (HRSA) service category definitions as reference.

The survey instrument gathered demographic data including county and category represented, perceived need at the county level for the HRSA designated service categories, perceived availability of the services at the county level, quality of services for HIV infected persons, barriers to service, impression of services on six quality measures and projected service needs.

B. Client Focus Groups (2006)

Focus groups were last conducted with HIV+ persons in the service area in 2006. The Planning and Evaluation Committee decided not to conduct focus groups in 2009/10 based on limited resources and the lack of participation in previous focus group activities. Focus groups have typically targeted hard-to-reach populations that were under-represented in previous surveys and focus groups such as Blacks, rural residents and males. In 2006, the target groups included Hillsborough and Manatee males and rural females.

Members of the Planning and Evaluation Committee were trained to facilitate the groups. Sites for the focus groups were chosen based on their accessibility to clients and included locations such as AIDS service organizations, health departments and a church. Participants were recruited through one-on-one contact with site staff and with posted announcements explaining the purpose of the groups. Participants were offered travel reimbursement, refreshments and door prizes.

Group facilitators used a standard script designed to identify current and future needs, perceived availability of services, and a prioritization of needs. A participant information sheet was used to collect general demographic data of the participants (i.e., county of residence, gender, age, race and mode of transmission).

A total of twenty persons participated in six groups conducted in Highlands, Hillsborough, Manatee and Polk counties in 2006.

C. Client Survey (2007)

PLWH/A residing throughout the Care Council's total service area (TSA) were surveyed. A total of 1747 clients completed the questionnaire which was an increase of 846 over the last client survey in 2004.

The 2007 questionnaire was developed in 2006 by the State of Florida HIV/AIDS Bureau in conjunction with the Patient Care Planning Group for Part B consortias. Input was sought from local planning areas in January of 2007. The Minority Advocacy Committee and Planning and Evaluation Committee carefully reviewed the draft survey and suggested changes, of which most were graciously incorporated into the survey. The survey instrument was pilot tested in a focus group format with clients of various ages, genders, races and reading abilities. Recommendations from the pilot test offered further refinement to the instrument, prior to its distribution.

The survey was required for all Part B consortia areas, but since our local area is a combined Part A planning body and a Part B consortia, permission was granted to make some minor local adjustments to the survey to make it fit the purposes of both. Now a single survey could be used locally for both Part A and B without creating survey fatigue for clients.

The instrument was composed of check boxes and fill-in-the-blank questions. The content of the questions included demographic information, participation in medical care, co-morbidities, payment sources, and service needs and barriers. To facilitate the participation of Spanish and Creole-speaking people living with HIV/AIDS (PLWH), the questionnaire was translated into Spanish and Creole, and was made available at all survey sites.

A survey link was posted online at the Care Council website as well as with several partner websites. Surveys were distributed to a total of 69 sites selected to ensure diversity and representativeness in the sample. The sites consisted of primary care providers (public and private), AIDS Drug Assistance Program offices, food banks, drug treatment providers, PLWH housing providers, homeless shelters, PLWH support groups and special events. The number of survey sites by county was as follows: Hardee County (1), Hernando County (5), Highlands County (4), Hillsborough County (21), Manatee County (4), Pasco County (7), Pinellas County (24) and Polk County (3).

Surveys were available at each site for multiple weeks except for support groups and special events. The length of time varied depending on the site's schedule and the number of PLWH projected to seek services. The survey remained available at most sites from April 2007 through November 2007.

The surveys were placed at locations where they were highly visible to clients, when appropriate. In some cases, confidentiality concerns led sites to find less obvious means of distributing the surveys including attaching the survey to a client file when an appointment was scheduled during the survey period. Each survey contained a cover sheet explaining the purpose of the survey and contact information for the Care Council.

A postage paid return envelope was provided with all surveys at sites without a collection box. Key staff at several of the sites collaborated in the distribution by asking

clients to complete the survey and by providing assistance with completing the survey as needed.

Local pharmacies who provide mail-order prescriptions agreed to include a survey and return envelope with all mail-outs. Several agencies also distributed the survey by mailing copies with return envelopes to each client of record. Several Ryan White and partner agencies posted a link to the survey on their website as well.

Representativeness of data was monitored as surveys were returned, and attempts were made to gather more responses in areas where under sampling occurred. In spite of these efforts, there were issues with under and over sampling as described below:

- Pinellas and Hernando had a sample size appropriate to the HIV/AIDS data while Hardee, Highlands, Hillsborough, Manatee, Pasco and Polk counties were under represented.
- Gender analysis showed females over represented in Hardee, Hillsborough and Manatee counties and very slightly in Pasco County. Males were over represented in Hernando and Highlands counties and very slightly in Polk County. Pinellas County had sample sizes appropriate to the HIV/AIDS data.
- Females were over represented in the TSA by 3.7% leaving males under represented by 4.2 percent.
- Race and ethnicity data indicated an over sampling of whites in every county except for Pasco. Hispanics were over represented in every county except Hernando which was slightly under and Manatee where the sample size corresponded to HIV/AIDS data. In the TSA, Hispanics were over sampled by 2% and blacks were under sampled by 10 percent.

Completing the survey was dependent to a large degree on the respondent's ability to read. While every attempt was made to make the terminology as simple as possible, there may still have been misunderstandings. In some cases staff members were available to assist individuals with literacy problems, but there were concerns expressed during the process that reading ability may have prevented certain individuals from participating in the survey.

The length of the survey may also have prevented some individuals from participating in the process. The length of time required to complete the survey was estimated to average 20 minutes, however this may have been longer for those with low reading ability. Respondents were instructed to skip questions that did not apply, or that they did not feel comfortable answering.

In addition, self reporting, particularly on issues surrounding mental health, substance use and sexual behavior can be unreliable. As previously mentioned, respondents were instructed to skip any questions they did not feel comfortable answering.

The client survey was revised and distributed throughout the TSA. The results were collected during the summer of 2010. Analysis of the survey results is in progress.

D. Epidemiologic Profile (2010)

The demographics and epidemiology report was completed in 2010. As in the past, the report examined the following demographic characteristics: gender, ethnicity, county of residence, mode of transmission and age at diagnosis. Information was broken out by geographic area including Total Service Area (TSA), Eligible Metropolitan Area (EMA) and non-EMA counties. Incidence data was provided to assess the increases and decreases in the epidemic.

Some of the findings of the report indicated that as of December 31, 2009, a total of 7,141 living AIDS cases and 5,356 living HIV cases had been reported for the TSA.

1. Race, Ethnicity and Gender (TSA)

- Overall, White males accounted for the highest percentage of reported living AIDS cases (40.2%) followed by Black males (21.8%) and Black Females (15.4%). The proportional breakdown among the living HIV (non-AIDS) cases was: White males 35.9%, Black males 21.8%, and Black females 17.3%.
- Among males, Whites accounted for the highest percentage of reported living AIDS cases (55.5%) and living HIV (non-AIDS) cases (52.5%) followed by Blacks (30.1% and 31.9%, respectively) and Hispanics (12.8% and 13.8%, respectively). Blacks are disproportionately impacted by HIV/AIDS with a rate of 1278.6 infections per 100,000 population compared to 373.6 for Whites and 390.9 for Hispanics.
- Among females, Blacks accounted for 56% of reported living AIDS cases and 54.8% of living HIV (non-AIDS) cases. Whites accounted for 26.6% of AIDS cases and 29.7% of HIV (non-AIDS) cases followed by Hispanics (15.7% and 13.8%, respectively). Blacks are disproportionately impacted by HIV/AIDS with a rate of 871.2 infections per 100,000 population compared to 75.1 for Whites and 192.2 for Hispanics.

2. Mode of Transmission and Gender (TSA)

- Among males, MSM transmission accounted for the largest percentage of reported AIDS and HIV (non-AIDS) cases (61.0% and 63.5%, respectively) followed by heterosexual transmission for AIDS (14.3%) and cases reported with risk not specified for HIV(non-AIDS) at 13.0%. Injection Drug Use (IDU) ranked third for AIDS cases (9.0%) and heterosexual transmission ranked third for HIV (non-AIDS) at 11.8%.
- For female AIDS and HIV (non-AIDS) cases, heterosexual transmission ranked highest (65.1% and 60.8%, respectively) followed by cases reported as IDU for AIDS (18.1%) and risk not specified for HIV (non-AIDS) at 23.7%. Risk not specified ranked third for AIDS cases (12.5%) and IDU ranked third for HIV (non-AIDS) at 12.8%.

Attachment 1 provides a synopsis of some additional data captured in the report.

E. Funding Stream Analysis (2008)

Another component consisted of an analysis of funding sources from federal, state and local government. All decisions relating to allocations must be viewed in the context of overall identified need as well as available resources. Services that have multiple funding sources may be less likely to require Ryan White dollars while those with little or no resources require Ryan White support.

The funding streams were analyzed by the Total Service Area (TSA), Eligible Metropolitan Area (EMA) which includes Hernando, Hillsborough, Pasco and Pinellas counties, the non-EMA counties (Hardee, Highlands, Manatee and Polk counties) and by county. However, the most accurate assessment was at the TSA level.

In 2008, Medicaid and Project AIDS Care (PAC) Waiver accounted for 65% of HIV/AIDS funding in the TSA. Part A represented 9% and the AIDS Drug Assistance Program (ADAP) represented 12%. Housing Opportunities for Persons With AIDS (HOPWA) represented 4%, and combined general revenue sources represented 3% of funding. Other Ryan White funding included Part B at 2% and Part C, Part D and MAI at 1% each. Combined county governments (Hillsborough, Manatee & Pinellas) represented 1% of the funds.

The services with the greatest expenditures included drug reimbursement (53%), outpatient/ambulatory care (14%), hospital inpatient services (12%), housing assistance (4%) and case management (3%).

F. Resource Analysis (2010)

Another component of the needs assessment was an analysis of the resources available in the TSA. The purpose of this analysis was to obtain information to help identify services within the continuum of care that may be unable to meet current needs, services that may not exist in certain geographic areas, and services where the number of providers is inadequate or exceeds the need.

The focus of the 2010 analysis was to obtain information on each of the Health Resources and Services Administration (HRSA) service categories. The geographical scope included all eight counties in the TSA.

The rural counties generally had minimal to non-existent public transportation. The large land areas and low population densities of many of these counties make travel to service providers problematic for some clients. The urban counties have bus service, but depending upon where a client lives, it can take several hours to reach a service provider located along a bus line. In addition, crossing county lines for service not readily available in the county of residence can also be problematic.

All counties had at least some services that were available in other languages, primarily Spanish, and all providers can access the state TDD assistance for the speaking and hearing impaired. Creole was available for some services in areas with concentrations of Haitian populations.

Waiting lists were not indicated for most services, however public housing across all counties indicated waiting lists that are often in excess of one year. The lack of a waiting list should not necessarily be interpreted to mean a service is readily available. Some providers simply do not maintain waiting lists, and access to service may be dependent upon having an acceptable payer source, or in the case of inpatient substance abuse treatment, an available bed.

Most areas also had some services provided after traditional hours (Monday-Friday 8 a.m. to 5 p.m.). Services most likely to have non-traditional hours included ambulatory/outpatient care, case management, counseling and support groups, substance abuse treatment, emergency shelters and food banks.

G. Unmet Need Estimate

Unmet need estimates must be considered when making allocations to services that would be initial points of entry for new clients accessing care. These data are generated from the electronic HIV/AIDS Reporting System (eHARS) database and the out of state (OOS) database. The OOS database contains those cases reported out of state but living and in care in Florida. The combination of these two databases provides a more complete picture of the epidemic of “living” HIV/AIDS cases in need of care in Florida, than by just using eHARS data alone. This revised process of excluding cases known to be living outside of Florida and including cases reported outside of Florida but obtaining care in Florida provides a more complete picture of those cases in need of care in Florida as well as addressing the in-migration and out-migration of cases in Florida. Note that total number of HIV and AIDS cases will not reflect the same numbers reported in the Demographics and Epidemiology report since the OOS database is not used in generating the case numbers for that data set.

TSA Unmet Need Framework (2009)

Population Sizes		Value		Data Source(s)
Row A.	Number of persons living with AIDS (PLWA), aware for the period of 01/01/2009 - 12/31/2009	7,421		eHARS ¹ and OOS ² data sets plus matches with ADAP ³ , Medicaid, HMS ⁴ , CAREWare ⁵ , and Labs ⁶ .
Row B.	Number of persons living with HIV (PLWH)/non-AIDS/aware, for the period of 01/01/2009 - 12/31/2009	5,462		
Row C.	Total number of HIV+ aware, for the period of 01/01/2009 - 12/31/2009	12,883		
Care Patterns		Value	Percent	Data Source(s)
Row D.	Number of PLWA, aware who <i>did</i> receive the specified HIV primary medical care services in 12-month period	5,640	76%	eHARS ¹ and OOS ² data sets plus matches with ADAP ³ , Medicaid, HMS ⁴ , CAREWare ⁵ , and Labs ⁶ .
Row E.	Number of PLWH/non-AIDS/aware who <i>did</i> receive the specified HIV primary medical care services in 12-month period	3,337	61%	
Row F.	Total number of HIV+/aware who <i>did</i> receive the specified HIV primary medical care services in 12-month period	8,977	70%	
Calculated Results		Value	Percent	Calculation
Row G.	Number of PLWA, aware who <i>did NOT</i> receive primary medical services	1,781	24%	Value: Value A - Value D. Percent: Value G/Value A.
Row H.	Number of PLWH/non-AIDS/aware who <i>did NOT</i> receive primary medical services	2,125	39%	Value: Value B - Value E. Percent: Value H/Value B.
Row I.	Total HIV+/aware who <i>did NOT</i> receive	3,906	30%	Value: Value G +

	specified primary medical care services (quantified estimate of unmet need)		Value H. Percent: Value I/Value C
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¹ The eHARS (electronic HIV/AIDS Data Reporting System) provided estimates of the number of infected individuals and proportions of HIV (non AIDS) and AIDS cases for the EMA.

² An out of state (OOS) database tracks cases reported from other states, but in care in specific Florida counties.

³ The ADAP (AIDS Drug Assistance Program) was used to determine individuals receiving anti-retroviral treatment.

⁴ HMS is the local county health departments' database.

⁵ CAREWare is an HIV/AIDS patient care data set.

⁶ Paper labs and the electronic lab database have yet to be imported into eHARS so matches must be made manually.

Rows A, B and C of the Unmet Need Framework Table provide populations estimates. Florida has had HIV reporting since July 1, 1997. 2009 data was used to determine the number of people reported as living with HIV (non-AIDS) and the number of people reported with AIDS. It is estimated that 7,421 people are living with AIDS and 5,462 people are living with HIV in the TSA.

Rows D, E and F of the Unmet Need Framework Table provide estimates of numbers of people in care. Estimates are based on the number and percent of people in care according to the HRSA definition (received HIV primary medical care as evidenced by one of the following in a defined 12-month time frame: viral load testing, CD4 count and/or the provision of anti-retroviral therapy). It is estimated that 8,977 HIV/AIDS cases are in care in the TSA.

Rows G, H and I of the Unmet Need Framework Table provide estimates of unmet need. Data sources were cross matches between eHARS, ADAP, Medicaid, HMS (Health Management System, a County Health Department database for client based services), CAREWare and Labs. Number in-care is subtracted from living HIV and AIDS cases to obtain the number and percent not in care according to the HRSA definition. It is estimated that 3,906 people are living with HIV/AIDS in the TSA and not in care.

H. EIIHA (Early Identification of Individuals with HIV/AIDS)

The Care Council and the Grantee's office have worked over the years to forge and expand partnerships with state and local agencies to ensure coordination of services and programs. These partnerships have matured into a well developed and organized network that is equipped to address and respond to the needs of the community and provide vital services throughout the TSA. This network will continue collaborations to ensure that current and newly developed strategies within the TSA will support HRSA's new objective in the early identification of individuals living with HIV/AIDS and subsequently getting them into care.

Florida's Prevention Planning Group (PPG) is responsible for the 2010 State of Florida Prevention Plan, which directs local HIV prevention planning. The HIV prevention plan details the existing linkages between the Care Council, the local HIV community planning partnership (CPP), and the FCPN (Florida HIV/AIDS Comprehensive Planning Network). Included in the 2010 State of Florida Prevention Plan are two major goals that concentrate on reaching those who are unaware of their HIV status by (1) ensuring that every resident in Florida has access to HIV testing, resulting in an increase in the proportion of HIV infected people in Florida who know their status; and (2) increasing the proportion of HIV infected people who are referred and linked to appropriate prevention, care, and treatment services.

In order to achieve these goals, the Florida DOH has implemented one of the largest publicly funded HIV testing programs in the country, with over 70 registered counseling and testing sites in the TSA. Publicly funded HIV testing programs offer free HIV testing and utilize three different methods (conventional blood draw, OraSure, or rapid testing) to ensure access to at-risk populations.

Early intervention programs offering HIV counseling and testing have been a priority within the TSA for several years, recently implementing these initiatives to ensure that every resident in the TSA and in Florida has access to HIV testing services. Local testing initiatives are described in the Prevention Plan which details how rapid testing, testing in correctional facilities, faith initiatives, and programs such as Sistas Organizing to Survive (S.O.S.), African American Testing Initiative (AATI)/ ETI (Expanded Testing Initiative (ETI) will increase access for historically underserved populations and most affected subpopulations. These initiatives are implemented in partnership with local hospitals, community health centers, substance abuse treatment centers, jails, STD clinics, community-based organizations and churches.

The local priority populations targeted for the allocation of resources in the TSA are included in this EIIHA Matrix:

1A. All Individuals Unaware of their HIV Status (<i>HIV positive & HIV negative</i>)								
2A. High Risk Individuals							2B. Moderate and Low Risk Individuals	
3A. MSM			3B. Heterosexuals			3C. Other		
4A. Black	4B. Hispanic	4C. White	4D. Black	4E. Hispanic	4F. White	4G. Partner of HIV+ Individual	4H. Infants of Infected	

						s	Mothers	
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The local partnerships have a rich history of collaborating on HIV prevention, care, and treatment issues throughout the TSA. This tradition will continue as the local networks develop new and innovative strategies with a goal of ensuring 100% of HIV+ clients are linked to services with the local Ryan White programs.

III. RESULTS

A. Service Priority Recommendations

Since the Care Council is a committee-driven structure, the Planning and Evaluation Committee was responsible for overseeing the completion of the needs assessment elements. Each element was reviewed, in conjunction with the comprehensive plan, unmet need estimates and emerging issues in the EMA. The limitations and strengths of each element were discussed.

The committee then assigned a weight to each element using the Popular Empirical Assessment for Community Health (PEACH) process. The results of the weighting exercise were as follows:

- Client survey results x 3
- Case manager/Expert survey results x 2
- Client focus groups x 1

This essentially meant that the information received from the client survey (1747 responses) received the greatest weight at three times greater than the focus groups.

A matrix was developed listing each HRSA service category in the previous year ranking, the service utilization from the surveys, expenditures and allocations to this service category across public funding streams and estimates of unmet need (see Attachment 2). The committee then discussed the implications of the service rankings, availability of other funding sources to support services, waiting list and unmet need data to further refine the priority recommendations.

Since the 2010 client survey data has not yet been analyzed and presented for consideration and the other elements were not updated in the 2010 planning year, the priorities remain the same as the previous year.

Core Services

1. Outpatient/Ambulatory Medical Care

2. AIDS Pharmaceutical Assistance (local)
3. Medical Case Management
4. Health Insurance Premium and Cost Sharing Assistance
5. Oral Health Care
6. Mental Health Services
7. Substance Abuse Services - outpatient
8. Medical Nutrition Therapy
9. Early Intervention Services
10. Home Health Care
11. Hospice Services
12. Home and Community Based Health Services

Support Services

1. Emergency Financial Assistance
2. Housing Services
3. Food Bank/Home Delivered Meals
4. Medical Transportation
5. Case Management (non-medical)
6. Health Education/Risk Reduction
7. Treatment Adherence Counseling
8. Outreach Services
9. Psychosocial Support
10. Rehabilitation Services
11. Linguistic Services
12. Respite Care
13. Child Care Services
14. Legal Services
15. Substance Abuse Services- residential
16. Referral Services

Mandated Services – HRSA requires that these administrative services be in place to support the local planning effort and to ensure the highest quality services for clients.

Quality Management

B. Service Barriers

During the focus groups and on the 2007 client survey, clients identified barriers to services.

Among the barriers listed during the focus groups were long waiting periods, lack of

specialists for certain services, complex paperwork, lack of public transportation in rural areas, being asked to supply excessive amounts of information, limited availability of housing, fear of discovery of their HIV+ status, and a limited number of culturally appropriate services.

The respondents to the client survey listed the following barriers to care in order from most selected to least: I don't want people to know I have HIV (34%), Transportation problems (33%), had to wait too long for service (26%), service sites located too far away (26%), didn't know where to apply (21%), other health problems (21%), didn't know how to apply (19%), needed evening appointment (15%), application process too complicated (15%), cost of service is too high (14%), turned down/not eligible (14%), on waiting list (14%), trouble communicating (9%), drug or alcohol addiction (7%), too busy taking care of partner (4%), too busy taking care of child (4%) and "other" reasons were listed by 15% of respondents. "Other" reasons cited included specific reasons the client was determined ineligible, length of time they had been on a waiting list, Medicare Part D coverage gap known as the 'donut hole' and various complications of getting through the process to receive assistance.

C. Service Needs

Participants in the client focus groups as well as respondents to the 2007 client survey and expert/case manager survey were all asked which services were most needed. Service needs ranked with client survey carrying the most weight, followed by the expert/case manager survey and then the client focus groups. Core services are listed in bold.

1. **Oral Health Care**
2. Housing Services
3. **Health Insurance Premium and Cost Sharing Assistance (tie)**
3. Emergency Financial Assistance (tie)
4. Medical Transportation
5. Food Bank
6. **Medical Case Management**
7. **AIDS Pharmaceutical Assistance (local)**
8. **Mental Health Services**
9. **Medical Nutrition Therapy (tie)**
9. **Early Intervention Services (tie)**
10. Legal Services
11. **Outpatient/Ambulatory Medical Care**
12. Rehabilitation Services
13. Treatment Adherence Counseling
14. Health Education/Risk Reduction

- 15. Outreach Services
- 16. Substance Abuse Services - outpatient**
- 17. Case Management (non-medical)
- 18. Referral Services
- 19. Home Health Care**
- 20. Psychosocial support
- 21. Home and Community Based Health Services**
- 22. Substance Abuse Services – residential
- 23. Respite Care
- 24. Child Care Services
- 25. Hospice Services**
- 26. Linguistic Services

D. Service Utilization

To determine which services clients needed and were accessing, respondents to the client survey were asked to select services that they had needed and received during the past year. Following is a list of services for the Total Service Area (TSA) from most to least utilized.

- 1. AIDS Pharmaceutical Assistance (local)**
- 2. Medical Case Management**
- 3. Outpatient/Ambulatory Medical Care**
- 4. Health Insurance Premium and Cost Sharing Assistance**
- 5. Oral Health Care**
- 6. Health Education/Risk Reduction
- 7. Mental Health Services**
- 8. Medical Nutrition Therapy**
- 9. Food Bank
- 10. Emergency Financial Assistance
- 11. Client Advocacy
- 12. Early Intervention Services**
- 13. Medical Transportation
- 14. Treatment Adherence
- 15. Housing Assistance
- 16. Legal Services
- 17. Substance Abuse Services**
- 18. Outreach Services
- 19. Home Health Care**
- 20. Rehabilitation Services
- 21. Other Support Services

22. Buddy/Companion Services

23. Hospice Services

24. Respite Care

25. Child Welfare

26. Child Daycare

ATTACHMENT 1
Epidemiology Fact Sheet: As of December 31, 2009

Proportions of the TSA's PLWA Population by County (2009)

County	County Totals	Male	Female	White	Black	Hispanic
Hardee	0.6%	0.4%	0.2%	0.1%	0.2%	0.3%
Hernando	1.3%	1.0%	0.3%	0.8%	0.2%	0.3%
Highlands	1.4%	0.9%	0.5%	0.4%	0.6%	0.4%
Hillsborough	44.1%	31.7%	12.4%	17.4%	18.5%	7.5%
Manatee	6.8%	4.7%	2.1%	2.7%	2.8%	1.2%
Pasco	5.1%	3.8%	1.4%	3.8%	0.6%	0.6%
Pinellas	27.4%	21.5%	5.9%	17.1%	7.9%	1.9%
Polk	13.3%	8.5%	4.8%	5.1%	6.4%	1.5%
TOTAL	100%	72.4%	27.6%	47.5%	37.2%	13.6%

Proportions of the TSA's PLWH Populations by County (2009)

County	County Totals	Male	Female	White	Black	Hispanic
Hardee	0.4%	0.2%	0.2%	0.1%	0.2%	0.1%
Hernando	1.6%	1.1%	0.5%	1.1%	0.2%	0.3%
Highlands	1.4%	0.7%	0.7%	0.3%	0.8%	0.3%
Hillsborough	46.2%	31.9%	14.4%	17.7%	20.2%	7.7%
Manatee	6.4%	5.5%	2.7%	2.7%	2.6%	1.0%
Pasco	5.2%	3.6%	1.6%	3.7%	0.7%	0.7%
Pinellas	27.1%	20.4%	6.8%	15.5%	9.0%	2.0%
Polk	11.6%	6.7%	4.8%	4.2%	5.4%	1.8%
TOTAL	100%	68.4%	31.6%	45.3%	39.2%	13.8%

TSA Living HIV (non-AIDS) and AIDS Prevalence by Gender, Race/Ethnicity, Age and Mode of Transmission (2009)

TSA Prevalence	Group (gen. pop. #)	Number		Rate per 100,000		Percentage		Total HIV/AIDS		
		AIDS	HIV	AIDS	HIV	AIDS	HIV	#	%	rate
Gender	Male (1,841,767)	5,173	3,664	280.9	198.9	72.4%	68.4%	8,837	70.7%	479.8
	Female (1,931,117)	1,968	1,692	101.9	87.6	27.6%	31.6%	3,660	29.3%	189.5
	Total (3,772,884)	7,141	5,356	189.3	142.0	100%	100%	12,497	100%	331.2
Race/ Ethnicity	White (2,648,052)	3,392	2,427	128.1	91.7	47.5%	45.3%	5,819	46.6%	219.7
	Black (446,295)	2,659	2,098	595.8	470.1	37.2%	39.2%	4,757	38.1%	1065.9
	Hispanic (580,568)	969	740	166.9	127.5	13.6%	13.8%	1,709	13.7%	294.4
	Other/Unk. (97,969)*	121	91	123.5	92.9	1.7%	1.7%	212	1.7%	216.4
	Total (3,772,884)	7,141	5,356	189.3	142.0	100%	100%	12,497	100%	331.2
Age	0-12 (590,301)	14	30	2.4	5.1	0.2%	0.6%	44	0.4%	7.5
	13-19 (323,496)	77	72	23.8	22.3	1.1%	1.3%	149	1.2%	46.1
	20-24 (222,282)	111	287	49.9	129.1	1.6%	5.4%	398	3.2%	179.1
	25-29 (224,584)	240	472	106.9	210.2	3.4%	8.8%	712	5.7%	317.0
	30-39 (445,256)	1,126	1,317	252.9	295.8	15.8%	24.6%	2,443	19.5%	548.7
	40-49 (514,214)	2,919	1,759	567.7	342.1	40.9%	32.8%	4,678	37.4%	909.7
	50-59 (507,706)	2,003	1,039	394.5	204.6	28.0%	19.4%	3,042	24.3%	599.2
	60+ (945,045)	651	380	68.9	40.2	9.1%	7.1%	1031	8.2%	109.1
	Total (3,772,884)	7,141	5,356	189.3	142.0	100%	100%	12,497	100%	331.2
Mode of Trans- mission	MSM	3,157	2,327			44.2%	43.4%	5,484	43.9%	
	IDU	824	439			11.5%	8.2%	1,263	10.1%	
	MSM/IDU	330	163			4.6%	3.0%	493	3.9%	

	Hetero	2,021	1,461			28.3%	27.3%	3,482	27.9%	
	Other	148	88			2.1%	1.7%	236	1.9%	
	Risk Not Specified	661	878			9.3%	16.4%	1,539	12.3%	
	Total	7,141	5,356			100%	100%	12,497	100%	

Caution should be used when relying on rate per 100,000 data when the population size is less than 100,000

Living TSA AIDS and HIV (non-AIDS) Cases and Rates per 100, 000 of Population by Gender and Race/Ethnicity (2009)

Group (% of pop)	TSA AIDS				TSA HIV (non-AIDS)				TSA HIV/AIDS			
	# of cases	Rate per 100,000	% cases in TSA	% cases by gender	# of cases	Rate per 100,000	% cases in TSA	% cases by gender	# of cases	Rate per 100,000	% cases in TSA	% cases by gender
MALES												
White (34%)	2,869	223.6	40.2%	55.5%	1,925	150.0	35.9%	52.5%	4,794	373.6	38.4%	54.2%
Black (6%)	1,557	730.0	21.8%	30.1%	1,170	548.6	21.8%	31.9%	2,727	1,278.6	21.8%	30.9%
Hispanic (8%)	660	221.0	9.2%	12.8%	507	169.8	9.5%	13.8%	1,167	390.9	9.3%	13.2%
Other/Unk. (1%)	87	186.4	1.2%	1.7%	62	132.8	1.2%	1.7%	149	319.2	1.2%	1.7%
Total (49%)	5,173	280.9	72.4%	100%	3,664	198.9	68.4%	100%	8,837	479.8	70.7%	100%
FEMALES												
White (36%)	523	38.3	7.3%	26.6%	502	36.8	9.4%	29.7%	1,025	75.1	8.2%	28.0%
Black (6%)	1,102	472.9	15.4%	56.0%	928	398.3	17.3%	54.8%	2,030	871.2	16.2%	55.5%
Hispanic (7%)	309	109.6	4.3%	15.7%	233	82.6	4.4%	13.8%	542	192.2	4.3%	14.8%
Other/Unk.* (1%)	34	66.3	0.5%	1.7%	29	56.5	0.5%	1.7%	63	122.8	0.5%	1.7%
Total (51%)	1,968	101.9	27.6%	100%	1,692	87.6	31.6%	100%	3,660	189.5	29.3%	100%
TSA Total	7,141				5,356				12,497			

* Caution should be used when relying on rate per 100,000 data when the population size is less than 100,000.

TSA HIV/AIDS Cases by Current Expanded Age and Gender (2009)

Group (% of pop)	TSA AIDS			TSA HIV(non-AIDS)			TSA HIV/AIDS		
	# of cases	Rate per 100,000	% cases in TSA	# of cases	Rate per 100,000	% cases in TSA	# of cases	Rate per 100,000	% cases in TSA
0-12 (16%)	14	2.4	0.2%	30	5.1	0.6%	44	7.5	0.4%
13-19 (9%)	77	23.8	1.1%	72	22.3	1.3%	149	46.1	1.2%
20-24 (6%)	111	49.9	1.6%	287	129.1	5.4%	398	179.1	3.2%
25-29 (6%)	240	106.9	3.4%	472	210.2	8.8%	712	317.0	5.7%
30-39 (12%)	1,126	252.9	15.8%	1,317	295.8	24.6%	2,443	548.7	19.5%
40-49 (14%)	2,919	567.7	40.9%	1,759	342.1	32.8%	4,678	909.7	37.4%
50-59 (13%)	2,003	394.5	28.0%	1,039	204.6	19.4%	3,042	599.2	24.3%
60+ (25%)	651	68.9	9.1%	380	40.2	7.1%	1,031	109.1	8.2%
Total (100%)	7,141	189.3	100%	5,356	142.0	100%	12,497	331.2	100%

TSA HIV/AIDS Cases by Mode of Transmission and Gender (2009)

Group	TSA AIDS			TSA HIV(non-AIDS)			TSA HIV/AIDS		
	# of cases	% cases in TSA	% cases by gender	# of cases	% cases in TSA	% cases by gender	# of cases	% cases in TSA	% cases by gender
MALES									
MSM	3,157	44.2%	61.0%	2,327	43.4%	63.5%	5,484	43.9%	62.1%
IDU	467	6.5%	9.0%	223	4.2%	6.1%	690	5.5%	7.8%
MSM/IDU	330	4.6%	6.4%	163	3.0%	4.4%	493	3.9%	5.6%
Heterosexual	740	10.4%	14.3%	432	8.1%	11.8%	1,172	9.4%	13.3%
Perinatal	43	0.6%	0.8%	31	0.6%	0.8%	74	0.6%	0.8%
Other Identified Risk	17	0.2%	0.3%	5	0.1%	0.1%	22	0.2%	0.2%
Risk Not Specified	415	5.8%	8.0%	477	8.9%	13.0%	892	7.1%	10.1%
Child	4	0.1%	0.1%	6	0.1%	0.2%	10	0.1%	0.1%
Total	5,173	72.4%	100%	3,664	68.4%	100%	8,837	70.7%	100%
FEMALES									
IDU	357	5.0%	18.1%	216	4.0%	12.8%	573	4.6%	15.7%
Heterosexual	1,281	17.9%	65.1%	1,029	19.2%	60.8%	2,310	18.5%	63.1%
Perinatal	69	1.0%	3.5%	40	0.7%	2.4%	109	0.9%	3.0%
Other Identified Risk	12	0.2%	0.6%	0	0.0%	0.0%	12	0.1%	0.3%
Risk Not Specified	246	3.4%	12.5%	401	7.5%	23.7%	647	5.2%	17.7%
Child	3	0.0%	0.2%	6	0.1%	0.4%	9	0.1%	0.2%
Total	1,968	27.6%	100%	1,692	31.6%	100%	3,660	29.3%	100%
TSA Total	7,141			5,356			12,497		

ATTACHMENT 2

Ryan White Program Services Definitions

CORE SERVICES

Service categories:

- a. *Outpatient/Ambulatory medical care (health services)*** is the provision of professional diagnostic and therapeutic services rendered by a physician, physician's assistant, clinical nurse specialist, or nurse practitioner in an outpatient setting. Settings include clinics, medical offices, and mobile vans where clients generally do not stay overnight. Emergency room services are not outpatient settings. Services include diagnostic testing, early intervention and risk assessment, preventive care and screening, practitioner examination, medical history taking, diagnosis and treatment of common physical and mental conditions, prescribing and managing medication therapy, education and counseling on health issues, well-baby care, continuing care and management of chronic conditions, and referral to and provision of specialty care (includes all medical subspecialties). *Primary medical care* for the treatment of HIV infection includes the provision of care that is consistent with the Public Health Service's guidelines. Such care must include access to antiretroviral and other drug therapies, including prophylaxis and treatment of opportunistic infections and combination antiretroviral therapies. NOTE: Early Intervention Services provided by Ryan White Part C and Part D Programs should be included here under *Outpatient/ Ambulatory medical care*.
- b. *AIDS Drug Assistance Program (ADAP treatments)*** is a State-administered program authorized under Part B of the Ryan White Program that provides FDA-approved medications to low-income individuals with HIV disease who have limited or no coverage from private insurance, Medicaid, or Medicare.
- c. *AIDS Pharmaceutical Assistance (local)*** includes local pharmacy assistance programs implemented by Part A or Part B Grantees to provide HIV/AIDS medications to clients. This assistance can be funded with Part A grant funds and/or Part B base award funds. Local pharmacy assistance programs are **not** funded with ADAP earmark funding.
- d. *Oral health care*** includes diagnostic, preventive, and therapeutic services provided by general dental practitioners, dental specialists, dental hygienists and auxiliaries, and other trained primary care providers.
- e. *Early intervention services (EIS)*** include counseling individuals with respect to HIV/AIDS; testing (including tests to confirm the presence of the disease, tests to diagnose to extent of immune deficiency, tests to provide information on appropriate therapeutic measures); referrals; other clinical and diagnostic services regarding

HIV/AIDS; periodic medical evaluations for individuals with HIV/AIDS; and providing therapeutic measures.

NOTE: EIS provided by Ryan White Part C and Part D Programs should NOT be reported here. Part C and Part D EIS should be included under *Outpatient/Ambulatory medical care*.

- f. *Health Insurance Premium & Cost Sharing Assistance*** is the provision of financial assistance for eligible individuals living with HIV to maintain a continuity of health insurance or to receive medical benefits under a health insurance program. This includes premium payments, risk pools, co-payments, and deductibles.
- g. *Home Health Care*** includes the provision of services in the home by licensed health care workers such as nurses and the administration of intravenous and aerosolized treatment, parenteral feeding, diagnostic testing, and other medical therapies.
- h. *Home and Community-based Health Services*** include skilled health services furnished to the individual in the individual's home based on a written plan of care established by a case management team that includes appropriate health care professionals. Services include durable medical equipment; home health aide services and personal care services in the home; day treatment or other partial hospitalization services; home intravenous and aerosolized drug therapy (including prescription drugs administered as part of such therapy); routine diagnostics testing administered in the home; and appropriate mental health, developmental, and rehabilitation services. Inpatient hospitals services, nursing home and other long term care facilities are **NOT** included.
- i. *Hospice services*** include room, board, nursing care, counseling, physician services, and palliative therapeutics provided to clients in the terminal stages of illness in a residential setting, including a non-acute-care section of a hospital that has been designated and staffed to provide hospice services for terminal clients.
- j. *Mental health services*** are psychological and psychiatric treatment and counseling services offered to individuals with a diagnosed mental illness, conducted in a group or individual setting, and provided by a mental health professional licensed or authorized within the State to render such services. This typically includes psychiatrists, psychologists, and licensed clinical social workers.
- k. *Medical nutrition therapy*** is provided by a licensed registered dietitian outside of a primary care visit and includes the provision of nutritional supplements. Medical nutrition therapy provided by someone other than a licensed/registered dietitian should be recorded under psychosocial support services.
- l. *Medical Case management services (including treatment adherence)*** are a range of client-centered services that link clients with health care, psychosocial, and other services. The coordination and follow-up of medical treatments is a component

of medical case management. These services ensure timely and coordinated access to medically appropriate levels of health and support services and continuity of care, through ongoing assessment of the client's and other key family members' needs and personal support systems. Medical case management includes the provision of treatment adherence counseling to ensure readiness for, and adherence to, complex HIV/AIDS treatments. Key activities include (1) initial assessment of service needs; (2) development of a comprehensive, individualized service plan; (3) coordination of services required to implement the plan; (4) client monitoring to assess the efficacy of the plan; and (5) periodic re-evaluation and adaptation of the plan as necessary over the life of the client. It includes client-specific advocacy and/or review of utilization of services. This includes all types of case management including face-to-face, phone contact, and any other forms of communication.

- m. *Substance abuse services outpatient*** is the provision of medical or other treatment and/or counseling to address substance abuse problems (i.e., alcohol and/or legal and illegal drugs) in an outpatient setting, rendered by a physician or under the supervision of a physician, or by other qualified personnel.

SUPPORT SERVICES

- n.** Case Management (non-Medical) includes the provision of advice and assistance in obtaining medical, social, community, legal, financial, and other needed services. Non-medical case management does not involve coordination and follow-up of medical treatments, as medical case management does.
- o.** *Child care services* are the provision of care for the children of clients who are HIV-positive while the clients attend medical or other appointments or Ryan White Program-related meetings, groups, or training.

NOTE: This does not include child care while a client is at work.
- p.** *Pediatric developmental assessment and early intervention services* are the provision of professional early interventions by physicians, developmental psychologists, educators, and others in the psychosocial and intellectual development of infants and children. These services involve the assessment of an infant's or child's developmental status and needs in relation to the involvement with the education system, including early assessment of educational intervention services. It includes comprehensive assessment of infants and children, taking into account the effects of chronic conditions associated with HIV, drug exposure, and other factors. Provision of information about access to Head Start services, appropriate educational settings for HIV-affected clients, and education/assistance to schools should also be reported in this category.

- q.** *Emergency financial assistance* is the provision of short-term payments to agencies or establishment of voucher programs to assist with emergency expenses related to essential utilities, housing, food (including groceries, food vouchers, and food stamps), and medication when other resources are not available.

NOTE: Part A and Part B programs must be allocated, tracked and report these funds under specific service categories as described under 2.6 in DSS Program Policy Guidance No. 2 (formally Policy No. 97-02).

- r.** *Food bank/home-delivered meals* include the provision of actual food or meals. It does not include finances to purchase food or meals. The provision of essential household supplies such as hygiene items and household cleaning supplies should be included in this item. Includes vouchers to purchase food.
- s.** *Health education/risk reduction* is the provision of services that educate clients with HIV about HIV transmission and how to reduce the risk of HIV transmission. It includes the provision of information; including information dissemination about medical and psychosocial support services and counseling to help clients with HIV improve their health status.
- t.** *Housing services* are the provision of short-term assistance to support emergency, temporary or transitional housing to enable an individual or family to gain or maintain medical care. Housing-related referral services include assessment, search, placement, advocacy, and the fees associated with them. Eligible housing can include both housing that does not provide direct medical or supportive services and housing that provides some type of medical or supportive services such as residential mental health services, foster care, or assisted living residential services.
- u.** *Legal services* are the provision of services to individuals with respect to powers of attorney, do-not-resuscitate orders and interventions necessary to ensure access to eligible benefits, including discrimination or breach of confidentiality litigation as it relates to services eligible for funding under the Ryan White Program. It does **not** include any legal services that arrange for guardianship or adoption of children after the death of their normal caregiver.
- v.** *Linguistics services* include the provision of interpretation and translation services.
- w.** Medical transportation services include conveyance services provided, directly or through voucher, to a client so that he or she may access health care services.
- x.** *Outreach services* are programs that have as their principal purpose identification of people with unknown HIV disease or those who know their status so that they may become aware of, and may be enrolled in care and treatment services (i.e., case finding), not HIV counseling and testing nor HIV prevention education. These services may target high-risk communities or individuals. Outreach programs must be

planned and delivered in coordination with local HIV prevention outreach programs to avoid duplication of effort; be targeted to populations known through local epidemiologic data to be at disproportionate risk for HIV infection; be conducted at times and in places where there is a high probability that individuals with HIV infection will be reached; and be designed with quantified program reporting that will accommodate local effectiveness evaluation.

- y.** *Permanency planning* is the provision of services to help clients or families make decisions about placement and care of minor children after the parents/caregivers are deceased or are no longer able to care for them.
- z.** *Psychosocial support services* are the provision of support and counseling activities, child abuse and neglect counseling, HIV support groups, pastoral care, caregiver support, and bereavement counseling. Includes nutrition counseling provided by a non-registered dietitian but excludes the provision of nutritional supplements.
- aa.** *Referral for health care/supportive services* is the act of directing a client to a service in person or through telephone, written, or other type of communication. Referrals may be made within the non-medical case management system by professional case managers, informally through support staff, or as part of an outreach program.
- ab.** *Rehabilitation services* are services provided by a licensed or authorized professional in accordance with an individualized plan of care intended to improve or maintain a client's quality of life and optimal capacity for self-care. Services include physical and occupational therapy, speech pathology, and low-vision training.
- ac.** *Respite care* is the provision of community or home-based, non-medical assistance designed to relieve the primary caregiver responsible for providing day-to-day care of a client with HIV/AIDS.
- ad.** *Substance abuse services—residential* is the provision of treatment to address substance abuse problems (including alcohol and/or legal and illegal drugs) in a residential health service setting (short-term).
- ae.** *Treatment adherence counseling* is the provision of counseling or special programs to ensure readiness for, and adherence to, complex HIV/AIDS treatments by non-medical personnel outside of the medical case management and clinical setting.

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Combined Epidemiologic Profile

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