

FY 2010 RYAN WHITE NEEDS ASSESSMENT: ANONYMOUS NEEDS SURVEY REPORT

Prepared By



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I. BACKGROUND

The Ryan White Care Council conducts a 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 (Hardee, Hernando, Highlands, Hillsborough, Manatee, Pasco, Pinellas and Polk) service area. One component of the FY 2010 needs assessment involved surveying HIV+ clients throughout the Total Service Area (TSA) to determine overall needs and service gaps.

II. METHODOLOGY

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 is used in conjunction with other qualitative data 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 the Sample

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.

To assess the representativeness of the 2,199 completed responses, a comparison of their demographic characteristics was made against those of each county’s cumulative HIV and AIDS reported cases through December 2009. Hispanic is an ethnicity and can be of any race. Totals may not equal 100% due to a respondent’s choice to not answer a specific question. No target was set for transgender since the specific data set for cumulative cases only reports males and females. (See Table 1).

Table 1
Representativeness of the Sample by TSA and by County:
Percent of HIV/AIDS Cases, Gender, Race/Ethnicity

Total Service Area (n= 2199)		
Characteristic	Target	% Received
% of cases in TSA	20%	18%
Male	71%	68%
Female	29%	31%
Transgender		1%
White	47%	58%

Black	38%	36%
Other/More than one	2%	6%
Hispanic – any race	14%	17%
HARDEE COUNTY (n=8)		
Characteristic	Target	% Received
Overall % of cases in TSA	<1%	<1%
% of cases in county	20%	12%
HERNANDO COUNTY (n=45)		
Characteristic	Target	% Received
Overall % of cases in TSA	1.4%	2%
% of cases in county	20%	25%
HIGHLANDS COUNTY (n=20)		
Characteristic	Target	% Received
Overall % of cases in TSA	1.4%	1%
% of cases in county	20%	11%
HILLSBOROUGH COUNTY (n=870)		
Characteristic	Target	% Received
Overall % of cases in TSA	45.0%	40%
% of cases in county	20%	16%
MANATEE COUNTY (n=68)		
Characteristic	Target	% Received
Overall % of cases in TSA	6.8%	3%
% of cases in county	20%	8%
PASCO COUNTY (n=116)		
Characteristic	Target	% Received
Overall % of cases in TSA	5.2%	5%
% of cases in county	20%	18%
PINELLAS COUNTY (n=839)		
Characteristic	Target	% Received
Overall % of cases in TSA	27.3%	38%
% of cases in county	20%	25%
POLK COUNTY (n=221)		
Characteristic	Target	% Received
Overall % of cases in TSA	12.5%	10%
% of cases in county	20%	14%

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.

**Table 2
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

Other Limitations of the Data

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.

III. RESULTS

Demographics

Demographic information including gender, race/ethnicity, age and orientation are included in Table 2.

Table 3
Demographics of Survey Respondents

Characteristic	TSA% (n=2199)
Gender	
Male	68%
Female	31%
Transgender	1%
Females pregnant in last 12 months	4%
Race	
White/Caucasian	58%
Black or African American	36%
Asian	0%
American Indian/Alaska Native	1%
Native Hawaiian/Pacific Islander	0%
Mixed/More Than One Race	5%
Ethnicity	
Hispanic	17%
Haitian	1%
Age	
Under 12	0%
13-24 years	3%
25-44 years	35%
45-64 years	59%
65 years and older	3%
Orientation	
Straight	48%
Gay	45%
Lesbian	1%
Bisexual	6%

Respondents were asked about their living situation currently and six months ago. Responses did not differ significantly so only current responses will be presented.

Overall, most respondents lived in an owned or rented apartment/house. Many others reported living with family or friends. Seventy-eight percent (78%) of the 1,942 respondents reported they had a permanent living situation, 20% temporary and 2% are homeless. Table 4 describes place of residence.

**Table 4
Housing**

Type of Housing	TSA % (n =1942)
Type of Housing	
Rent house/apartment	47%
Own house/apartment	27%
Staying/living with family or friends	16%
In a room or boarding house	2%
Housing provided by the city, county or state (such as Section 8 voucher or Shelter+care)	2%
Homeless	2%
In jail/prison	1%
Homeless shelter	1%
In a 'supportive living' facility	1%
In a half-way house, transitional housing or treatment facility (drug or mental health)	1%

Ninety-three percent of respondents indicated that they had a place to sleep every night in the past six months (from the time they completed the survey). Of the 95 respondents who did not have a place to sleep every night, 5% did not have a place of their own for 1-3 nights, 18% had no place of their own for 4 nights – 1 month, 27% had no place for 31 nights - 179 nights and 40% had no place of their own for the entire 6 months.

Survey respondents were asked about the amount they paid in monthly rent or mortgage. Thirteen percent indicated that they do not contribute anything. Of the 1,311 respondents who contributed to the monthly rent or mortgage 41% contributed \$1 - \$500, forty-eight percent (48%) contributed \$501 - \$1000, ten percent (10%) contributed \$1,001 - \$2,000 and less than 1% contributed \$2,001 or more.

Respondents were asked to indicate what, if anything about their current living situation stops them from taking care of their HIV/AIDS. 85% of respondents (N=1,691) indicated that nothing where they live now stops them from taking care of their HIV/AIDS.

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**Table 5
Housing Barriers to HIV/AIDS Care**

51. Think about where you live now: which of the following stop you from taking care of your HIV/AIDS? (Mark all that apply)	
Answer Options	Percent of Respondents
I do not have money to pay for rent	47%
I am afraid of others knowing I have HIV	32%
I do not have enough food to eat	27%
I do not have a safe and private room	13%
I do not have a telephone where someone can call me	13%
I do not have heat and/or air conditioning	13%
I do not have a place to store my medications	10%
I do not have a bed to sleep in	10%
I do not feel safe in the neighborhood	9%
I cannot get away from drugs and/or alcohol in the neighborhood	6%
I have an abusive spouse or partner	2%
Other	8%

Respondents were asked to indicate what HIV/AIDS housing services were needed and which were received in the prior six months. Responses for ‘needed service but could not get service’ and ‘needed service but did not know about service’ were classified as a service gap. Respondents who indicated that they did NOT need the services were excluded.

**Table 6
Housing Services Needed**

54. Now we’re interested in the HIV/AIDS housing services you needed and what HIV/AIDS housing services you got in the past 6 months.			
Answer Options	Percent Service Gap	Percent Received Needed Service	Total Response Count (N)
Help finding a place to live	65%	35%	446
Permanent, independent housing	69%	31%	434
Temporary short-term housing	73%	27%	208
Housing where my child(ren) can live with me	62%	38%	128
Nursing home	60%	40%	53
Money to pay utilities	73%	27%	768
Money to pay rent/mortgage	78%	22%	717
House for persons living with HIV/AIDS	74%	26%	300
Assisted Living facility	66%	34%	104

Respondents were asked to indicate what, if anything kept them from getting the housing services they needed. 53% of respondents (N=765) indicated that they got the housing services they needed.

**Table 7
Housing Service Barriers**

55. What kept you from getting the housing services you needed? (Mark all that apply)	
Answer Options	Percent of Respondents (N=681)
I did not know where to get services	48%
I did not qualify for housing services	27%
I was put on the waiting list	20%
I did not want anyone to know I have HIV	6%
I have not been treated with respect at the agency	6%
I could not get there when the agency was open	4%
Services were not in my language	1%
Other	14%

Respondents were asked to indicate what problems they had getting housing. Respondents who indicated that they did NOT have any problems getting housing were excluded.

**Table 8
Housing Difficulties**

57. What problems did you have getting housing? (Mark all that apply)	
Answer Options	Percent of Respondents (N=279)
I did not have enough money for the deposit	59%
I had bad credit	39%
I could not find affordable housing	38%
I had no transportation to search for housing	29%
I had a criminal record	34%
I did not qualify for housing assistance	16%
I was put on a waiting list	29%
I feel I was discriminated against	11%
I had a mental/physical disability	14%
I had substance use issues	4%
Other	7%

Employment status was collected along with reasons for not working. Sixty-five percent of the respondents reported that they were not working and seventy-four percent of those were not working for health reasons with sixty percent being on disability. Table 9 provides the results of employment status information and reasons for not working.

**Table 9
Employment Status**

	TSA% (n =2163)
Employment Status	
Working full time	16%
Working part time	8%
Working off and on	6%
Self employed	5%
Not Working	65%
Reasons for not working (n=999)	
For health reasons, on disability	60%
Looking for a job	12%
For health reasons, NOT on disability	14%
Retired	4%
Student	4%
Attending job training	1%
Other	5%

Health, Access and Treatment Indicators

Diagnosis and Care

Questions were asked to get a better understanding of the respondents including current care, where services are accessed and how information about care is passed along.

Place of diagnosis was explored to identify how many persons were diagnosed outside of the TSA and the State of Florida to begin understanding the impact in-migration plays in service needs. Funding is based upon cases diagnosed in the state and individuals diagnosed elsewhere are not included in calculations for the funding received through a variety of sources in the TSA. A total of 76% of respondents were diagnosed in Florida.

A summary of place of diagnosis appears in Table 10.

Table 10
Place of Initial Diagnosis

Place of Diagnosis	Percent (n= 2114)
In the same county I live now	59%
In another county in Florida	17%
In another state	22%
Out of the United States	1%

Respondents were asked to indicate if they were currently receiving care for their HIV/AIDS and if not, to provide a reason for not accessing care.

Table 11
Currently in Care

	TSA% (n = 2131)
Yes	94%
No	6%
Reasons for not Accessing Care (n=53)	
I did not feel sick	21%
I could not pay for services	23%
I did not want people to know that I have HIV	19%
I did not know where to go	13%
I was not ready to deal with having HIV	17%
I was depressed	17%
I could not get transportation	4%
I missed my appointment(s)	2%
I had a bad experience with the medical staff	8%
I could not get time off work	2%
I could not get an appointment	2%
I was too busy taking care of my partner	4%
There are not enough doctors in my area	4%
I could not get childcare	6%
Other	23%

“Other” reasons cited included a recent diagnosis or previously unaware of infection, and various complications of getting through the process to receive assistance (waiting list, waiting for lab work or copies of paperwork). Several respondents listed jail or prison as a barrier while others listed lack of insurance or financial resources to pay for care.

During data analysis, for each question with an ‘other’ option, many of the entries are actually one of the listed options. For example, a respondent who wrote in ‘financial pay status’ should have selected ‘I could not pay for services’ or the respondent who wrote ‘I do not have transportation to go to the clinic for help’ should have selected ‘I could not get transportation’. These responses falsely inflate the percentage in the ‘other’ category and decrease the actual percentage of the true response.

Respondents were also asked to tell the clinical setting where they receive care.

Table 12
Where Care is Received

	TSA% (n = 1884)
Doctor’s Office	33%
Public Clinic/Health Department	30%
HIV Specialty Clinic	29%
Veteran’s Administration (VA)	1%
Walk-in/Emergency Clinic	1%
Hospital emergency Room	0%
Other	5%

Accessing Care Outside County of Residence

Eighty-five percent (85%) of respondents indicated that they receive medical care in the same county where they live. Cross-over occurs throughout the TSA as clients must travel to obtain particular services, specialty care or access VA facilities. Of those who receive care in a county outside their county of residence, 26% do so to receive care closer to where they live or work, 14% do so because services are not available in their county and 13% do so because they do not want people to know they have HIV. Other reasons cited for accessing services outside the county of residence are for doctor or clinic preference or perceived quality of care/service.

Information Dissemination

Respondents were also asked to identify where they get most of their information about HIV/AIDS services in their local area. The most commonly preferred source for information was from the clinic/doctor’s office. The health department was the second highest preferred method of receiving information, followed closely by the case manager, an AIDS service organization and then the internet. Table 13 provides a summary of those responses. Totals may exceed 100% as more than one answer was permitted.

**Table 13
Dissemination of HIV/AIDS Information about Local Services**

Method	TSA % (n=1919)
Clinic/doctor's office	43%
Health department	24%
Case manager	18%
AIDS organization/advocacy group	6%
Internet	5%
Friends/family	2%
Community based organizations	1%
Newspaper/radio/TV	0%
Community health fair	0%
Place of worship	0%
Other	4%

Service Utilization

Seventy-four percent (74%) of respondents indicated that they did not have private health insurance during the preceding twelve months. Since a goal of the Ryan White Program is to avoid more costly emergency room care, respondents were asked if they had been to the emergency room for an HIV/AIDS related condition during the past twelve months. 88% had not been to the emergency room and only 9% of respondents had been hospitalized for an HIV/AIDS related condition during the same period of time. Table 14 provides a list of all fundable services and the percentage of respondents 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.

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 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. This will be important to remember as the planning council uses these data to set priorities.

**Table 14
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

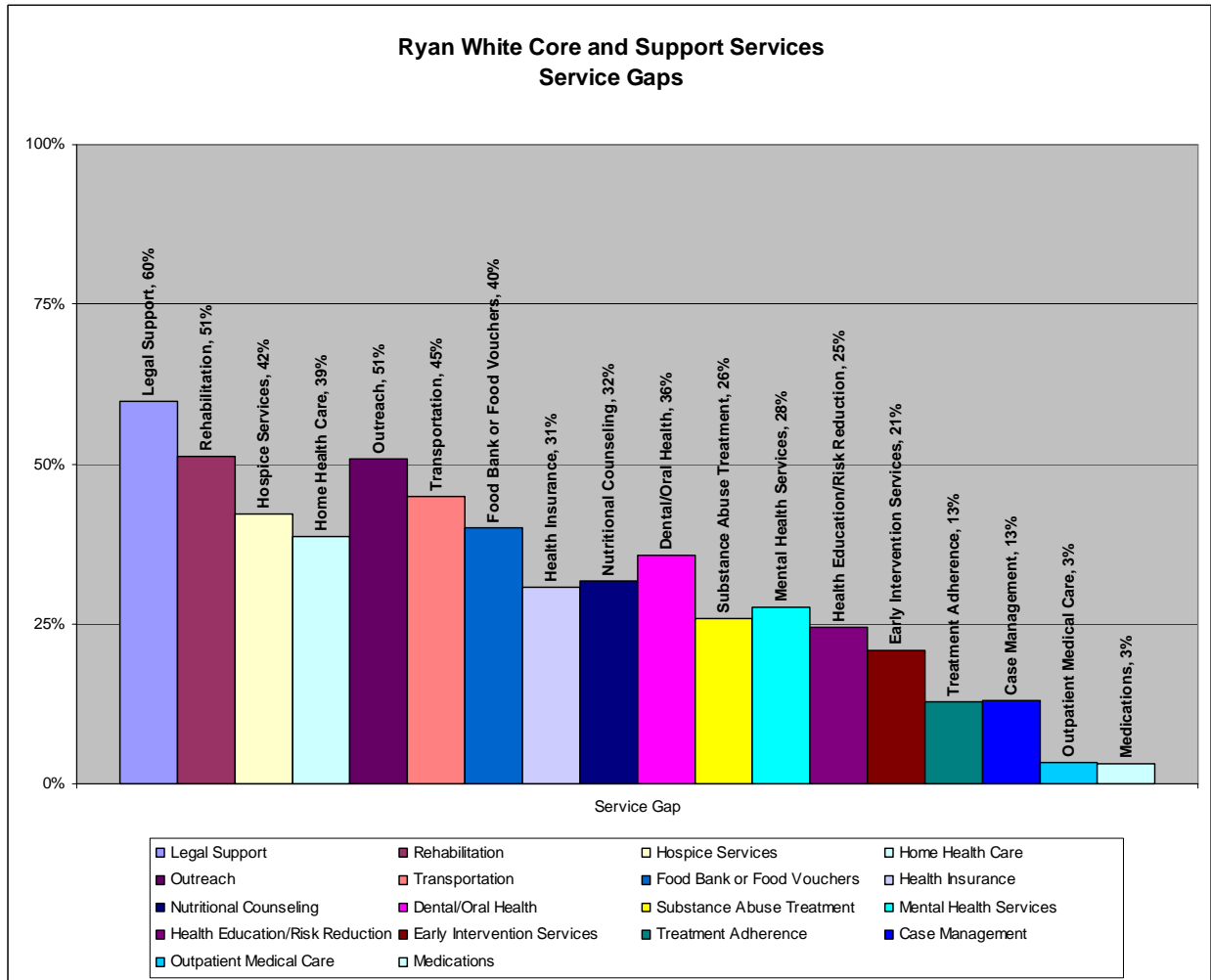
* Service gap combines respondents who selected “Needed Service, But Could Not get Service” and “Needed Service, But Did Not Know About Service”

Service Gaps

Service gaps were determined by respondents indicating which services they needed over the past year but could not get and those who needed a service, but did not know about it.

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**Table 15
Service Gaps for the TSA**



Service gaps were analyzed for several subpopulation groups: Blacks, Hispanics, women, youth and MSM. The service gaps noted for each group are in Table 16 and are in descending order from greatest to least.

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Table 16
Service Gaps by Population Group

	Blacks (N= 755)	Hispanics (N= 298)	Women (N= 668)	Youth (N= 59)	MSM (N= 967)
1	Dental/Oral Health	Dental/Oral Health	Dental/Oral Health	Dental/Oral Health	Dental/Oral Health
2	Food Bank or Vouchers	Food Bank or Vouchers	Food Bank or Vouchers	Food Bank or Vouchers	Health Insurance
3	Health Insurance	Legal Support	Transportation	Health Insurance	Legal Support
4	Transportation	Transportation	Legal Support	Legal Support	Food Bank or Vouchers
5	Legal Support	Health Insurance	Health Insurance	Transportation	Nutritional Counseling
6	Case Management	Nutritional Counseling	Mental Health Services	Mental Health Services	Transportation
7	Outreach	Outreach	Outreach	Outreach	Case Management
8	Mental Health Services	Case Management	Rehabilitation	Health Education/Risk Reduction	Mental Health Services
9	Nutritional Counseling	Rehabilitation	Case Management	Nutritional Counseling	Rehabilitation
10	Health Education/Risk Reduction	Mental Health Services	Nutritional Counseling	Early Intervention Services	Early Intervention Services
11	Rehabilitation	Early Intervention Services	Health Education/Risk Reduction	Home Health Care	Outreach
12	Early Intervention Services	Health Education/Risk Reduction	Home Health Care	Case Management	Health Education/Risk Reduction
13	Other Service	Home Health Care	Early Intervention Services	Rehabilitation	Other Service
14	Home Health Care	Other Service	Other Service	Hospice Services	Home Health Care
15	Treatment Adherence	Hospice Services	Hospice Services	Treatment Adherence	Treatment Adherence
16	Substance Abuse Treatment	Treatment Adherence	Substance Abuse Treatment	Medications	Outpatient Medical Care
17	Outpatient Medical Care	Substance Abuse Treatment	Treatment Adherence	Outpatient Medical Care	Substance Abuse Treatment
18	Medications	Medications	Outpatient Medical Care	Other Service	Medications
19	Hospice Services	Outpatient Medical Care	Medications	Substance Abuse Treatment	Hospice Services

Service gap information is used to guide the comprehensive planning process to assist in determining where new funding should be allocated if it becomes available,

information for Minority AIDS Initiative (MAI) services and where additional cooperative agreements or service linkages should be developed.

Barriers to Service

Respondents were asked to describe the reasons they did not receive a service they needed. 69% of respondents (N=1,352) indicated that they received the services needed during the last 12 months. Totals do not equal 100% as more than one response was permitted. Table 17 provides a summary of data for the TSA.

**Table 17
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.

Barriers to care were analyzed for several subpopulation groups: Blacks, Hispanics, women, youth and MSM. The barriers to care noted for each group are in Table 18 and are in descending order from greatest to least.

**Table 18
Barriers to Care by Population Group**

Service gaps	Blacks (N= 755)	Hispanics (N= 298)	Women (N= 668)	Youth (N= 59)	MSM (N= 967)
1	Did not know where to get services	Did not know where to get services	Did not know where to get services	Did not know where to get services	Did not know where to get services
2	No transportation	Could not pay	No transportation	Could not pay	Could not pay
3	Depressed	No transportation	Depressed	Depressed	Did not qualify
4	Could not pay	Depressed	Could not pay	No transportation	Depressed
5	Missed my appointment(s)	Put on waiting list	Stigma	Missed my appointment(s)	Could not get appointment
6	Stigma	Did not qualify	Missed my appointment(s)	Could not get appointment	Put on waiting list
7	Did not qualify	Could not get appointment	Did not qualify	Busy taking care of partner	No transportation
8	Put on waiting list	Missed my appointment(s)	Put on waiting list	Stigma	Bad staff experience
9	Could not get appointment	Couldn't get time off work	Could not get appointment	Bad staff experience	Missed my appointment(s)
10	Couldn't get time off work	Stigma	Couldn't get time off work	No Childcare	Stigma
11	No Childcare	Bad staff experience	Bad staff experience	Couldn't get time off work	Couldn't get time off work
12	Bad staff experience	Not in my language	No Childcare	Not in my language	Busy taking care of partner
13	Busy taking care of partner	No Childcare	Busy taking care of partner	Put on waiting list	No Childcare
14	Not in my language	Busy taking care of partner	Not in my language	Did not qualify	Not in my language

Perceived Needs for PLWH/A

Previous questions regarding service needs and gaps were specific to the respondent. In the survey, respondents were also asked to rank the five services they felt were most important. Responses are listed in order of how frequently they were selected.

Although brief definitions were provided for each service earlier in the survey, it is important to remember that not all respondents may understand what each service encompasses or the terminology that may be used to describe a certain service, i.e. outpatient medical care versus the more familiar, primary care.

Table 19
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.

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Jail/Prison Care

Respondents were asked if they had been in jail or prison during the past 12 months, if they received care while incarcerated, and which services they were provided upon release. 96 of the 1,991 respondents had been in jail, 43 in prison and 8 had been in both jail and prison. 94% of those who had been in jail/prison indicated that the jail/prison medical staff knew that they had HIV and 68% received HIV/AIDS-related medical care while in jail/prison.

Upon release, 42% received a referral to medical care, 46% received a supply of HIV medication to take with them, 36% received a referral to case management, 21% received information about housing and 12% received other information.

75% of respondents stated that they were able to get needed HIV/AIDS services after release. The 30 individuals who were not able to get services after release stated that it was due to lack of insurance/financial reasons (53%), they did not want anyone to know they had HIV (33%), they were having trouble finding friends they could trust (27%), they did not know where to go (20%), they could not get away from drugs (20%) or that they did not have ID or documentation to qualify (3%).

County Specific Results

The summary results presented in earlier tables have been re-aligned to provide the results for each individual county in the Total Service Area. County specific results include service utilization, service gaps and the ranking of the most important services. Some services were not selected by any respondents as a service that was utilized, needed but not received or one of the most important resulting in empty cells in the tables. Caution should be used when considering some data due to the small sample size. Refer to Table 1 to determine how the number of respondents in each county relates to the total HIV positive population reported for that county. Actual number of responses are listed in parenthesis following each service. Services excluded as a service category in the questions pertaining to utilization, service need or to be ranked by level of importance: 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.

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Table 20
Service Utilization, Service Gaps, and Important Services for
Hardee County

#	Service Utilization (n=7)	Service Gaps (n=7)	Most Important (n=7)
1	Outpatient Medical Care (7)	Dental/Oral Health (2)	Medications (7)
2	Medications (7)	Medical Case Management (1)	Outpatient Medical Care (5)
3	Medical Case Management (6)	Health Insurance (1)	Health Insurance (4)
4	Dental/Oral Health (3)	Mental Health Services (1)	Medical Case Management (4)
5	Transportation (3)	Substance Abuse Treatment (1)	Dental/Oral Health (3)
6	Early Intervention Services (2)	Transportation (1)	Transportation (3)
7	Health Insurance (1)	Legal Support (1)	Mental Health Services (2)
8	Nutritional Counseling (1)		Food Bank/Food Voucher (2)
9	Food Bank/Food Voucher (1)		Substance Abuse Treatment (1)
10	Treatment Adherence (1)		Early Intervention Services (1)
11			Health Education/Risk Reduction (1)
12			Treatment Adherence (1)

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Table 21
Service Utilization, Service Gaps, and Important Services for
Hernando County

#	Service Utilization (n=41)	Service Gaps (n=39)	Most Important (n=42)
1	Medications (34)	Food Bank/Food Voucher (14)	Medications (33)
2	Outpatient Medical Care (34)	Legal Support (10)	Dental/Oral Health (27)
3	Medical Case Management (28)	Dental/Oral Health (9)	Outpatient Medical Care (26)
4	Dental/Oral Health (27)	Mental Health Services (9)	Medical Case Management (25)
5	Health Insurance (22)	Medical Case Management (6)	Health Insurance (20)
6	Mental Health Services (13)	Nutritional Counseling (5)	Mental Health Services (16)
7	Early Intervention services (11)	Health Education/Risk Reduction (5)	Food Bank/Food Voucher (12)
8	Treatment Adherence (11)	Rehabilitation (5)	Nutritional Counseling (7)
9	Nutritional Counseling (10)	Other Support Services (5)	Early Intervention Services (6)
10	Food Bank/Food Voucher (9)	Health Insurance (4)	Transportation (6)
11	Transportation (7)	Early Intervention services (4)	Outreach (6)
12	Health Education/Risk Reduction (7)	Outreach (3)	Health Education/Risk Reduction (6)
13	Home Health Care (6)	Home Health Care (3)	Home Health Care (4)
14	Other Support Services (3)	Hospice Services (3)	Hospice Services (3)
15	Substance Abuse Treatment (2)	Medications (2)	Substance Abuse Treatment (2)
16	Hospice Services (2)	Outpatient Medical Care (1)	Rehabilitation (2)
17	Outreach (2)	Transportation (1)	Legal Support (1)
18	Rehabilitation (2)	Treatment Adherence (1)	
19	Legal Support (1)		

Table 22
Service Utilization, Service Gaps, and Important Services for
Highlands County

#	Service Utilization (n=15)	Service Gaps (n=15)	Most Important (n=16)
1	Outpatient Medical Care (15)	Mental Health Services (5)	Medications (15)
2	Medications (14)	Health Insurance (3)	Medical Case Management (13)
3	Medical Case Management (13)	Dental/Oral Health (3)	Dental/Oral Health (13)
4	Dental/Oral Health (9)	Early Intervention services (2)	Outpatient Medical Care (11)
5	Treatment Adherence (8)	Food Bank/Food Voucher (2)	Health Insurance (9)
6	Early Intervention services (7)	Legal Support (2)	Mental Health Services (6)
7	Health Insurance (6)	Rehabilitation (1)	Food Bank/Food Voucher (4)
8	Nutritional Counseling (6)		Substance Abuse Treatment (1)
9	Health Education/Risk Reduction (5)		Nutritional Counseling
10	Mental Health Services (3)		Hospice Services (1)
11	Transportation (3)		Legal Support (1)
12	Rehabilitation (2)		
13	Hospice Services (1)		
14	Food Bank/Food Voucher (1)		

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Table 23
Service Utilization, Service Gaps, and Important Services for Hillsborough County

#	Service Utilization (n=803)	Service Gaps (n=803)	Most Important (n=784)
1	Medications (685)	Dental/Oral Health (201)	Medications (646)
2	Outpatient Medical Care (673)	Food Bank/Food Voucher (150)	Medical Case Management (513)
3	Medical Case Management (557)	Legal Support (131)	Outpatient Medical Care (499)
4	Dental/Oral Health (397)	Health Insurance (128)	Dental/Oral Health (461)
5	Health Insurance (342)	Transportation (122)	Health Insurance (430)
6	Food Bank/Food Voucher (299)	Medical Case Management (107)	Food Bank/Food Voucher (311)
7	Mental Health Services (241)	Nutritional Counseling (102)	Mental Health Services (218)
8	Treatment Adherence (239)	Mental Health Services (89)	Transportation (173)
9	Early Intervention Services (226)	Outreach (83)	Legal Support (82)
10	Health Education/Risk Reduction (203)	Rehabilitation (67)	Early Intervention Services (80)
11	Nutritional Counseling (202)	Early Intervention Services (59)	Health Education/Risk Reduction (80)
12	Transportation (173)	Health Education/Risk Reduction (59)	Nutritional Counseling (73)
13	Legal Support (120)	Home Health Care (49)	Substance Abuse Treatment (64)
14	Outreach (95)	Other Support Services (37)	Home Health Care (63)
15	Substance Abuse Treatment (80)	Treatment Adherence (34)	Hospice Services (58)
16	Rehabilitation (72)	Substance Abuse Treatment (31)	Treatment Adherence (47)
17	Home Health Care (71)	Medications (27)	Outreach (40)
18	Other Support Services (48)	Hospice Services (23)	Rehabilitation (27)
19	Hospice Services (31)	Outpatient Medical Care (20)	

Table 24
Service Utilization, Service Gaps, and Important Services for
Manatee County

#	Service Utilization (n=62)	Service Gaps (n=62)	Most Important (n=57)
1	Medications (51)	Food Bank/Food Voucher (19)	Medications (48)
2	Outpatient Medical Care (48)	Dental/Oral Health (13)	Medical Case Management (38)
3	Medical Case Management (45)	Health Insurance (13)	Dental/Oral Health (34)
4	Dental/Oral Health (37)	Legal Support (11)	Food Bank/Food Voucher (34)
5	Health Insurance (32)	Mental Health Services (9)	Outpatient Medical Care (32)
6	Nutritional Counseling (32)	Transportation (9)	Health Insurance (29)
7	Food Bank/Food Voucher (27)	Outreach (8)	Nutritional Counseling (15)
8	Treatment Adherence (24)	Medical Case Management (6)	Mental Health Services (11)
9	Early Intervention services (22)	Early Intervention services (4)	Legal Support (11)
10	Mental Health Services (20)	Rehabilitation (4)	Transportation (9)
11	Health Education/Risk Reduction (15)	Nutritional Counseling (3)	Treatment Adherence (8)
12	Transportation (8)	Hospice services (3)	Home Health Care (7)
13	Legal Support (7)	Health Education/Risk Reduction (3)	Health Education/Risk Reduction (7)
14	Rehabilitation (6)	Other Support Services (3)	Early Intervention services (6)
15	Outreach (6)	Outpatient Medical Care (2)	Rehabilitation (6)
16	Home Health Care (4)	Home Health Care (2)	Outreach (5)
17	Substance Abuse Treatment (3)	Treatment Adherence (2)	Hospice services (4)
18	Other Support Services (3)	Substance Abuse Treatment (1)	Substance Abuse Treatment (3)
19	Hospice services (2)		

Table 25
Service Utilization, Service Gaps, and Important Services for
Pasco County

#	Service Utilization (n=110)	Service Gaps (n=110)	Most Important (n=110)
1	Medications (97)	Food Bank/Food Voucher (37)	Medications (95)
2	Outpatient Medical Care (493)	Legal Support (31)	Medical Case Management (85)
3	Medical Case Management (86)	Dental/Oral Health (23)	Dental/Oral Health (71)
4	Dental/Oral Health (74)	Health Insurance (22)	Health Insurance (58)
5	Health Insurance (63)	Nutritional Counseling (18)	Outpatient Medical Care (56)
6	Food Bank/Food Voucher (43)	Transportation (16)	Food Bank/Food Voucher (52)
7	Mental Health Services (38)	Medical Case Management (15)	Mental Health Services (24)
8	Early Intervention services (38)	Mental Health Services (15)	Transportation (22)
9	Treatment Adherence (29)	Rehabilitation (15)	Home Health Care (20)
10	Transportation (25)	Outreach (13)	Legal Support (13)
11	Health Education/Risk Reduction (25)	Other Support Services (11)	Nutritional Counseling (9)
12	Nutritional Counseling (22)	Early Intervention services (8)	Hospice Services (9)
13	Legal Support (20)	Outpatient Medical Care (5)	Early Intervention services (7)
14	Rehabilitation (18)	Medications (5)	Health Education/Risk Reduction (6)
15	Home Health Care (17)	Home Health Care (4)	Treatment Adherence (5)
16	Substance Abuse Treatment (12)	Health Education/Risk Reduction (4)	Substance Abuse Treatment (4)
17	Hospice services (10)	Treatment Adherence (4)	Rehabilitation (3)
18	Outreach (9)	Substance Abuse Treatment (2)	Outreach (2)
19	Other Support Services (7)		

Table 26
Service Utilization, Service Gaps, and Important Services for
Pinellas County

#	Service Utilization (n=777)	Service Gaps (n=777)	Most Important (n=762)
1	Medications (669)	Dental/Oral Health (240)	Medications (641)
2	Outpatient Medical Care (645)	Health Insurance (163)	Medical Case Management (524)
3	Medical Case Management (598)	Legal Support (155)	Dental/Oral Health (500)
4	Dental/Oral Health (393)	Food Bank/Food Voucher (136)	Outpatient Medical Care (474)
5	Health Insurance (320)	Transportation (117)	Health Insurance (363)
6	Mental Health Services (256)	Nutritional Counseling (106)	Food Bank/Food Voucher (229)
7	Food Bank/Food Voucher (253)	Rehabilitation (82)	Mental Health Services (224)
8	Early Intervention Services (217)	Mental Health Services (79)	Transportation (142)
9	Nutritional Counseling (188)	Outreach (71)	Legal Support (83)
10	Treatment Adherence (186)	Other Support Services (67)	Hospice Services (83)
11	Health Education/Risk Reduction (146)	Medical Case Management (64)	Home Health Care (82)
12	Transportation (123)	Early Intervention Services (62)	Nutritional Counseling (76)
13	Legal Support (89)	Health Education/Risk Reduction (53)	Early Intervention Services (62)
14	Substance Abuse Treatment (80)	Home Health Care (46)	Substance Abuse Treatment (58)
15	Home Health Care (68)	Treatment Adherence (29)	Health Education/Risk Reduction (55)
16	Rehabilitation (66)	Substance Abuse Treatment (24)	Treatment Adherence (36)
17	Outreach (63)	Hospice Services (23)	Outreach (30)
18	Other Support Services (34)	Outpatient Medical Care (16)	Rehabilitation (24)
19	Hospice Services (33)	Medications (14)	

Table 27
Service Utilization, Service Gaps, and Important Services for
Polk County

#	Service Utilization (n=200)	Service Gaps (n=200)	Most Important (n=190)
1	Medications (170)	Food Bank/Food Voucher (70)	Medications (161)
2	Outpatient Medical Care (155)	Dental/Oral Health (67)	Medical Case Management (123)
3	Medical Case Management (151)	Health Insurance (52)	Outpatient Medical Care (114)
4	Health Insurance (78)	Legal Support (40)	Dental/Oral Health (104)
5	Nutritional Counseling (78)	Transportation (35)	Health Insurance (101)
6	Dental/Oral Health (77)	Mental Health Services (29)	Food Bank/Food Voucher (48)
7	Early Intervention services (73)	Medical Case Management (24)	Mental Health Services (46)
8	Treatment Adherence (66)	Rehabilitation (22)	Transportation (46)
9	Mental Health Services (53)	Outreach (20)	Nutritional Counseling (38)
10	Health Education/Risk Reduction (45)	Health Education/Risk Reduction (20)	Home Health Care (23)
11	Transportation (26)	Early Intervention services (19)	Health Education/Risk Reduction (19)
12	Rehabilitation (23)	Nutritional Counseling (16)	Legal Support (19)
13	Legal Support (22)	Outpatient Medical Care (15)	Early Intervention services (15)
14	Food Bank/Food Voucher (21)	Treatment Adherence (12)	Rehabilitation (15)
15	Substance Abuse Treatment (17)	Other Support Services (10)	Treatment Adherence (13)
16	Home Health Care (17)	Home Health Care (9)	Hospice services (11)
17	Outreach (16)	Medications (8)	Substance Abuse Treatment (9)
18	Other Support Services (8)	Substance Abuse Treatment (6)	Outreach (7)
19	Hospice services (2)	Hospice services (5)	

Fifty-four percent of respondents indicated that the survey was an appropriate length, 32% felt it was too long, but covered the information. Six percent felt it was too long and they did not want to finish it while 8% believed it was too short and there were more things that could have been asked.

The data gathered and summarized in this report will be used as a tool to guide the planning council in their decisions regarding priority setting, service needs and funding allocations.

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Planning and Evaluation Committee Members

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DACCO
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Doctor Martinez
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Doctor Rodwick
Doctor Sastry
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Good Samaritan
Hernando County Health Department
Highlands County Health Department

Hillsborough County Health Department
Judeo-Christian Clinic
Manatee County Health Department
Mercy House
METRO Wellness and Community
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Manatee Rural Health
Operation HOPE
Pharmacy One Pro
Pinellas Care Clinic
Pinellas County Health Department
Polk County Health Department
Salvation Army
Spring Oaks
St. Pete Free Clinic
St. Vincent DePaul
Tampa Care Clinic
Tampa Hillsborough Action Plan (THAP)
THAP - RESTORE
Trinity Charities
USF Pediatrics
WestCare
West Coast Infectious Diseases
Youth Education Services

Attachment 1:
2010 Florida Ryan White Anonymous Needs Survey

Introduction

If you have HIV/AIDS, this is your chance to tell us what services YOU need. Your answers will help your local Planning Group decide how funding is used in your area for HIV services.

Some questions are personal. We have to ask them to know how best to help you. All the answers will be combined so no one will be able to identify you.

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

If you take care of someone who cannot fill out the form alone, please help them.

Return completed surveys to: The Health Councils, 9600 Koger Blvd., Suite 221, St. Petersburg, FL 33702

Survey may be completed online. Go to www.thecarecouncil.org and select the link for "Anonymous Needs Survey"

If you have completed this survey in the past 12 months, do not turn one in again.

Please completely fill in the circles ● when answering this survey.

General Information

1. What is your gender?
 Male
 Female
 Transgender (Male to Female)
 Transgender (Female to Male)
2. Have you been pregnant in the **past 12 months**?
 This does not apply to me. I am not female.
 Yes
 No
3. How do you identify yourself?
 Straight
 Gay
 Lesbian
 Bisexual
4. What is your ethnicity?
 Hispanic/Latina/o
 Non - Hispanic/Latina/o
5. What is your race?
 Haitian
 White/Caucasian
 Black or African American
 Asian
 American Indian or Alaskan Native
 Native Hawaiian or Pacific Islander
 Mixed/more than one race
6. What year were you born?

--	--	--	--
7. What best describes your work situation in the **past 12 months**?
(Please mark ONLY ONE answer)
 Working full-time job
 Working part-time job
 Self employed
 Working off and on
 Not working

8. Why were you not working during the **past 12 months?** **(Please mark ONLY ONE answer)**

- This does not apply to me. I worked during the past 12 months.
- Student
- Looking for a job
- Attending job training
- Retired
- For health reasons, on disability
- For health reasons, NOT on disability
- Other:

HIV/AIDS Medical Care

12. Did you get HIV/AIDS related medical care OR a CD4 T-Cell count OR a viral load lab test during the **past 12 months?**

- Yes
- No

13. Why did you not get HIV/AIDS related medical care during the **past 12 months?** **(Mark all that apply)**

- This does not apply to me. I got HIV/AIDS related medical care in the past 12 months.
- I did not know where to go
- I could not get an appointment
- I could not get transportation
- I could not get childcare
- I was too busy taking care of my partner
- I could not pay for services
- I did not want people to know that I have HIV
- I was not ready to deal with having HIV
- I did not feel sick
- There are not enough doctors in my area
- I could not get time off work
- I was depressed
- I missed my appointment(s)
- I had a bad experience with the medical staff
- Other:

14. Where did you regularly receive your HIV/AIDS medical care during the **past 12 months?**

9. Where do you live?

10. County: _____

Zip code: _____

11. Where were you living when you first tested positive for HIV?

- In the same county I live now
- In another county in Florida
- In another state
- Outside of the United States

(Please mark ONLY ONE answer)

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

- Walk-In / Emergency Clinic
- Doctor's Office
- Hospital Emergency Room
- Veteran's Administration
- Public Clinic/Health Department
- HIV Specialty Clinic
- Other:

15. In which county did you get your HIV/AIDS related medical care during the **past 12 months?** County: _____

16. Why did you get your HIV/AIDS related medical care in a different county than you live?

(Please mark ONLY ONE answer)

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

- Services were not available in my county
- I did not want people to know that I have HIV
- I got care closer to where I live or work
- Other:

17. Have you been hospitalized for an HIV/AIDS related condition during the **past 12 months?**

Yes No

18. Have you been to the Emergency Room for an HIV/AIDS related condition during the **past 12 months**?

Yes No

19. Did you have private health insurance during the **past 12 months**?

Yes No

20. Do you know what your CD4 count means?

Yes No

21. Do you know what your viral load means?

Yes No

22. How often do you take your medications to treat your HIV/AIDS just as the doctor said you should? **(Please mark ONLY ONE answer)**

This does not apply to me. I have not been prescribed HIV medications. (If you have not been prescribed HIV medications, you can skip to Question #23)

- Always
- Most of the time
- Some of the time
- Never

I do not know what the directions are

23. Why do you sometimes miss taking medications to treat your HIV/AIDS?

(Mark all that apply)

This does not apply to me. I have not been prescribed HIV medications or I always take my HIV medications as prescribed.

- I do not know where to get them
- I cannot afford the cost
- They made me feel really bad
- I am on a 'Drug holiday' directed by my doctor
- I am on a 'Drug holiday' decided by myself
- I feel healthy
- I do not like taking medications
- These medications are not a priority for me
- I have trouble remembering to take my medications
- I have trouble understanding how to take my medications
- My doctor wanted to treat another medical problem first
- Religious/Cultural beliefs
- I have an abusive spouse or partner
- Other:

Ryan White Services

The services below MAY or MAY NOT be available in your area. Please fill in the circles next to the services that you have used or needed in the past 12 months.	Needed Service & Got Service	Needed Service, But Could Not Get Service	Needed Service, But Did Not Know About Service	Did Not Need Service
CORE SERVICES				
24. Outpatient Medical Care: Regular doctor visits to doctor's office or clinic for HIV medical care	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
25. Case Management: Case managers help clients receive services and then follow-up on their care	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
26. Medications: Pills for HIV and related issues	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
27. Dental/Oral Health: General teeth and mouth care, dentures, oral surgery, etc.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
28. Health Insurance: Helps pay insurance costs or co-pays if client has private insurance	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
29. Mental Health Services: Professional counseling, therapy, or support groups	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

30. Substance Abuse Treatment: Professional counseling for drug or alcohol addiction	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
31. Nutritional Counseling: Professional counseling for healthy eating habits	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
32. Early Intervention Services: Assistance getting a doctor appointment and other needed services	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
33. Home Health Care: Professional healthcare services in client's home by a licensed/certified home-health agency	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
34. Hospice Services: Nursing and counseling services for the terminally ill and their family	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
SUPPORT SERVICES				
35. Food Bank or Food Vouchers: Food bags, grocery certificates, home-delivered meals, and nutritional supplements	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
36. Transportation: Help getting to the doctor's office and other HIV related appointments	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
37. Outreach: Someone who finds people with HIV not in care and helps them to visit their doctor and get services they may need	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
38. Health Education/Risk Reduction: Someone who tells clients about HIV, how it's spread, current medications, and how to live with HIV	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
39. Treatment Adherence: Instructions on how to take HIV medications properly	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
40. Legal Support: Help clients with HIV related legal issues (will, living will, etc.)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
41. Rehabilitation: Physical therapy, occupational therapy, speech therapy, low vision training, etc.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
42. Other: A service that is not listed above _____	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

43. What kept you from getting the services you needed during the **past 12 months?** (**Mark all that apply**)

- This does not apply to me. I did get the services I needed during the past 12 months.
- I did not know where to get services
- I could not get an appointment
- I could not get transportation
- I could not get childcare
- I was too busy taking care of my partner
- I could not pay for services
- I did not want people to know that I have HIV
- I could not get time off work
- I was depressed

- I missed my appointment(s)
- I had a bad experience with the staff
- Services were not in my language
- I was put on the waiting list
- I did not qualify for services
- Other:

44. Where do you get most of your information about HIV/AIDS services in your area?

(Please mark ONLY ONE answer)

- Clinic/doctor's office
- Health Department
- Case manager
- Community health fair

- Community based organizations
 - AIDS organization/advocacy group
 - Place of worship
 - Friends/family
 - Internet
 - Newspaper/radio/TV
 - Other: -
-

- Dental/Oral Health
 - Health Insurance
 - Mental Health Services
 - Substance Abuse Treatment
 - Nutritional Counseling
 - Early Intervention Services
 - Home Health Care
 - Hospice Services
 - Food Bank/Food Voucher
 - Transportation
 - Outreach
 - Health Education/Risk Reduction
 - Treatment Adherence
 - Legal Support
 - Rehabilitation
 - Other: A service not listed here
-

45. Which five services do you think are most important for the state to provide for people with HIV/AIDS?

(Select ONLY 5)

See description of each service below in questions 23-41.

- Outpatient Medical Care
- Case Management
- Medications

Jail/Prison Release Services

46. Were you in jail and/or prison during the **past 12 months**?

- Yes, I was in jail
- Yes, I was in prison
- Yes, I was in jail and prison
- No (If you answered No, you can skip to Question #50)

ONLY answer the next four questions if you answered yes, you were in jail and/or prison during the past 12 months.

47. Did the jail/prison medical staff know you had HIV?

- Yes
- No

- A supply of HIV medication to take with you
 - Other:
-

48. Did you receive HIV/AIDS-related medical care while in jail/prison?

- Yes
- No

50. What prevented you from getting the HIV/AIDS services you needed after you were released?

(Mark all that apply)

49. When you were released from jail/prison, which of the following did you receive?

- Information about finding housing
- Referral to medical care
- Referral to case management

- This does not apply to me. I was able to get HIV services after my release.
- No insurance – financial reasons
- I did not know where to go
- I did not want anyone to know I have HIV

- I could not get away from drugs
- I was having trouble finding friends I could trust
- I did not want to take off from work
- I did not have transportation to get

- services
- I did not have ID or documentation to qualify
- Other: _____

Housing

For the questions in the housing section you will be asked to think back over the past six months

51. Mark both of the columns that tell us where you live **now** and where you lived **6 months ago**, even if it is the same.

	Now	6 months ago
In an apartment/house that I own	<input type="radio"/>	<input type="radio"/>
In an apartment/house that I rent	<input type="radio"/>	<input type="radio"/>
At my parent's /relative's/ someone else's apartment/house	<input type="radio"/>	<input type="radio"/>
In a room or boarding house	<input type="radio"/>	<input type="radio"/>
In a "supportive living" facility (Assisted Living Facility)	<input type="radio"/>	<input type="radio"/>
In a half-way house, transitional housing, or treatment facility (drug or mental health)	<input type="radio"/>	<input type="radio"/>
Nursing home	<input type="radio"/>	<input type="radio"/>
Homeless (on street/in car/abandoned building)	<input type="radio"/>	<input type="radio"/>
Homeless shelter	<input type="radio"/>	<input type="radio"/>
Domestic violence shelter	<input type="radio"/>	<input type="radio"/>
Other housing provided by the city, county, or state (such as Section 8 voucher or Shelter+care)	<input type="radio"/>	<input type="radio"/>
In jail/prison	<input type="radio"/>	<input type="radio"/>

52. Think about where you live now: which of the following stop you from taking care of your HIV/AIDS?

(Mark all that apply)

This does not apply to me. Nothing where I live now stops me from taking care of my HIV/AIDS.

- I do not have a safe and private room
- I do not have a bed to sleep in
- I do not have a place to store my medications
- I do not have a telephone where someone can call me
- I do not have enough food to eat
- I do not have money to pay for rent
- I do not have heat and/or air conditioning
- I am afraid of others knowing I have HIV
- I cannot get away from drugs and/or alcohol in the neighborhood
- I do not feel safe in the neighborhood
- I have an abusive spouse or partner

O Other: _____

53. In the **past 6 months**, how many nights have you NOT had a place of your own to sleep?

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54. How much do you and/or your household contribute monthly to the rent or mortgage? (How much you and your household members **actually pay**.)

\$

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55. Now we're interested in the HIV/AIDS housing services you needed and what HIV/AIDS housing services you got in the **past 6 months**.

The services below MAY or MAY NOT be available in your area. Please fill in the circles next to the housing services that you have used or needed in the past year. HOUSING	Needed Service & Got Service	Needed Service, But Could Not Get Service	Needed Service, But Did Not Know About Service	Did Not Need Service
Help finding a place to live	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Permanent, independent housing	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Temporary short-term housing	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Housing where my child(ren) can live with me	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Nursing home	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Money to pay utilities	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Money to pay rent/mortgage	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
House for persons living with HIV/AIDS	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Assisted Living facility	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

(If you did not need any of the housing services listed in the table above, you can skip to Question #56.)

56. What kept you from getting the housing services you needed? ***(Mark all that apply)***

- This does not apply to me. I did get the housing services I needed.
- I did not know where to get services
- Services were not in my language
- I could not get there when the agency was open
- I did not want anyone to know I have HIV
- I did not qualify for housing services
- I have not been treated with respect at the agency
- I was put on the waiting list
- Other: _____

57. Now we are interested in general problems you had getting housing, in the **past 6 months**, did you have trouble getting housing?

- Yes
- No

58. What problems did you have getting housing? ***(Mark all that apply)***
- This does not apply to me. I did not have any problems getting housing.
 - I did not have enough money for the deposit
 - I had no transportation to search for housing
 - I had bad credit
 - I had a criminal record
 - I had a mental/physical disability
 - I had substance use issues
 - I was put on a waiting list
 - I did not qualify for housing assistance
 - I could not find affordable housing
 - I feel I was discriminated against
 - Other: _____

Additional Comments

59. Are you aware of any HIV Planning or Advisory Committees in your area?
- Yes
 - No (If you answered No, you can skip to Question #60)
60. If yes, do you currently participate on any of these bodies or their committees?
- Yes
 - No
61. Overall, did you think this survey was:
- Too long, but covered all the information
 - Too long, and I did not want to finish it
 - Too short, there were more things you could have asked
 - Just right

62. Did you need help completing this survey? Yes No

63. Is there anything else you would like to tell us?

**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 includes diagnostic testing, early intervention and risk assessment, preventive care and screening, practitioner examination, medical history taking, diagnosis and treatment of common physical and mental conditions, prescribing and managing medication therapy, education and counseling on health issues, well-baby care, continuing care and management of chronic conditions, and referral to and provision of specialty care (includes all medical subspecialties). *Primary medical care* for the treatment of HIV infection includes the provision of care that is consistent with the Public Health Service's guidelines. Such care must include access to antiretroviral and other drug therapies, including prophylaxis and treatment of opportunistic infections and combination antiretroviral therapies. **NOTE: Early Intervention Services provided by Ryan White Part C and Part D Programs should be included here under *Outpatient/ Ambulatory medical care*.**
- b. *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.