

FY 2008 RYAN WHITE NEEDS ASSESSMENT: EXPERT/CASE MANAGER 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 2008 needs assessment involved surveying case managers who serve people living with HIV/AIDS (PLWHA) and surveying experts. Experts were defined as members of the Care Council and/or its nine standing committees (both voting and non-voting) and former Care Council members.

II. METHODOLOGY

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

The survey requested that each individual respond regarding the needs of **all** people living with HIV/AIDS (PLWHA) for their respective county. Individuals that served more than one county were asked to complete a separate survey for each county served. Respondents were provided with a copy of the Health Resources and Services Administration (HRSA) service category definitions as reference.

The survey instrument gathered demographic data including county and category represented, perceived need at the county level for the HRSA designated service categories, perceived availability of the services at the county level, quality of services for HIV infected persons, barriers to service, impression of services on six quality measures and projected service needs. (See Attachment 1)

III. RESULTS

Data analysis was conducted at the following levels:

- Total Service Area (TSA) (eight county service area including Hardee, Hernando, Highlands, Hillsborough, Manatee, Pasco, Pinellas and Polk counties)
- Eligible Metropolitan Area (EMA) (Hernando, Hillsborough, Pasco, and Pinellas counties)
- Non-EMA (Hardee, Highlands, Manatee and Polk counties)
- Individual counties

Due to the small sample size for some areas, caution must be used in interpreting results.

A. Demographic Data on Respondents

1. Counties Represented

All counties were represented in the survey responses. Table 1 provides the percentage of respondents by county for total responses.

Table 1
Respondent County of Representation

County	% Responses	# of Responses
Hardee	1.7%	2
Hernando	5.2%	6
Highlands	2.6%	3
Hillsborough	31.3%	36
Manatee	7.0%	8
Pasco	11.3%	13
Pinellas	32.2%	37
Polk	8.7%	10

2. Category Represented

Respondents were asked to identify themselves using the following five categories: Ryan White funded agency, affected community (includes infected individuals), other provider, general population, or other. The results appear in Table 2. Totals may not equal 100% as more than one category could be selected.

Table 2
Category Represented by Survey Respondents

Category Represented	TSA (n=115)	EMA (n=92)	Non-EMA (n=23)
Ryan White Funded Provider	72.2% (83)	73.9% (68)	65.2% (15)
Other Provider	9.6% (11)	10.9% (10)	4.3% (1)
Affected Community	18.3% (21)	15.2% (14)	30.4% (7)
General Population	5.2% (6)	4.3% (4)	8.7% (2)
Other	2.6% (3)	3.3% (3)	0% (0)

3. Length of Time Involved with HIV Services

Respondents were asked to describe the length of time they had been involved with HIV services. Table 3 provides an overview for TSA, EMA and non-EMA responses.

Table 3
Length of Time Involved with HIV Services

Length of Time	TSA (n=115)	EMA (n=92)	Non-EMA (n=23)
Less than 6 months	43.4% (5)	5.4% (5)	0% (0)
Up to One Year	7.8% (9)	7.6% (7)	8.7% (2)
1 to 3 years	20.9% (24)	21.7% (20)	17.4% (4)
4 to 6 years	14.8% (17)	14.1% (13)	17.4% (4)
7 to 10 years	20.9% (24)	20.7% (19)	21.7% (5)
More than 10 years	31.3% (36)	30.4% (28)	34.8% (8)

B. Current Service Need

Respondents rated each of the twenty-eight (28) HRSA service categories on a scale of one to five with one representing a low need and five representing a high need. Table 4 provides the results of the TSA, EMA and non-EMA areas. The table also represents both met needs and service gaps.

1. Highest Ranked Service Needs

The Total Service Area selected the five highest needs as AIDS Pharmaceutical Assistance, Oral Health Care, Housing Services, Medical Transportation and Medical Case Management.

Within the EMA, services ranked as follows: AIDS Pharmaceutical Assistance, Housing Services, Health Insurance, Oral Health Care and Medical Transportation.

The non-EMA area rated Oral Health Care as the most needed service followed by Medical Case Management, Outpatient/Ambulatory Medical Care, Housing Services and Medical Transportation.

2. Lowest Ranked Service Needs

The Total Service Area ranked the lowest three service needs as Linguistic Services, Respite Care and Child Care Services.

The EMA ranked Linguistic Services, Respite Care and Home Health Services the lowest.

The non-EMA area ranked Child Care Services as the lowest need followed by Hospice Services and Linguistic Services.

Table 4
Service Need by TSA, EMA and Non-EMA

Service	TSA (n=113)	EMA (n=90)	Non-EMA (n=23)
AIDS Pharmaceutical Assistance	4.32	4.37	4.13
Early Intervention Services	3.74	3.64	4.13
Health Insurance Premium & Cost Sharing Assistance	4.07	4.14	3.78
Home Health Care	3.05	2.94	3.48
Home and Community Based Health Services	3.55	3.46	3.91
Hospice Services	3.24	3.26	3.17
Medical Case Management	4.09	3.97	4.57
Medical Nutrition Therapy	3.55	3.52	3.65
Mental Health Services	4.06	4.04	4.13
Oral Health Care	4.24	4.12	4.70
Outpatient/Ambulatory Medical Care	4.02	3.92	4.39
Substance Abuse Services - Outpatient	3.69	3.64	3.87
Case Management (non-medical)	3.94	3.89	4.13
Child Care Services	2.95	2.96	2.91
Emergency Financial Assistance	4.06	4.07	4.04
Food Bank/Home Delivered Meals	3.92	3.96	3.78
Health Education/Risk Reduction	3.57	3.56	3.61
Housing Services	4.17	4.17	4.17
Legal Services	3.44	3.46	3.39
Linguistic Services	2.89	2.80	3.26
Medical Transportation	4.12	4.10	4.17
Outreach Services	3.29	3.16	3.83
Psychosocial Support	3.66	3.57	4.04
Referral for Healthcare/Supportive Services	3.70	3.60	4.09
Rehabilitation Services	3.32	3.20	3.78
Respite Care	2.90	2.80	3.30
Substance Abuse Services - Residential	3.51	3.43	3.83
Treatment Adherence Counseling	3.63	3.54	3.96

3. Most Needed Services by County

Analyzed responses for individual counties are included. Average scaled score is in parenthesis following each service with one representing a low need and five representing a high need.

a. Hardee County

Respondents selected AIDS Pharmaceutical Assistance (5.0), Early Intervention Services (5.0) and Medical Case Management (5.0) as the most needed services.

b. Highlands County

Respondents chose Early Intervention Services (5.0), Oral Health Care (5.0), Outpatient/Ambulatory Medical Care (5.0), Outreach Services (5.0), Psychosocial Support Services (5.0) and Referral for Healthcare/Supportive Services (5.0).

c. Hernando County

AIDS Pharmaceutical Assistance (4.7), Medical Case Management (4.5), Oral Health Care (4.5), Emergency Financial Assistance (4.5), Food Bank (4.5) and Housing Services (4.5) were selected as most needed.

d. Hillsborough County

Housing Services (4.4), Medical Transportation (4.3), Food Bank (4.3) and Health Insurance (4.3) were selected.

e. Manatee County

Medical Case Management (4.5), Oral Health Care (4.5), AIDS Pharmaceutical Assistance (4.0) and Outpatient/Ambulatory medical Care (4.0) were the most needed services chosen by respondents.

f. Pasco County

The highest ranked services were Mental Health Services (4.5), AIDS Pharmaceutical Assistance (4.2), Medical Transportation (4.2), Housing Services (4.2) and Oral Health Care (4.2).

g. Pinellas County

AIDS Pharmaceutical Assistance (4.3), Health Insurance (4.1), Oral Health Care (4.1) and Housing Services (4.0) were ranked the highest among respondents.

h. Polk County

Housing Services (4.8), Oral Health Care (4.8), Home & Community Based Health Services (4.6), Mental Health

Services (4.6) and Substance Abuse Services – Outpatient (4.6) were most needed.

C. Service Availability

Respondents rated each of the twenty-eight (28) HRSA service categories on a scale of one to five with one representing a low availability and five representing a high availability. Table 5 provides the results of the TSA, EMA and non-EMA areas. Availability includes from all funding sources, not just Ryan White Part A and B funds.

1. High Availability

The Total Service Area selected the five most available services as AIDS Pharmaceutical Assistance, Health Insurance, Hospice Services, Medical Case Management and Case Management (non-medical).

Within the EMA, the most available services ranked as follows: AIDS Pharmaceutical Assistance, Health Insurance, Hospice Services, Medical Case Management and Case Management (non-medical).

The non-EMA area rated AIDS Pharmaceutical Assistance as the most available service followed by Case Management (non-medical), Outpatient/Ambulatory Medical Care, Health Insurance and Medical Case Management.

2. Low Availability

The Total Service Area ranked the three least available services as Legal Services, Child Care Services and Respite Care.

The EMA ranked Legal Services, Child Care Services and Respite Care as the least available.

The non-EMA area ranked Child Care Services as the least available followed by Emergency Financial Assistance and Respite Care.

**Table 5
Service Availability by TSA, EMA and Non-EMA**

Service	TSA (n=113)	EMA (n=90)	Non-EMA (n=23)
AIDS Pharmaceutical Assistance	4.41	4.47	4.17
Early Intervention Services	3.05	3.04	3.09
Health Insurance Premium & Cost	4.14	4.26	3.70

Service	TSA (n=113)	EMA (n=90)	Non-EMA (n=23)
Sharing Assistance			
Home Health Care	2.73	2.79	2.48
Home and Community Based Health Services	3.50	3.60	3.13
Hospice Services	4.06	4.19	3.57
Medical Case Management	4.00	4.08	3.70
Medical Nutrition Therapy	2.99	2.90	3.35
Mental Health Services	3.57	3.60	3.43
Oral Health Care	3.52	3.66	3.00
Outpatient/Ambulatory Medical Care	3.75	3.70	3.96
Substance Abuse Services - Outpatient	3.17	3.19	3.09
Case Management (non-medical)	3.93	3.91	4.00
Child Care Services	2.16	2.23	1.87
Emergency Financial Assistance	2.61	2.74	2.09
Food Bank/Home Delivered Meals	3.39	3.50	2.96
Health Education/Risk Reduction	3.30	3.27	3.43
Housing Services	2.53	2.47	2.78
Legal Services	2.05	2.00	2.26
Linguistic Services	2.44	2.34	2.83
Medical Transportation	3.14	3.27	2.65
Outreach Services	3.15	3.12	3.26
Psychosocial Support	3.00	3.09	2.65
Referral for Healthcare/Supportive Services	3.30	3.38	3.00
Rehabilitation Services	2.70	2.71	2.65
Respite Care	2.28	2.32	2.13
Substance Abuse Services - Residential	2.62	2.58	2.78
Treatment Adherence Counseling	3.25	3.28	3.13

3. Excess Services

Respondents were asked whether there were any services in their county which they considered to be available in excess.

a. Hardee County

No excess services were listed.

b. Highlands County

No excess services were listed.

c. Hernando County

No excess services were listed.

d. Hillsborough County

Five respondents indicated services in surplus including food (3), housing (3), primary care (1), legal (1), acupuncture (1) and financial assistance (1).

e. Manatee County

No excess services were listed.

f. Pasco County

One respondent listed food, financial and legal.

g. Pinellas County

Four respondents indicated services in surplus including housing (1), substance abuse treatment (1), case management/early intervention services (1) and financial assistance (1).

h. Polk County

One respondent listed treatment adherence counseling as a service available in excess.

D. Essential Services

Respondents were asked to select the top five services they felt were essential for PLWHA. Table 7 displays the results for the entire eight county service area, the Eligible Metropolitan Area and the non-EMA.

The Total Service Area selected the five most essential services as AIDS Pharmaceutical Assistance, Housing Services, Case Management (non-medical), Medical Case Management and Health Insurance.

Within the EMA, the most essential services ranked as follows: AIDS Pharmaceutical Assistance, Housing Services, Case Management (non-medical), Health Insurance and Medical Case Management.

The non-EMA rated Housing Services as the most essential service followed by Case Management (non-medical), Medical Transportation and Medical Case Management, with Oral Health Care and AIDS Pharmaceutical Assistance tied for fifth most essential.

Table 6
Essential Services by TSA, EMA and Non-EMA

Service	TSA (n=115)	EMA (n=92)	Non-EMA (n=23)
AIDS Pharmaceutical Assistance	61.7% (71)	67.4% (62)	39.1% (9)
Early Intervention Services	6.9% (8)	5.4% (5)	13.0% (3)
Health Insurance Premium & Cost Sharing Assistance	35.7% (41)	40.2% (37)	17.4% (4)
Home Health Care	0.9% (1)	0% (0)	4.3% (1)
Home and Community Based Health Services	10.4% (12)	9.8% (9)	13.0% (3)
Hospice Services	2.6% (3)	3.3% (3)	0% (0)
Medical Case Management	0.4% (46)	39.1% (36)	43.5% (10)
Medical Nutrition Therapy	7.0% (8)	5.4% (5)	13.0% (3)
Mental Health Services	18.3% (21)	18.5% (17)	17.4% (4)
Oral Health Care	31.3% (36)	29.3% (27)	39.1% (9)
Outpatient/Ambulatory Medical Care	0.2% (23)	16.3% (15)	34.8% (8)
Substance Abuse Services - Outpatient	8.7% (10)	10.9% (10)	0% (0)
Case Management (non-medical)	48.7% (56)	48.9% (45)	47.8% (11)
Child Care Services	6.0% (7)	6.5% (6)	4.3% (1)
Emergency Financial Assistance	24.3% (28)	21.7% (20)	34.8% (8)
Food Bank/Home Delivered Meals	29.6% (34)	31.5% (29)	21.7% (5)
Health Education/Risk Reduction	6.1% (7)	5.4% (5)	8.7% (2)
Housing Services	56.5% (65)	56.5% (52)	56.5% (13)
Legal Services	1.7% (2)	2.2% (2)	0% (0)
Linguistic Services	2.6% (3)	3.3% (3)	0% (0)
Medical Transportation	28.7%	25.0%	43.5%

Service	TSA (n=115)	EMA (n=92)	Non-EMA (n=23)
	(33)	(23)	(10)
Outreach Services	3.5% (4)	3.3% (3)	4.3% (1)
Psychosocial Support	7.8% (9)	7.6% (7)	8.7% (2)
Referral for Healthcare/Supportive Services	0% (0)	0% (0)	0% (0)
Rehabilitation Services	1.7% (2)	2.2% (2)	0% (0)
Respite Care	0% (0)	0% (0)	0% (0)
Substance Abuse Services - Residential	3.5% (4)	3.3% (3)	4.3% (1)
Treatment Adherence Counseling	7.8% (9)	8.7% (8)	4.3% (1)

E. Perceived Quality of Life for PLWHA

1. Overall Perceived Quality of Life

Respondents were asked to rank the quality of life for PLWHA on a scale of one to six with one representing unacceptable and six representing excellent. Since this question was asked during the previous Expert/Case Manager surveys conducted in 2001 and 2004, comparisons with the previous responses are indicated in Table 7. Overall indications for TSA, EMA and non-EMA fall within the 'fair' to 'good' range.

**Table 7
Response on Overall Quality of Life for PLWHA**

Year	TSA Average	EMA Average	Non-EMA Average
2001	3.51	3.64	2.94
2004	3.43	3.44	3.39
2008	3.63	3.74	3.39

The responses for each county are as follows:

- Hardee County, 2.0 (poor)
- Hernando County, 2.83 (poor to fair)
- Highlands County, 3.66 (fair to good)
- Hillsborough County, 3.8 (fair to good)
- Manatee County, 3.5 (fair to good)
- Pasco County, 3.54 (fair to good)
- Pinellas County, 3.89 (fair to good)
- Polk County, 3.5 (fair to good)

2. Special Populations

Respondents were asked if there were any specific populations that have a lower quality of life. Responses were categorized by general theme and number of responses and include:

a. Hardee County

Both respondents listed minority populations (Black, Hispanic and Haitian).

b. Highlands County

One respondent listed minorities (Blacks and Hispanics), and one respondent listed individuals who are not legal residents.

c. Hernando County

Three respondents listed minorities, and one respondent listed non-English speakers.

d. Hillsborough County

Respondents listed minorities (6), ex-offenders (5), homeless (1), substance abusers (1), non-English speakers (1), children (1), minority women (1), those in subsidized housing (1), those pending Social Security (1) and the poor/low income (1).

e. Manatee County

Four respondents listed minority populations (Blacks and Hispanics).

f. Pasco County

Respondents listed minorities (2), heterosexual HIV+ individuals (1), homeless (1), migrant workers (1), adolescents (1), rural clients (1) and the poor/low income (1).

g. Pinellas County

Respondents listed minorities (6), homeless (5), poor/low income (3), uninsured (2), ex-offenders (1), substance abusers (1), non-English speakers (1), children (1), minority women with children (1), those with mental health needs (1), recipients of Social Security (1), adolescents (1), geriatric clients (1), those just over 300% federal poverty level (1), those with assets but low pay (1), clients with ambulatory assistance needs (1), those with co-morbidities (1), clients with no support system (1) and the poor/low income with housing needs (1).

h. Polk County

Respondents listed minorities (3), men who have sex with men (1), immigrants (1), substance abusers (1), women with children who have no one to help them (1) and the poor/low income (1).

3. Barriers to Improving Quality of Life

Respondents were asked to identify the three greatest barriers to improving the quality of life for PLWHA. Table 8 provides a summary of data by TSA, EMA and non-EMA.

The TSA, EMA and non-EMA each selected lack of affordable housing, then lack of transportation and shortage of funding for needed services as the greatest barriers to improving the quality of life for PLWHA.

Table 8
Barriers to Care by TSA, EMA and Non-EMA

Reason	TSA (n=115)	EMA (n=92)	Non-EMA (n=23)
Lack of transportation	43.5% (50)	43.5% (40)	43.5% (10)
Lack of affordable housing	67.8% (78)	76.1% (70)	34.8% (8)
Shortage of funding for needed services	42.6% (49)	42.4% (39)	43.5% (10)
Lack of specialty medical care	8.7% (10)	6.5% (6)	17.4% (4)
Lack of on-going assistance for utilities	10.4% (12)	10.9% (10)	8.7% (2)
Lack of staff training	2.6% (3)	2.2% (2)	4.4% (1)
Poor coordination of services	8.7% (10)	8.7% (8)	8.7% (2)
Concerns regarding confidentiality	1.7% (2)	2.2% (2)	0% (0)
Lack of providers for services	13.9% (16)	10.9% (10)	26.1% (6)
PLWHA not involved in advocacy	6.1% (7)	5.4% (5)	8.7% (2)
Service caps	2.6% (3)	2.2% (2)	4.4% (1)
Stigma	14.8% (17)	10.9% (10)	30.4% (7)
Not eligible for services	7.0%	8.7%	0%

Reason	TSA (n=115)	EMA (n=92)	Non-EMA (n=23)
	(8)	(8)	(0)
Compliance/adherence among PLWHA	17.4% (20)	20.7% (19)	4.4% (1)
Education about HIV progression	0.9% (1)	1.1% (1)	0% (0)
Education about HIV prevention	5.2% (6)	3.3% (3)	13.0% (3)
Need for job training and placement assistance	13.0% (15)	15.2% (14)	4.4% (1)
Motivating PLWHA to get into care	8.7% (10)	8.7% (8)	8.7% (2)
Lack of child care	2.6% (3)	3.3% (3)	0% (0)
Waiting lists	16.5% (19)	19.6% (18)	4.4% (1)
Clients not legal residents	6.1% (7)	5.4% (5)	8.7% (2)
Language barriers	7.0% (8)	6.5% (6)	8.7% (2)
Cultural barriers	5.2% (6)	6.5% (6)	0% (0)
Service locations inconvenient	3.5% (4)	2.2% (2)	8.7% (2)
Service hours are inconvenient	0% (0)	0% (0)	0% (0)
Other	0.9% (1)	0% (0)	4.4% (1)

“Other” reasons cited included cultural insensitivity.

4. Barriers by county

a. Hardee County

The greatest barriers to improving the quality of life for PLWHA selected by Hardee County respondents were shortage of funding for needed services and education about HIV prevention.

b. Highlands County

Highlands County respondents selected lack of transportation as the greatest barrier in their county.

c. Hernando County

Those who responded from Hernando County chose lack of affordable housing, lack of transportation and lack of specialty medical care.

d. Hillsborough County

Hillsborough County respondents feel that the three greatest barriers to improving the quality of life for PLWHA in their county are lack of affordable housing, lack of transportation and shortage of funding for needed services.

e. Manatee County

Manatee County respondents selected lack of transportation and lack of affordable housing as the greatest barriers in their county.

f. Pasco County

Those who responded from Pasco County chose lack of affordable housing, lack of transportation and shortage of funding for needed services as barriers to PLWH quality of life.

g. Pinellas County

The greatest barriers to improving the quality of life for PLWHA selected by Pinellas County respondents were lack of affordable housing, shortage of funding for needed services and lack of transportation.

h. Polk County

Polk County respondents feel that the three greatest barriers to improving the quality of life for PLWHA in their county are shortage of funding for needed services, lack of affordable housing and lack of providers for services.

F. Quality of Services/Agencies

The survey provided a Likert item requesting respondents to specify their level of agreement with each positively worded statement. Agreement levels included strongly agree, agree, neutral, disagree, or strongly disagree to the following statements:

1. PLWHA services are convenient.
2. PLWHA services are well coordinated.
3. PLWHA services are client focused.
4. PLWHA services are high quality.
5. PLWHA services have concerned staff.
6. PLWHA service agencies work together.

The results for TSA, EMA, non-EMA and each county are included in Table 9.

Table 9
Quality of Services/Agencies by TSA, EMA, Non-EMA and County

	Characteristic	% Strongly Agree	% Agree	% Neutral	% Disagree	% Strongly Disagree
TSA	Convenience	9.6%	41.7%	20.9%	25.2%	2.6%
	Coordination	8.7%	40.0%	26.1%	21.7%	3.5%
	Client Focused	13.0%	58.3%	12.2%	15.7%	0.9%
	Quality	9.6%	49.6%	31.3%	7.8%	1.7%
	Staff Concern	30.4%	54.8%	11.3%	2.6%	0.9%
	Agency Collaboration	7.8%	54.8%	24.4%	7.8%	5.2%
EMA	Convenience	10.9%	42.4%	20.7%	25.0%	1.1%
	Coordination	8.7%	41.3%	23.9%	25.0%	1.1%
	Client Focused	15.2%	57.6%	9.8%	17.4%	0%
	Quality	7.6%	53.3%	30.4%	8.7%	0%
	Staff Concern	29.4%	56.5%	12.0%	2.2%	0%
	Agency Collaboration	7.6%	58.7%	21.7%	8.7%	3.3%
Non-EMA	Convenience	4.4%	39.1%	21.7%	26.1%	8.7%
	Coordination	8.7%	34.8%	34.8%	8.7%	13.0%
	Client Focused	4.4%	60.9%	21.7%	8.7%	4.4%
	Quality	17.4%	34.8%	34.8%	4.4%	8.7%
	Staff Concern	34.8%	47.8%	8.7%	4.4%	4.4%
	Agency Collaboration	8.7%	39.1%	34.8%	4.4%	13.0%
Hardee County	Convenience	0%	50%	0%	50%	0%
	Coordination	0%	0%	50%	50%	0%
	Client Focused	0%	100%	0%	0%	0%
	Quality	50%	0%	50%	0%	0%
	Staff Concern	50%	50%	0%	0%	0%
	Agency Collaboration	0%	50%	50%	0%	0%
Hernando County	Convenience	0%	16.7%	0%	83.3%	0%
	Coordination	16.7%	0%	33.3%	50%	0%
	Client Focused	16.7%	50%	33.3%	0%	0%
	Quality	0%	33.3%	66.7%	0%	0%
	Staff Concern	16.7%	50%	33.3%	0%	0%
	Agency Collaboration	0%	33.3%	33.3%	33.3%	0%
Highlands County	Convenience	0%	33.3%	33.3%	33.3%	0%
	Coordination	0%	66.7%	33.3%	0%	0%
	Client Focused	0%	66.7%	33.3%	0%	0%
	Quality	0%	66.7%	33.3%	0%	0%
	Staff Concern	33.3%	33.3%	33.3%	0%	0%

	Characteristic	% Strongly Agree	% Agree	% Neutral	% Disagree	% Strongly Disagree
Hillsborough County	Agency Collaboration	33.3%	33.3%	33.3%	0%	0%
	Convenience	11.1%	47.2%	25.0%	13.9%	2.8%
	Coordination	11.1%	44.4%	19.4%	22.2%	2.8%
	Client Focused	22.2%	38.9%	11.1%	27.8%	0%
	Quality	13.9%	38.9%	30.6%	16.7%	0%
	Staff Concern	33.3%	52.8%	13.9%	0%	0%
	Agency Collaboration	11.1%	50.0%	19.4%	11.1%	8.3%
Manatee County	Convenience	12.5%	37.5%	25.0%	25.0%	0%
	Coordination	12.5%	25.0%	37.5%	12.5%	12.5%
	Client Focused	0%	37.5%	37.5%	25.0%	0%
	Quality	12.5%	37.5%	37.5%	0%	12.5%
	Staff Concern	37.5%	50.0%	12.5%	0%	0%
	Agency Collaboration	0%	37.5%	37.5%	12.5%	12.5%
Pasco County	Convenience	7.7%	46.2%	15.4%	30.8%	0%
	Coordination	7.7%	61.5%	7.7%	23.1%	0%
	Client Focused	7.7%	84.6%	0%	7.7%	0%
	Quality	7.7%	76.9%	7.7%	7.7%	0%
	Staff Concern	38.5%	53.8%	7.7%	0%	0%
	Agency Collaboration	7.7%	84.6%	7.7%	0%	0%
Pinellas County	Convenience	13.5%	40.5%	21.6%	24.3%	0%
	Coordination	5.4%	37.8%	32.4%	24.3%	0%
	Client Focused	10.8%	67.6%	8.1%	13.5%	0%
	Quality	2.7%	62.2%	32.4%	2.7%	0%
	Staff Concern	24.3%	62.2%	8.1%	5.4%	0%
	Agency Collaboration	5.4%	62.2%	27.0%	5.4%	0%
Polk County	Convenience	0%	40.0%	20.0%	20.0%	20.0%
	Coordination	10.0%	40.0%	30.0%	0%	20.0%
	Client Focused	10.0%	70.0%	10.0%	0%	10.0%
	Quality	20.0%	30.0%	30.0%	10.0%	10.0%
	Staff Concern	30.0%	50.0%	0%	10.0%	10.0%
	Agency Collaboration	10.0%	40.0%	30.0%	0%	20.0%

G. Other Comments

Respondents were given the opportunity to provide additional comments regarding service availability. The comments received and the county represented are as follows:

- Pasco & Hernando need more of a cooperative relationship like Pinellas & Hillsborough. (Hernando)

- As a rural community, many services are limited or not available at all and the community awareness and involvement is very low. (Highlands)
- Less paperwork to obtain services. Clients are going through crisis and some are really ill. We put more stress on them with detailed paperwork. (Hillsborough)
- We have provided and encouraged a needy client base. Many clients feel a sense of entitlement rather than a special benefit. I would like to see a much more active role from the Grantee's office to remove wait lists. I would also recommend the grantee's office spend a 'day in the life' of a RW funded provider and provide a critical review of operations. (Hillsborough)
- Deposit assistance and/or first month's rent assistance is needed. This will help more clients establish residence. Housing is the biggest issue. More HOPWA vouchers would be helpful. More programs for positive ex-offenders are essential. Housing and job opportunities will lessen the chances that they may re-offend. (Hillsborough)
- Cutting RW funds for rent/utility assistance was a mistake. The lack of available housing for clients is already too great and funding that has been used to maintain existing housing has been taken away. This could potentially leave a client homeless if they are unable to pay expenses, and then what? They have little to no resources. I have seen firsthand how cutting this program has negatively affected my clients. This needs to be reevaluated. Maintaining food pantry services and cutting both housing assistance and legal aid does not seem like a rational choice. (Hillsborough)
- Though services may be available, capacity and resources needed to meet the need is inadequate. (Hillsborough)
- Increase funding to increase number of case managers so wait lists can be eliminated. (Hillsborough)
- Services are available with eligibility criteria. There seems to be a growing group of PLWH who are looking at services as 'entitlement' rather than eligibility based. PLWHs who have been diagnosed many years ago and are in the system seem to actually understand that services are limited and based on eligibility rather than those clients who are newly diagnosed. (Hillsborough)
- I believe Hillsborough has done well in providing services with the funding received. I would like to see more funding provided so that more services could be given. (Hillsborough)
- I think some clients are falling through the cracks medically because of the medical eligibility for ISP and AICP. One housing specialist at an agency makes processing financial requests very difficult. It takes over a month to get something approved during

which time the client's utilities are shut off and they have an eviction notice. (Hillsborough)

- I regret the lack of quality compassion with case management. (Hillsborough)
- Not enough food or transportation. (Hillsborough)
- Need more housing and financial assistance. (Hillsborough)
- Need better communication between providers. (Hillsborough)
- Transportation is a problem and financial assistance for rent and utilities. (Hillsborough)
- There should be a greater continuity of guidelines. (Hillsborough)
- Need more education about sex and HIV virus, more funding for case management, medications, co-pays and labs. (Hillsborough)
- Lack of transportation de facto makes other services unavailable. Housing and utility costs are barriers to other care. Lack of cooperation from AFDC, Social Security and legal/law enforcement. (Manatee)
- Lack of transportation (Medical, case management) for indigent clients because of contract numbers that are required, lack of quality care. (Manatee)
- There is a lack of client involvement, no focus on the needs of minorities – much is said, little is done. (Manatee)
- I feel Pasco does well for what we have. Clients need to take part in their care. Many are non-adherent, high no-show rates. (Pasco)
- I believe all the listed services are necessary. Picking only five is difficult. (Pasco)
- Not enough funding for food, transportation, housing and utilities. Very low income, have barely enough to survive every month. Medicaid/Medicare co-pays cause problems. (Pasco)
- Need to work more cooperatively with Hernando County. (Pasco)
- There are several services needed, but we are limited to choosing five. Many resources limited. (Pinellas)
- Funding has been cut for housing assistance. Majority of clients are on a low, fixed income (disability) and need assistance with rent/utilities. There are not enough community resources available to meet the need. (Pinellas)
- Housing is a major concern. Employment and continual follow-up for ex offenders released back into general population. (Pinellas)
- For the funding we get, we do pretty well. (Pinellas)
- Many resources are limited. (Pinellas)
- Not enough resources for PLWHA in the county for them to have a better quality of life. (Polk)
- In general, the majority of the services are accessible and reasonably helpful. (Polk)
- More PAC waiver providers and providers in general are needed. (Polk)
- Wait list for medication co-pays are a problem. (Polk)

- Mail order pharmacy is constantly a problem. (Polk)
- Lack of oral health care is forcing people to have problems eating thus causing malnutrition. Transportation is deplorable (non-existent) if you are not seeing a Medicaid provider. How do we get there? Walk? (Polk)
- Polk County needs CBO, funding to help reduce stigma, more HIV services not just DOH. They are the only service for PLWH. (Polk)
- Need money to cover necessities if possible. (Polk)

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The Ryan White Care Council wishes to recognize the contributions of the

Planning and Evaluation Committee Members

James McGarvey, Chair
 Marty Clemmons, Co-Chair
 Ginny Boucher
 David Hasiba
 Barb Green
 Lee Luther
 John Melartin

Patrick Mercier
 Marylin Merida
 Bob Reynolds
 Jim Roth
 Jackie Walsch
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Attachment 1:

Needs Assessment Survey for Experts/Case Managers

As a valued partner of the West Central Florida Ryan White Care Council, you play an important role in assessing the needs of People Living with HIV/AIDS (PLWHA). Please take a few moments to complete this survey. A list of service definitions is attached.

1. **What county do you represent/serve? (Check ONE – if you serve more than one county, please complete a different survey for each county).**

- Hardee Highlands Manatee Pinellas
- Hernando Hillsborough Pasco Polk

2. **Which of the following best describes you? (Check ALL that apply)**

- RW funded provider Affected community
- Other provider General population
- Other: _____

3. **How long have you been involved with HIV/AIDS services?**

- Less than six months 1 to 3 years 7 to 10 years
- Up to one year 4 to 6 years More than 10 years

4. **Please check the answer that best describes PLWHA services in your county.**

PLWHA services are convenient.

- Strongly Agree Agree Neutral Disagree Strongly Disagree

PLWHA services are well coordinated.

- Strongly Agree Agree Neutral Disagree Strongly Disagree

PLWHA services are client focused.

- Strongly Agree Agree Neutral Disagree Strongly Disagree

PLWHA services are high quality.

- Strongly Agree Agree Neutral Disagree Strongly Disagree

PLWHA services have concerned staff.

- Strongly Agree Agree Neutral Disagree Strongly Disagree

PLWHA service agencies work together.

- Strongly Agree Agree Neutral Disagree Strongly Disagree

5. Based on your knowledge of your community, please indicate the degree to which PLWHA in your county need each service (1=low need...5=high need). Please circle the number.

	Low			High
AIDS Pharmaceutical Assistance.....	1	2	3	4 5
Early Intervention Services	1	2	3	4 5
Health Insurance Premium & Cost Sharing Assistance	1	2	3	4 5
Home Health Care	1	2	3	4 5
Home and Community Based Health Services	1	2	3	4 5
Hospice Services	1	2	3	4 5
Medical Case Management (including treatment adherence)	1	2	3	4 5
Medical Nutrition Therapy	1	2	3	4 5
Mental Health Services	1	2	3	4 5
Oral health Care.....	1	2	3	4 5
Outpatient/Ambulatory Medical Care	1	2	3	4 5
Substance Abuse Services Outpatient.....	1	2	3	4 5
Case Management (non-medical).....	1	2	3	4 5
Child Care Services	1	2	3	4 5
Emergency Financial Assistance	1	2	3	4 5
Food Bank/Home delivered Meals.....	1	2	3	4 5
Health Education/Risk Reduction.....	1	2	3	4 5
Housing Services	1	2	3	4 5
Legal Services	1	2	3	4 5
Linguistic Services	1	2	3	4 5
Medical Transportation.....	1	2	3	4 5
Outreach Services.....	1	2	3	4 5
Psychosocial Support.....	1	2	3	4 5
Referral for healthcare/supportive services.....	1	2	3	4 5
Rehabilitation Services.....	1	2	3	4 5
Respite Care	1	2	3	4 5
Substance Abuse Services – Residential.....	1	2	3	4 5
Treatment Adherence Counseling	1	2	3	4 5

6. Please indicate the degree to which each service is available to PLWHA in your county from any source. Please circle your answer.

	Not Available					Available				
	1	2	3	4	5	1	2	3	4	5
AIDS Pharmaceutical Assistance.....	1	2	3	4	5					
Early Intervention Services	1	2	3	4	5					
Health Insurance Premium & Cost Sharing Assistance	1	2	3	4	5					
Home Health Care	1	2	3	4	5					
Home and Community Based Health Services	1	2	3	4	5					
Hospice Services	1	2	3	4	5					
Medical Case Management (including treatment adherence)	1	2	3	4	5					
Medical Nutrition Therapy	1	2	3	4	5					
Mental Health Services	1	2	3	4	5					
Oral health Care.....	1	2	3	4	5					
Outpatient/Ambulatory Medical Care	1	2	3	4	5					
Substance Abuse Services Outpatient.....	1	2	3	4	5					
Case Management (non-medical).....	1	2	3	4	5					
Child Care Services	1	2	3	4	5					
Emergency Financial Assistance	1	2	3	4	5					
Food Bank/Home delivered Meals	1	2	3	4	5					
Health Education/Risk Reduction.....	1	2	3	4	5					
Housing Services	1	2	3	4	5					
Legal Services	1	2	3	4	5					
Linguistic Services	1	2	3	4	5					
Medical Transportation.....	1	2	3	4	5					
Outreach Services.....	1	2	3	4	5					
Psychosocial Support.....	1	2	3	4	5					
Referral for healthcare/supportive services.....	1	2	3	4	5					
Rehabilitation Services.....	1	2	3	4	5					
Respite Care	1	2	3	4	5					
Substance Abuse Services – Residential.....	1	2	3	4	5					
Treatment Adherence Counseling	1	2	3	4	5					

7. In your county, are there any services you consider to be in surplus (available services exceed demand)?

- No Yes, specify what and where:

Service(s) with surplus:

8. How do you perceive the overall quality of life for PLWHA in your county?

- Unacceptable Poor Fair Good Very Good Excellent

9. Are there specific populations in your county that you perceive as having a lower quality of life? If so please list specific groups.

10. What are the three greatest barriers to improving the quality of life for PLWHA in your county?

- Lack of transportation
- Lack of affordable housing
- Shortage of funding for needed services
- Lack of specialty medical care
- Lack of on-going assistance for utilities
- Lack of staff training
- Poor coordination of services
- Concerns regarding confidentiality
- Lack of providers for services
- PLWHA not involved in advocacy
- Service Caps
- Stigma
- Not eligible for services
- Compliance/adherence among PLWHA
- Education about HIV progression
- Education about HIV prevention
- Need for job training and placement assistance
- Motivating PLWHA to get into care
- Lack of child care
- Waiting lists
- Clients not legal residents
- Language barriers
- Cultural barriers
- Service locations inconvenient
- Service hours are inconvenient
- Other: _____

11. What five services do you feel are essential for PLWHA in your county? (Check five)

- AIDS Pharmaceutical Assistance
- Early Intervention Services
- Health Insurance Premium & Cost Sharing Assistance
- Home Health Care
- Home and Community Based Health Services
- Hospice Services
- Medical Case Management (including treatment adherence)
- Medical Nutrition Therapy
- Mental Health Services
- Oral health Care
- Outpatient/ Ambulatory Medical Care
- Substance Abuse Services – Outpatient
- Treatment Adherence Counseling
- Case Management (non-medical including eligibility)
- Child Care Services
- Emergency Financial Assistance
- Food Bank/Home delivered Meals
- Health Education/Risk Reduction
- Housing Services
- Legal Services
- Linguistic Services
- Medical Transportation
- Outreach Services
- Psychosocial Support
- Referral for healthcare/supportive services
- Rehabilitation Services
- Respite Care
- Substance Abuse Services – Residential

12. Please provide any additional comments regarding service availability in your county.

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.