

FY 2012 RYAN WHITE NEEDS ASSESSMENT: EXECUTIVE SUMMARY REPORT

Adopted:

February 6, 2013



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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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Table 2 Representativeness of the Sample by TSA and by County: Percent of HIV/AIDS Cases, Gender, Race/Ethnicity	3
Table 27 Barriers to Care by TSA, EMA and Non-EMA	13
Table 30 Perceived Needs by TSA, EMA and Non-EMA	14
H. Perceived Needs for PLWH	15
A. Service Priority Recommendations	11
B. Service Barriers	12
C. Service Needs	14
D. Service Utilization	15

LIST OF ATTACHMENTS

Attachment 1: TSA HIV/AIDS Demographics.....	16
Attachment 2: EIIHA Matrix	20
Attachment 3: Service Category Definitions.....	21

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 FY2012 assessment and the year the component was completed is noted in parentheses:

- < Client Survey (2010)
- < Epidemiologic Profile (2012)
- < Funding Stream Analysis (2011)
- < Resource Analysis (2010)
- < Unmet Need Estimate (2012)
- < Early Identification of Individuals with HIV/AIDS (EIIHA)(2012)

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. Client Survey (2010)

PLWH/A residing throughout the Care Council's total service area (TSA) were surveyed. A total of 2,199 surveys were returned. With the use of online data collection software, all surveys can be used for each question that was answered. The 2004 Client Survey consisted of 901 usable responses, and the 2007 client survey consisted of 1747 useable surveys.

The 2010 questionnaire was developed in 2009 by the State of Florida HIV/AIDS Bureau in conjunction with the Patient Care Planning Group for Part B consortias. 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 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 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 survey was intended to provide quantitative (measurable) data and to assure client input into the needs assessment process.

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, housing, and service needs and barriers. (See Attachment 1) To facilitate the participation of Spanish-speaking people living with HIV/AIDS (PLWHA), the questionnaire was translated into Spanish and was made available at all survey sites.

A survey link was posted online at the Care Council website. Surveys were distributed to a total of 48 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.

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 2010 through June 2010.

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 an introduction 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.

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:

The state encouraged an overall return rate of 20% of the cumulative HIV and AIDS

reported cases through December 2008. Overall results indicated an under sampling by 2% or 242 surveys. For return rates by county, 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. Minorities, particularly minority males, were underrepresented.

Recommended Sample Sizes and Surveys Returned in the TSA

	Number of white males	Number of white females	Number of nonwhite males	Number of nonwhite females	Responses that did not answer both gender and race questions	Sample size (20% living cases*)
Total Service Area	943	204	776	518		2441
Total collected	978	248	490	405	78	2,199

*Recommended sample sizes based on 2008 epi data of living cases

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 was 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. In addition, self reporting, particularly on issues surrounding mental health, substance use and sexual behavior can be unreliable.

D. Epidemiologic Profile (2012)

The demographics and epidemiology report was completed in 2012. 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, 2011, a total of 7,499 living AIDS cases and 5,564 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 (39.3%) followed by Black males (22.4%) and Black Females (15.6%). The proportional breakdown among the living HIV (non-AIDS) cases was: White males 35.2%, Black males 22.7%, and Black females 17.2%.
- Among males, Whites accounted for the highest percentage of reported living AIDS cases (54.4%) and living HIV (non-AIDS) cases (51.0%) followed by Blacks (31.0% and 32.9%, respectively) and Hispanics (12.9% and 14.3%, respectively). Blacks are disproportionately impacted by HIV/AIDS with a rate of 1378.2 infections per 100,000 population compared to Hispanics at 398.4 and Whites at 391.8.
- Among females, Blacks accounted for 56.3% of reported living AIDS cases and 55.7% of living HIV (non-AIDS) cases. Whites accounted for 26.1% of AIDS cases and 28.4% of HIV (non-AIDS) cases followed by Hispanics (15.5% and 14.3%, respectively). Blacks are disproportionately impacted by HIV/AIDS with a rate of 907.4 infections per 100,000 population compared to Hispanics at 181.9 and Whites at 77.2.

2. Mode of Transmission and Gender (TSA)

- Among males, MSM transmission accounted for the largest percentage of reported AIDS and HIV (non-AIDS) cases (61.4% and 65.9%, respectively) followed by heterosexual transmission for AIDS (14.7%) and cases reported with risk not specified for HIV(non-AIDS) at 11.4%. Injection Drug Use (IDU) ranked third for AIDS cases (9.0%) and heterosexual transmission ranked third for HIV (non-AIDS) at 11.4%.
- For female AIDS and HIV (non-AIDS) cases, heterosexual transmission ranked highest (67.5% and 64.0%, respectively) followed by cases reported as IDU for AIDS (17.6%) and risk not specified for HIV (non-AIDS) at 20.9%. Risk not specified ranked third for AIDS cases (10.8%) and IDU ranked third for HIV (non-AIDS) at 12.6%.

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

E. Funding Stream Analysis (2011)

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 2010, 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 (50%), outpatient/ambulatory care (15%), hospital inpatient services (8%), case management (5%) and housing assistance (5%).

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.

Due to the sheer volume of these OOS (Out of State) cases, there currently is a back log of over 1,000 OOS cases to be entered into the eHARS system, thus, for this year, the

total number of cases and their care status will be underreported. The OOS data only represent a minimal amount of the prevalent cases that have migrated into Florida (3-4%), yet it is still valuable data to include in the analyses as it represents persons living and in care in Florida, regardless of where they were reported.

**TAMPA-ST. PETERSBURG TSA
UNMET NEED FRAMEWORK TABLE**

Population Sizes		Value		Data Source(s)
Row A.	Number of persons living with AIDS (PLWA), aware for the period of 01/01/2011 - 12/31/2011	8,052		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 01/01/2011 - 12/31/2011	6,038		
Row C.	Total number of HIV+ aware, for the period of 01/01/2011 - 12/31/2011	14,090		
Care Patterns		Value	Percent	Data Source(s)
Row D.	Number of PLWA who <i>did</i> receive the specified HIV primary medical care services in 12-month period	5,835	72%	eHARS ¹ and OOS ² data sets and 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	3,726	54%	
Row F.	Total number of HIV+/aware who <i>did</i> receive the specified HIV primary medical care services in 12-month period	9,111	65%	
Calculated Results		Value	Percent	Calculation
Row G.	Number of PLWA who <i>did NOT</i> receive primary medical services	2,217	28%	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	2,762	46%	Value: Value B - Value E. Percent: Value H/Value B.
Row I.	Total HIV+/aware who <i>did NOT</i> receive specified primary medical care services (quantified estimate of unmet need)	4,979	35%	Value: Value G + Value H. Percent: Value I/Value C

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 TSA.

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. The eHARS data are specifically tailored to each EMA and consortia. Data from 2011 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 8,052 people are living with AIDS and 6,038 people are living with HIV in the Total Service Area (TSA).

Rows D, E and F of the Unmet Need Framework Table provide estimates of numbers 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 9,111 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. 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 4,979 people are living with HIV/AIDS in the TSA and are not in care.

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

Over the last two decades, the Grantee, in conjunction with the local Ryan White Planning Council, has focused on improving and expanding their partnership with the FCPN (Florida HIV/AIDS Comprehensive Planning Network), PPG (Prevention Planning Group), PCPG (Patient Care Planning Group), the Viral Hepatitis Council, and the local Florida DOH (Department of Health) HAPCs (HIV/AIDS Program Coordinators) to ensure coordination of services and programs. The network will continue these collaborations to ensure that current and newly developed strategies within the EMA will support HRSA's objective in the early identification of individuals living with HIV/AIDS and subsequently getting them into care.

Currently, no Part A funds are allocated to Early Intervention Services in the EMA. The State of Florida, the CDC and HRSA (Health Resources and Services Administration) allocate approximately \$36.5 million dollars to support the HIV prevention efforts of Florida's CBOs (Community-Based Organizations), ASOs (AIDS Service Organizations), CHDs (County Health Departments), and DOH (Department of Health). In an effort to maximize the efficiency, effectiveness and allocation of limited HIV prevention resources

throughout the state, the DOH has taken the lead in the area of prevention and early intervention.

Florida's PPG is responsible for the 2012-2014 Florida Jurisdictional HIV Prevention Plan, which directs local HIV prevention planning. The HIV prevention plan details the existing linkages between the Planning Council, the local HIV CPP (Community Planning Partnership), and the FCPN. Until October 2012, the Grantee served dual roles as the Ryan White Part A Grantee, as well as the lead agency for the Part B patient care funds within the EMA. Now the Pinellas County Health Department serves as the Part B lead agency. We have, however, continued the Part A Planning Council and the Part B Consortium as a combined planning body. The EMA is, therefore, in a unique position to strengthen existing and future relationships with HIV prevention by having direct access to the DOH, which serves as the Grantee for HIV prevention and testing activities.

Included in the 2012-2014 Florida Jurisdictional HIV Prevention Plan are two major goals that concentrate on reaching those who are unaware of their HIV status and on linking HIV positive persons to care. The first of these goals reads: "Through voluntary counseling and testing, increase the proportion of people who know their HIV status." The second goal reads: "Increase the proportion of HIV-positive individuals receiving prevention with positives services (e.g., linkage to/retention/re-engagement in care, treatment adherence, partner services, integrated screening, health education/risk reduction interventions) by 2016."

In order to achieve these goals, the Florida DOH has implemented one of the largest publicly funded HIV testing programs in the country, performing approximately 420,000 tests in 2011. There are more than 1,600 registered HIV counseling and testing sites statewide and 151 different site numbers within the EMA as of August 2012. The local number reflects an increase in testing site numbers from last year, illustrating the emphasis that is being placed on expanded testing in the EMA. Publicly funded HIV testing programs utilize three different methods (conventional blood draw, OraSure, and rapid testing) to ensure access to at-risk populations.

HIV counseling, testing, and referrals into care and treatment will be the focus of subsequent joint planning activities between the local Planning Council and the CPP. Recently expanded early intervention activities (such as rapid testing and jail outreach programs) have resulted in successful outcomes in the EMA over the past two years. The post-test counseling requires that HIV positive individuals are referred and linked to appropriate care and treatment, which are documented on the post-test counseling form. Local surveillance staff tracks each new positive to determine if they have received a CD4 or viral load test within three months of being informed of their positive status.

Early intervention programs offering HIV counseling and testing have been a priority within the EMA for several years, recently implementing these initiatives to ensure that

every resident in the EMA and in Florida has access to HIV testing services. However, more programs are needed to guarantee universal access throughout Florida and ensure the early identification of individuals living with HIV/AIDS. Local testing initiatives are described in the following Plan Section which details how this increases access for historically underserved populations.

The local partnerships have a rich history of collaborating on HIV prevention, care, and treatment issues throughout the EMA. This tradition will continue as the local networks implement a plan to incorporate HIV EIS with a goal of ensuring 100% of HIV+ clients are linked to services with the local Ryan White programs. Bi-monthly meetings between the Grantee and the local DOH HIV/AIDS Administrators occur to ensure optimal service delivery using limited federal, state, and local resources. Included in the agenda are discussions on linking HIV care and prevention services. Meetings focus on service coordination between Ryan White Part A and B (ADAP and Patient Care) programs and ways to maximize funding as well as planning program integration (HIV, STD, TB, Hepatitis) within the EMA.

Florida began a wait list for ADAP in June 2010, just as the need for free or low cost medications dramatically increased. While Florida's unemployment rate soared, with millions losing jobs and health insurance, HIV patients treated with powerful antiretroviral drugs are living longer, and staying on ADAP's rolls. AIDS programs expanded testing and new federal health standards mandated treating patients at lower viral loads, requiring more medications. All new positives needing ARV treatment are referred to patient assistance programs if they qualify. Otherwise, the Part A program is covering the cost for medications in addition to the lab testing and clinic visits to determine the treatment plan and adherence. As of January 2013, a wait list no longer exists for ADAP services.

The Planning Council has incorporated a local HIV prevention perspective by utilizing the "other federal HIV programs" seat specifically for HIV prevention services. The Planning Council has an HIV prevention update as a standing agenda item at every Planning Council meeting. This ensures that monthly updates on early intervention services are occurring, but also allows for ongoing enhancement and collaboration.

The Grantee and Planning Council work with the existing network of partnerships by supporting local initiatives to increase HIV testing services within the EMA. The Early Intervention Services (EIS) plan focuses on four major activities: (1) expansion of publicly supported HIV counseling sites; (2) incorporation of EIS into clinical services (STD, TB); (3) coordination of case management services; and (4) incorporation of EIS in all HIV prevention services in the EMA.

The following objectives will be used to evaluate the progress made on the EIS activities: (1) integration of EIS in all HIV prevention services; (2) outreach and recruitment to HIV

testing services; (3) 95% post-test counseling for HIV positive tests; (4) case finding and identification of clients; (5) develop a tracking method for HIV infected individuals from HIV testing to primary care providers; and (6) enhancement of referral linkages into primary care programs that link back with HIV testing services.

The Grantee has incorporated the EIIHA strategy into the local Requests for Proposals document by giving additional consideration and weight to those bidders who demonstrate viable descriptions and narrative which requires them to explain how they will further expand, integrate, and link their patient care activities with counseling and testing. The Grantee specifically references EIIHA and the importance of this objective in the bidder's pre-conference to ensure the understanding of the objective and the expected outcome.

The EIS program and objectives will result in the enhancement of existing HIV programs, development of a local referral and tracking methodology for HIV positive individuals, and utilization of the existing system of care within the EMA.

The local priority populations targeted for the allocation of resources in the TSA are included in this EIIHA Matrix (Attachment 2).

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

This essentially meant that the information received from the client survey 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 3). 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.

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
13. Emergency Financial Assistance
14. Housing Services
15. Food Bank/Home Delivered Meals
16. Medical Transportation
17. Case Management (non-medical)
18. Health Education/Risk Reduction
19. Treatment Adherence Counseling
20. Outreach Services
21. Psychosocial Support
22. Rehabilitation Services
23. Linguistic Services
24. Respite Care
25. Child Care Services
26. Legal Services
27. Substance Abuse Services- residential
28. 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 2010 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.

Barriers to Care in the TSA

42. What kept you from getting the services you needed during the past 12 months? (Mark all that apply)	
Answer Options	Percent of Respondents (N=616)
I did not know where to get services	39%
I could not pay for services	28%
I was depressed	18%
I could not get transportation	18%
I did not qualify for services	17%
I did not want people to know that I have HIV	8%
I missed my appointment(s)	8%
I could not get an appointment	13%
I was put on the waiting list	13%
I had a bad experience with the staff	7%
I could not get time off work	4%
Services were not in my language	0%
I was too busy taking care of my partner	2%
I could not get childcare	1%
Other	14%

“Other” reasons cited included specific reasons the client was determined ineligible, length of time they had been on a waiting list, Medicare donut hole and various complications of getting through the process to receive assistance. Several respondents listed jail or prison as a barrier. Others listed the need for a service that was unavailable to them or lacks funding such as vision care, specialty dentistry and legal services.

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C. Service Needs

Respondents to the 2010 client survey were asked what are the most important services to provide for people with HIV/AIDS in the TSA.

44. Which five services do you think are most important for the state to provide for people with HIV/AIDS? (Select ONLY 5)		
Answer Options*	Percent of Respondents	Number of Respondents (N=2,011)
Medications	83%	1,674
Case Management	67%	1,341
Outpatient Medical Care	61%	1,236
Dental/Oral Health	62%	1,237
Health Insurance	52%	1,037
Food Bank/Food Voucher	35%	703
Mental Health Services	28%	554
Transportation	20%	410
Nutritional Counseling	11%	223
Legal Support	11%	215
Substance Abuse Treatment	7%	143
Early Intervention Services	9%	181
Health Education/Risk Reduction	9%	178
Home Health Care	10%	202
Hospice Services	9%	172
Treatment Adherence	6%	112
Outreach	5%	92
Rehabilitation	4%	79
Other	5%	101

* Services excluded as a service category in the survey question: Housing Services, Home and Community Based Health Services, Emergency Financial Assistance, Psychosocial Support Services, Case Management (non-medical), Linguistics Services, Child Care Services, Permanency Planning, Referral Services, Respite

Care, Substance Abuse Services (residential), Treatment Adherence Counseling and Pediatric Developmental Assessment and Early Intervention Services.

Respondents were given the opportunity to enter a service that is not listed under the option for “other.” Six people indicated that all of the services were important or that they needed to be able to select more than five as most important and seven respondents listed services included among the answer choices. Fifty-five (55) people indicated that housing assistance was needed, nine (9) people listed emergency financial assistance, seven (7) people listed support groups, seven (7) people listed acupuncture/massage services, and one respondent listed each of the following services: life insurance, vision coverage, Medicare co-pays, AICP, SSI, disability, AIDS service organization, prevention education, personal hygiene and sterilization.

D. Service Utilization

The below table provides a list of all fundable services and the percentage of respondents to the client survey who did not need the service and of those that did need the service, the percentage who received the service and the percentage for which there was a service gap.

Service Utilization

Service	Percent That Received Needed Service	Service Gap* Percentage	Percent that Did Not Need Service
CORE SERVICES			
Outpatient Medical Care	97	3	11
Case Management	87	13	13
Medications	97	3	9
Dental/Oral Health	64	36	18
Health Insurance	69	31	34
Mental Health Services	72	28	55
Substance Abuse Treatment	74	26	86
Nutritional Counseling	68	32	58
Early Intervention Services	79	21	60
Home Health Care	61	39	84
Hospice Services	58	42	93
SUPPORT SERVICES			
Food Bank or Food Vouchers	60	40	44
Transportation	55	45	66
Outreach	49	51	79
Health Education/Risk Reduction	75	25	69

Treatment Adherence	87	13	66
Legal Support	40	60	67
Rehabilitation	49	51	80

* Service gap combines respondents who selected "Needed Service, but Could Not get Service" and "Needed Service, But Did Not Know about Service"

During the analysis of data for service utilization, service gaps and the most important needs perceived by PLWHA, it was noted that since housing was dealt with as a separate issue in the client survey, apparently the state chose to exclude housing as a service category in the questions pertaining to utilization, service need or to be ranked by level of importance. Other services excluded: Home and Community Based Health Services, Emergency Financial Assistance, Psychosocial Support Services, Case Management (non-medical), Linguistics Services, Child Care Services, Permanency Planning, Referral Services, Respite Care, Substance Abuse Services (residential), Treatment Adherence Counseling and Pediatric Developmental Assessment and Early Intervention Services.

ATTACHMENT 1
Epidemiology Fact Sheet: As of December 31, 2011

Proportions of the TSA's PLWA Population by County (2011)

County	County Totals	Male	Female	White	Black	Hispanic
Hardee	0.5%	0.3%	0.2%	0.1%	0.2%	0.2%
Hernando	1.3%	1.0%	0.3%	0.8%	0.2%	0.2%
Highlands	1.4%	0.9%	0.5%	0.4%	0.6%	0.4%
Hillsborough	44.0%	31.8%	12.2%	17.1%	18.7%	7.5%
Manatee	6.7%	4.6%	2.0%	2.7%	2.9%	1.1%
Pasco	5.1%	3.7%	1.4%	3.7%	0.6%	0.6%
Pinellas	27.2%	21.3%	5.9%	16.6%	8.1%	2.0%
Polk	13.9%	8.7%	5.2%	5.2%	6.8%	1.6%
TOTAL	100%	72.3%	27.7%	46.5%	38.0%	13.6%

Figure 5: Proportions of the TSA's PLWH Populations by County (2011)

County	County Totals	Male	Female	White	Black	Hispanic
Hardee	0.4%	0.2%	0.2%	0.1%	0.3%	0.1%
Hernando	1.6%	1.1%	0.5%	1.0%	0.2%	0.3%
Highlands	1.5%	0.7%	0.7%	0.4%	0.8%	0.3%
Hillsborough	46.5%	32.5%	14.1%	17.4%	20.4%	8.0%
Manatee	6.3%	3.6%	2.7%	2.6%	2.7%	1.0%
Pasco	5.1%	3.6%	1.5%	3.6%	0.7%	0.7%
Pinellas	26.7%	20.1%	6.6%	15.0%	9.1%	2.0%
Polk	11.8%	7.2%	4.6%	4.1%	5.8%	1.8%
TOTAL	100%	69.1%	30.9%	44.0%	39.9%	14.2%

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

TSA Prevalence	Group (gen. pop. #)	Number		Rate per 100,000		Percentage		Total HIV/AIDS		
Gender	Male (1,875,791)	5,421	3,844	289.0	204.9	72.3%	69.1%	9,265	70.9%	493.9
	Female (1,984,182)	2,078	1,720	104.7	86.7	27.7%	30.9%	3,798	29.1%	191.4
	Total (3,859,973)	7,499	5,564	194.3	144.1	100%	100%	13,063	100%	338.4
	White (2,587,072)	3,490	2,447	134.9	94.6	46.5%	44.0%	5,937	45.4%	229.5
Race/ Ethnicity	Black (448,227)	2,851	2,222	636.1	495.7	38.0%	39.9%	5,073	38.8%	1131.8
	Hispanic (621,879)	1,021	789	164.2	126.9	13.6%	14.2%	1,810	13.9%	291.1
	Other/Unk. (202,795)*	137	106	67.6	52.3	1.8%	1.9%	243	1.9%	119.8
	Total (3,859,973)	7,499	5,564	194.3	144.1	100%	100%	13,063	100%	338.4
	0-12 (581,658)	8	24	1.4	4.1	0.1%	0.4%	332	0.2%	5.5
Age	13-19 (331,718)	66	70	19.9	21.1	0.9%	1.3%	136	1.0%	41.0
	20-24 (230,841)	131	297	56.7	128.7	1.7%	5.3%	428	3.3%	185.4
	25-29 (231,144)	225	502	97.3	217.2	3.0%	9.0%	727	5.6%	314.5
	30-39 (458,247)	1,026	1,200	223.9	261.9	13.7%	21.6%	2,226	17.0%	485.8
	40-49 (522,603)	2,774	1,785	530.8	341.6	37.0%	32.1%	4,559	34.9%	872.4
	50-59 (535,539)	2,378	1,181	444.0	220.5	31.7%	21.2%	3,559	27.2%	664.6
	60+ (968,223)	891	505	92.0	52.2	11.9%	9.1%	1,396	10.7%	144.2
	Total (3,859,973)	7,499	5,564	194.3	144.1	100%	100%	13,063	100%	338.4
	MSM	3,331	2,533			44.4%	45.5%	5,864	44.9%	
Mode of Transmission	IDU	854	438			11.4%	7.9%	1,292	9.9%	
	MSM/IDU	352	165			4.7%	3.0%	517	4.0%	
	Hetero	2,201	1,540			29.4%	27.7%	3,741	28.6%	

	Perinatal	121	83			1.6%	1.5%	204	1.6%	
	Other	29	6			0.4%	0.1%	35	0.3%	
	Risk Not Specified	611	799			8.1%	14.4%	1,410	10.8%	
	Total	7,499	5,564			100%	100%	13,063	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

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	2,947	235.4	39.3%	54.4%	1,959	156.4	35.2%	51.0%	4,906	391.8	37.6%	53.0%
Black	1,681	786.5	22.4%	31.0%	1,264	591.4	22.7%	32.9%	2,945	1,378.0	22.5%	31.8%
Hispanic	698	222.6	9.3%	12.9%	551	175.7	9.9%	14.3%	1,249	398.4	9.6%	13.5%
Other/Unk.	95	98.6	1.3%	1.8%	70	72.6	1.3%	1.8%	165	171.2	1.3%	1.8%
Total	5,421	289.0	72.3%	100%	3,844	204.9	69.1%	100%	9,265	493.9	70.9%	100%
FEMALES												
White	543	40.7	7.2%	26.1%	488	36.6	8.8%	28.4%	1,031	77.2	7.9%	27.1%
Black	1,170	498.9	15.6%	56.3%	958	408.5	17.2%	55.7%	2,128	907.4	16.3%	56.0%
Hispanic	323	104.7	4.3%	15.5%	238	77.2	4.3%	13.8%	561	181.9	4.3%	14.8%
Other/Unk.*	42	39.5	0.6%	2.0%	36	33.8	0.6%	2.1%	78	73.3	0.6%	2.1%
Total	2,078	104.7	27.7%	100%	1,720	86.7	30.9%	100%	3,798	191.4	29.1%	100%
TSA Total	7,499				5,564				13,063			

* 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 (2011)

Age Group	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	8	1.4	0.1%	24	4.1	0.4%	32	5.5	0.2%
13-19	66	19.9	0.9%	70	21.1	1.3%	136	41.0	1.0%
20-24	131	56.7	1.7%	297	128.7	5.3%	428	185.4	3.3%
25-29	225	97.3	3.0%	502	217.2	9.0%	727	314.5	5.6%
30-39	1,026	223.9	13.7%	1,200	261.9	21.6%	2,226	485.8	17.0%
40-49	2,774	530.8	37.0%	1,785	341.6	32.1%	4,559	872.4	34.9%
50-59	2,378	444.0	31.7%	1,181	220.5	21.2%	3,559	664.6	27.2%
60+	891	92.0	11.9%	505	52.2	9.1%	1,396	144.2	10.7%
Total	7,499	194.3	100%	5,564	144.1	100%	13,063	338.4	100%

TSA HIV/AIDS Cases by Mode of Transmission and Gender (2011)

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	3,331	44.4%	61.4%	2,533	45.5%	65.9%	5,864	44.9%	63.3%
IDU	489	6.5%	9.0%	222	4.0%	5.8%	711	5.4%	7.7%
MSM/IDU	352	4.7%	6.5%	165	3.0%	4.3%	517	4.0%	5.6%
Heterosexual	798	10.6%	14.7%	439	7.9%	11.4%	1,237	9.5%	13.4%
Perinatal	47	0.6%	0.9%	40	0.7%	1.0%	87	0.7%	0.9%
Other Identified Risk	17	0.2%	0.3%	5	0.1%	0.1%	22	0.2%	0.2%
No Identified Risk	387	5.2%	7.1%	440	7.9%	11.4%	827	6.3%	8.9%
Total	5,421	72.3%	100%	3,844	69.1%	100%	9,265	70.9%	100%
FEMALES									
IDU	365	4.9%	17.6%	216	3.9%	12.6%	581	4.4%	15.3%
Heterosexual	1,403	18.7%	67.5%	1,101	19.8%	64.0%	2,504	19.2%	65.9%
Perinatal	74	1.0%	3.6%	43	0.8%	2.5%	117	0.9%	3.1%
Other Identified Risk	12	0.2%	0.6%	1	0.0%	0.1%	13	0.1%	0.3%
No Identified Risk	224	3.0%	10.8%	359	6.5%	20.9%	583	4.5%	15.4%
Total	2,078	27.7%	100%	1,720	30.9%	100%	3,798	29.1%	100%
TSA Total	7,499			5,564			13,063		

ATTACHMENT 2

EIIHA Matrix

1A. All Individuals Unaware of their HIV Status (HIV positive & HIV negative)									
2A. Tested in the Past 12 Months		2B. Not Tested in the Past 12 Months		3D. Moderate and Low Risk Individuals					
3A. Individuals Not Post-Test Counseled		3B. Received Preliminary HIV Positive Result Only – No Confirmatory Test		3C. High Risk Individuals			4E. Other		
4A. Tested Confidentially		4B. Tested Anonymously		4C. MSM			4D. Heterosexuals		
				5A. Black	5B. Hispanic	5C. White	5D. Black	5E. Hispanic	5F. White
							5G. Partner of HIV+ Individuals	5H. Infants of Infected Mothers	
				6A. Youth age 13-24					

ATTACHMENT 3

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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