

FY 2006 RYAN WHITE NEEDS ASSESSMENT: CLIENT FOCUS GROUPS

Prepared By

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I. BACKGROUND

The Ryan White Care Council conducts an annual needs assessment for the purpose of gathering service need data. The results are utilized, in conjunction with other information, to prioritize and allocate Ryan White funding. One component of the FY 2006 needs assessment involved conducting focus groups of clients in Ryan White care/service to reach those populations that were under-represented in previous client surveys. They are also used to gather more expansive and descriptive information than could be collected using a survey format. Previous client focus groups were conducted in 2003.

II. METHODOLOGY

Members of the Planning and Evaluation Committee and other Care Council members were trained to facilitate the groups with staff. In order to assure the best possible outcomes, facilitators did not conduct focus groups in the county of their residency or employment to minimize the possibility of knowing group participants or inhibiting candid responses. Committee members also assisted with locating sites and recruiting participants.

Sites for the focus groups were chosen based on their accessibility to clients. They included locations such as AIDS service organizations, primary care clinics, health departments, and sites of support group meetings. Participants were recruited through one-to-one contact with program staff and through posted announcements explaining the purpose of the meeting. They received door prizes and mileage reimbursement.

Facilitators used a standard script (Attachment 1) reviewed and approved by the Planning and Evaluation Committee. The script was designed to identify needs and barriers to receiving care. Basic demographic data was collected on participants.

Based on a review of data, six focus groups were conducted in Highlands, Manatee, Polk and Hillsborough counties which included:

- ◆ One group of white females (Highlands County)
- ◆ One group of black males (Manatee County)
- ◆ One group of black females (Polk County)
- ◆ Two groups of white males (Hillsborough County)
- ◆ One group of black males (Hillsborough County)

A. Implementation

The focus group approach was intended to elicit participation of targeted populations that are historically hard to reach through other methods of client input, including client surveys. Focus group sites were selected for easy accessibility for clients, and whenever possible focus groups were scheduled to coincide with times when clients normally accessed services. Participants were offered donated door prizes and mileage reimbursement.

Focus groups were conducted in a secluded and relaxed setting, and participants were assured of confidentiality. While sessions were audio taped with the participants' consent, they were assured that names will not be used and the tapes will be destroyed after data analysis. All participants completed a Focus Group Participant Information Form (Attachment 2).

A list of thirty-one service categories was posted in the room, and participants were given red, blue, green and yellow adhesive dots to place on the list. Each participant received three blue dots to identify the three most important service categories. Participants each received two yellow dots to identify the two most critical services in the future. Participants received unlimited green dots to identify easy to access services and unlimited red dots to identify difficult to access services.

Turnout on the days of focus groups was generally very low, ranging from two to four participants per group. While it is difficult to generalize the reasons for the low turnout, some participants indicated that stigma, especially in rural communities, and fear of revealing their HIV status may have hindered participation. Other possible reasons may be a lack of trust in the system, or the lack of financial incentives to attend.

III. RESULTS

The information that follows is a summary of the completed client focus groups. Due to the small numbers of participants, analysis of individual target group data and combined priority rankings should be used with caution.

A. Demographics

A total of twenty persons attended six focus groups. Table 1 illustrates the participant county of residence and target group represented.

Table 1
Participant County of Residence and Target Group Represented

County	Percent of All Participants Number of All Participants
Highlands	20% (4)
Hillsborough	55% (11)
Manatee	15% (3)
Polk	10% (2)
Target Group	
White Females	20% (4)
Black Males (Two groups)	35% (7)
Black Females	10% (2)
White Males (Two groups)	35% (7)

The gender of focus group participants is indicated in Table 2.

Table 2
Gender, of Participants

Category	Percent of All Participants Number of All Participants
Gender	
Male	70% (14)
Female	30% (6)

The race and age of focus group participants is indicated in Table 3.

**Table 3
Race and Age of Participants**

Race	Percent of All Participants Number of All Participants
African-American/Black	45% (9)
Hispanic	0% (0)
White	55% (11)
Other	0% (0)
Age	
13-24	0% (0)
25-44	25% (5)
45-64	70% (14)
65-older	5% (1)

Participants were asked to identify the way in which they contracted HIV. The results are displayed in Table 4.

**Table 4
Mode of Transmission**

Mode of Transmission	Percent of All Participants Number of All Participants
Heterosexual Sex	20% 4
Sharing Needles	5% 1
Blood Transfusion	15% 3
Homosexual/Bisexual Sex	55% 11
Homosexual/Bisexual Sex And Sharing Needles	0% 0
Other	5% 1

Participants were asked to indicate the last time they were seen by an HIV doctor or nurse. The results are displayed in Table 5.

Table 5
Participation in Primary Care

Last Time Seen by HIV Doctor or Nurse	Percent of All Participants Number of All Participants
Within last Month	55% 11
Two Months Ago	10% 2
Three Months Ago	25% 5
Six Months Ago	10% 2
One Year Ago	0%
Do not go to a Doctor	0%
Other	0%

B. Service Needs and Rankings

Participants were provided with a complete list of HRSA service categories and asked to identify additional services needed by people living with HIV/AIDS. Once the list was generated, participants were asked to select the three services they felt were most important, excluding the HRSA core services (primary care, case management, drug reimbursement, oral health, mental health, and substance abuse services). Note that some participants still selected core services. The results of service need rankings and scores are displayed in Table 6.

Ranking represents perceived urgency/importance of need for services, in descending order. Score represents the number of points assigned by participants to each service category.

**Table 6
Service Needs, Rankings and Scores**

Service Category	Ranking	Score
Housing Assistance	1	8
Health Insurance	2	7
Health Education/Risk Reduction	2	7
Emergency Financial Assistance	3	6
Home Health Care	4	5
Housing Related Services	5	4
Food Bank/Home Delivered Meals/Nutritional Supplements	6	3
In-patient Personnel	6	3
Transportation	7	2
Rehabilitation Services	7	2
Treatment Adherence	7	2
Ambulatory/Outpatient	8	1
Drug Reimbursement	8	1
Mental Health	8	1
Referral Services	8	1
Client Advocacy	8	1
Permanency Planning	8	1
Hospice Services	8	1
Day/Respite Services	8	1
Other Support Services	8	1
Program Support	8	1
Case Management	Not Ranked	0
Oral Health	Not Ranked	0
Substance Abuse Treatment	Not Ranked	0
Psycho-social Support	Not Ranked	0
Legal Services	Not Ranked	0
Nutritional Counseling	Not Ranked	0
Early Intervention Services	Not Ranked	0
Outreach	Not Ranked	0
Buddy/Companion Services	Not Ranked	0
Child Welfare Services	Not Ranked	0

C. Service Accessibility

Participants were asked to identify services on their list that were easily accessible and those that were hard to obtain. Several participants noted that access to services depended to some degree on their knowledge and their case manager's knowledge of the service system and availability of payer sources. Experienced consumers indicated that some services were not really difficult to access once they knew where to go.

1. Easily Accessible Services

Participants were asked to identify services on the list that were easy to access.

a. White Females

In Highlands County, White Females felt that Case Management and Ambulatory/Outpatient services were the easiest to access.

b. Black Males

In Manatee County, Black Males felt that the services easiest to obtain were Case Management, Food and Nutritional Supplements and Oral Health.

In Hillsborough County, Black Males felt that Drug Reimbursement, Transportation and Nutritional Counseling services were the easiest to access.

c. Black Females

In Polk County, Black Females listed Case Management, Food and Nutritional Supplements, Referral Services, Outreach, Early Intervention Services and Permanency Planning as services that are the easiest to access.

d. White Males

In Hillsborough County, White Males listed Psycho-Social Support, Referral Services, Nutritional Counseling, Treatment Adherence and Case Management as services easiest to access.

Table 7 displays results for services that are easy to access.

**Table 7
Results for Services with Easy Access**

Service Category	Ranking	Score
Case Management	1	14
Referral Services	2	12
Food Bank/Home Delivered Meals/Nutritional Supplements	3	10
Nutritional Counseling	4	9
Mental Health	5	8
Psycho-social Support	5	8
Treatment Adherence	5	8
Oral Health	6	7
Legal Services	6	7
Health Education/Risk Reduction	6	7
Ambulatory/Outpatient	6	7
Emergency Financial Assistance	7	6
Client Advocacy	7	6
Early Intervention Services	7	6
Substance Abuse Treatment	8	5
Transportation	8	5
Home Health Care	8	5
Hospice Services	8	5
Drug Reimbursement	9	4
Health Insurance	9	4
Outreach	9	4
Housing Related Services	10	3
Other Support Services	10	3
Housing Assistance	11	2
Permanency Planning	11	2
Rehabilitation Services	12	1
Child Welfare Services	12	1
Program Support	12	1
Day/Respite Services	Not Ranked	0
Buddy/Companion Services	Not Ranked	0
In-patient Personnel	Not Ranked	0

2. Services Difficult to Access

Participants were asked to identify services on the list that were difficult to access.

a. White Females

In Highlands County, White Females felt that it was most difficult to access Dental Services and Drug Reimbursement. Other difficult to access services included Health Insurance, Emergency Financial Assistance, Housing Related Services, Psycho-Social Support and Legal Services.

When asked what other services are needed by PLWHs in the community, participants listed mammograms as a needed additional service.

b. Black Males

In Manatee County, Black Males felt that the services most difficult to obtain were Housing Related Services, Health Insurance, Substance Abuse Treatment and Transportation.

In Hillsborough County, Black Males felt that Transportation, Health Insurance, Housing Assistance and Housing Related Services were the most difficult to access. Participants also felt that people need to be advocates for themselves, and providers should see clients as individuals: "don't pigeonhole people".

When asked what other services are needed by PLWHs in the community, participants expressed a need for a more thorough Treatment Adherence program. They also felt that a fitness program would be beneficial for PLWHs.

c. Black Females

In Polk County, Black Females listed Oral Health, Health Insurance, Housing Related Services, Legal Services, Client Advocacy, Nutritional Counseling, Treatment Adherence, Home Health Care, Program Support and Other Support Services as most difficult to access.

When asked what other services are needed by PLWHs in the community, participants listed alternative medicine, including vitamins, herbals, nutritionals, and homeopathic remedies as a necessary additional service.

d. White Males

In Hillsborough County, White Males listed Case Management, Housing Assistance, Housing Related Services, Permanency Planning and In-Patient Personnel as services most difficult to access.

When asked what other services are needed by PLWHs in the community, participants stated that while acupuncture is currently available, massage therapy is not, and it is a service that would be beneficial to the PLWHs in the community.

Results of services that are seen as difficult to access are displayed in Table 8.

Table 8
Results for Services that are Difficult to Access

Service Category	Ranking	Score
Housing Related Services	1	14
Health Insurance	2	12
Housing Assistance	3	11
Transportation	4	10
Case Management	5	9
Oral Health	5	9
Drug Reimbursement	6	6
Emergency Financial Assistance	6	6
Home Health Care	6	6
Other Support Services	6	6
In-patient Personnel	7	5
Food Bank/Home Delivered Meals/Nutritional Supplements	8	4
Rehabilitation Services	8	4
Legal Services	8	4
Nutritional Counseling	8	4
Outreach	8	4
Health Education/Risk Reduction	9	3
Permanency Planning	9	3
Buddy/Companion Services	9	3
Program Support	9	3
Substance Abuse	10	2

Treatment		
Psycho-social Support	10	2
Client Advocacy	10	2
Treatment Adherence	10	2
Hospice Services	10	2
Child Welfare Services	10	2
Ambulatory/Outpatient	11	1
Early Intervention Services	11	1
Day/Respite Services	11	1
Referral Services	Not Ranked	0
Mental Health	Not Ranked	0

D. BARRIERS

As participants were discussing service needs, barriers to obtaining services were often cited. A summary of barriers indicated is listed below.

a. White Females

In Highlands County, White Females cited long waiting periods to get an appointment with a dental specialist, high turnover of dentists at the health department, and currently having no dentist for adults at the health department.

Barriers to getting Drug Reimbursement services included not being able to get authorization until the first of the month, slowness of the authorization process, having to make several phone calls to get through, and not being able to get medications when pharmacies are not open on weekends.

b. Black Males

In Manatee County, Black Males cited the requirement of giving excessive amounts of information in order to get transportation as a barrier to services. Another barrier to transportation is the limited capacity of the bus system, no service on Sundays, and difficulty obtaining bus passes.

Barriers to Housing included limited availability: it is only available for females or single parents, and people with a prior felony charge are not eligible for housing.

Barriers to Substance Abuse Treatment included lack of communication from providers, and lack of local services: clients are mostly sent over to other counties after many phone calls.

In Hillsborough County, Black Males cited providers' lack of seeing people as individuals as a barrier to services.

c. Black Females

In Polk County, Black Females cited a lack of a comprehensive resource guide to services, a strong stigma of HIV in rural communities and resulting PLWHs' fear of discovery of their HIV + status as some of the barriers to services. Other barriers included limited involvement of faith based organizations to carry the message, a limited number of culturally appropriate services for target groups, and lack of female support groups in the county.

d. White Males

In Hillsborough County, White Males cited excessive bureaucracy, the requirement to fill out complex paperwork, duplication of questions and answers on paperwork across providers, and slow processing time as barriers to services. Current income limits and income verification requirements also delay or prevent the efficient provision of services to clients. The current practice of not presenting all grievances directly to the Grantee presents a barrier to resolving service issues as clients fear potential retaliation of agencies against them. Participants expressed the need for more accurate and helpful Nutritional Counseling: they felt that the current counselor was accessible but not effective.

E. FUTURE NEEDS

PLWHs' needs change over time depending on health status, finances, and availability of assistance from family and friends. Participants were asked to identify two services most critical to them in the future.

a. White Females

In Highlands County, White Females felt that Home Health Care and Emergency Financial Assistance were the two most critical services for them in the future. Comments included: "If I can't drive or cook, I will need home assistance"; "If ill, I'll need financial,

home, and health assistance”. Participants also expressed future need for more food service options.

b. Black Males

In Manatee County, Black Males felt that the most important future needs for PLWHs are Housing Assistance, Transportation, Health Insurance and Emergency Financial Assistance. Participants commented that in the future they may not have Medicaid/Medicare because of budget cuts. Participants also voiced their dislike of nursing homes and the desire not to be alone. A participant commented: “I need someone to help me fight for medical insurance and my right to services”.

In Hillsborough County, Black Males felt that the most important future needs for PLWHs are Housing Assistance and Health Insurance.

Both Male groups listed Health Education/Risk Reduction as a very important future need.

c. Black Females

In Polk County, Black Females felt that the most important future needs for PLWHs are Housing and Health Insurance. Participants commented on future need for transitional housing for those who can no longer live alone but don’t need Hospice services. Participants also stated there is a future need for Housing Assistance to help those who can live alone and maintain their independence as long as possible.

In regards to future Health Insurance needs, participants stated there is a crucial need to get coverage with status: (insurance companies may exclude clients with pre-existing conditions). Comments also included the future need for dealing with co-infection issues and non-HIV-medication issues. Health Education/Risk Reduction was also listed by the group as a very important future need.

d. White Males

In Hillsborough County White Males felt that Health Insurance is a very critical service in the future so people can continue to get medical care and medications. A participant stated that Housing and Housing Related Services will also need attention. Mental Health Counseling was also seen as a service priority in the future:

“No quality of life without mental health counseling for those who need it”. Home Health Care for those who lack transportation, Permanency Planning and Legal Services were also viewed as crucial services in the future.

A participant commented that the dental providers needed a more efficient system. The client had multiple appointments and at each appointment additional paperwork was required and additional tests were needed. The client felt that the provider should compile a list of necessary documents, tests, etc., and share that with the client prior to the scheduled visit so that the client would not have to reschedule multiple times – each visit being several months apart.

Participants felt there is a need for an umbrella organization to reduce competition among provider agencies; competition among agencies for funding produces negative results for clients. Participants also felt that provider agencies should improve interaction/communication with each other.

Other recommendations for the future included: provide more information to VA clients who are unsure about where to go for assistance for services; reduce the time lag between diagnosis and provision of services; as people and programs have limited funds, focus more on education leading to independence; deal with aging relates issues.

Other comments from participants included the need to raise the income limits on programs, and to provide more incentive to work and less punitive results if money is earned.

A summary of most critical future needs is displayed in Table 9.

Table 9
Most Critical Service Needs in the Future
Rankings and Scores

Service Category	Ranking	Score
Home Health Care	1	9
Health Insurance	2	8
Housing Assistance	3	4
Emergency Financial Assistance	4	3
Permanency Planning	4	3
Food Bank/Home Delivered	5	2

Meals/Nutritional Supplements		
Housing Related Services	5	2
Legal Services	5	2
Health Education/Risk Reduction	5	2
Transportation	5	2
Nutritional Counseling	5	1
Mental Health	6	1
Buddy/Companion Services	6	1
Day/Respite Services	6	1
Ambulatory/Outpatient	Not Ranked	0
Drug Reimbursement	Not Ranked	0
Case Management	Not Ranked	0
Oral Health	Not Ranked	0
Substance Abuse Treatment	Not Ranked	0
Psycho-social Support	Not Ranked	0
Rehabilitation Services	Not Ranked	0
Referral Services	Not Ranked	0
Client Advocacy	Not Ranked	0
Early Intervention Services	Not Ranked	0
Treatment Adherence	Not Ranked	0
Outreach	Not Ranked	0
Hospice Services	Not Ranked	0
Child Welfare Services	Not Ranked	0
Other Support Services	Not Ranked	0
Program Support	Not Ranked	0
In-patient Personnel	Not Ranked	0

F. INITIAL ACCESS TO SERVICES

Participants were asked, if they were new residents in the area who are HIV+, where would be the most convenient location for them to access information about local services.

a. White Females

In Highlands County, White Females stated that the health department would be the most convenient location for them to access information about local services.

b. Black Males

In Manatee County, Black Males stated that the health department, the Internet, the library, a doctor's office, an AIDS service organization, or a local church would be the most convenient locations for them to access information about local services.

In Hillsborough County, Black Males listed a doctor's office, billboards, the health department, the Internet and outreach services as the most convenient locations for them to access information about local services.

c. Black Females

In Polk County, Black Females listed the health department, a phone book, the Department of Children and Families, a child welfare office, a referral list, and Get Involved Community Outreach, Inc. as the most convenient locations for them to access information about local services.

d. White Males

In Hillsborough County, White Males listed the public library, a doctor's office, a hospital, television, the Internet, magazines, service providers, and bars as the most convenient locations for them to access information about local services.

Attachment 1 Client Focus Group Script

(Collect demographic sheets before starting)

➤ Introduction

“Hello and thanks for joining us. My name is _____ and this is _____. We are from the Ryan White Care Council. The Ryan White Act funds services for people with HIV. This is one of several focus groups being held to gather information about the service needs of people with HIV. We are here to learn from you. Just as companies like Nike hold focus groups to determine if their commercials appeal to the target audience, we want to hear from you about the services you need.”

“A focus group helps people to come together in one place to share their opinions on a topic. Each of you is representing your own ideas. Please be as honest and open as possible in your responses. Your privacy will be protected.”

“We will **not** use your name in any reports that come from this group. We will use the general information and recommendations that you and others provide to help us decide how to spend Ryan White funds.”

“I am going to ask you questions and listen to your answers. **This is not a test and there are no right or wrong answers to these questions!** We want you to give your opinion, even if you don’t agree with something else that was said. But, please speak one at a time.”

“During the group, _____ will be taking notes and after an hour she/he will give us a summary of the main points so you can verify if we have captured your information correctly. We also will be tape recording the group to help us write our reports.”

“Help yourself to refreshments at any time. If you need to use the bathroom it is located _____. We should be done in an hour and a half.”

➤ Icebreaker

“Lets go around the room and introduce ourselves (using our **first** names) and tell the group what your favorite food, TV show, book, movie is. I’ll start...”

Questions

1. “Please raise your hand if you or someone you know is currently receiving any help for your HIV?”

2. (Tape service list on wall). “Most people will agree that the services on this list may be needed by Persons Living With HIV. What other services are needed by PLWHs in your community?” *(Write responses on flip chart)*

“You will notice that each participant has been given colored sticky dots. As we ask the next few questions, we would like for you to place the colored dots directly on the charts to indicate your choices.”

3. “We have quite a list of services. Which of these services are easy to get in your community **today**? *(Have participants place green dot by selected services)*
4. “Looking at the list of services, which is the most difficult to get **today**?” *(Have participants place red dot by selected services)*
5. “What changes are necessary for you to be able to get the services that are difficult to access?”
6. “Our needs change over time depending on our health, finances, and help from our family/friends. In the **future**, which two services do you think will be most critical to you?” *(Have participants place yellow dot by selected services)*
“What are some of the reasons that lead you to anticipate the need for these services?”
7. “There are never enough funds to provide all the services a community needs. We need your help. Please look carefully at the list and select the **three** most important services. *(Have participants place blue dot by selected services)*
8. “If you are a new resident who is HIV+, where would be the most convenient location for you to access information about local services?”

➤ **Summary**

“_____ will provide a summary of the main ideas that emerged today.” *(Two or three minute summary provided)*

(Look at the participants and ask) “Is this summary complete?” (Record any changes)

(Offer freebies or draw for prize)

“THANK YOU FOR COMING TODAY.”

Attachment 2
FOCUS GROUP PARTICIPANT INFORMATION

Ryan White Care Council is conducting focus groups to gather information about PLWH service needs. You have the right to refuse to answer any question and you may leave the room at any time. All information will be kept strictly confidential.

The focus group will be tape recorded and notes will be taken. But, all this information is confidential and will only be used to help the Care Council decide how to spend Ryan White funds in your community.

If you have any questions, please ask the people hosting this meeting.

Please answer the questions below:

The County You Live In: _____ Your Gender: Male
Female

Your Age: Years

Your Race: African-American/Black White
 Hispanic Other

How Do You Think You Got HIV?

Heterosexual sex Blood transfusion
 Sharing needles Homosexual/ bisexual sex
 Homosexual/bisexual sex and sharing needles
 Other: _____

When was the last time you were seen by your HIV doctor or nurse?

Within the last month Two months ago
 Three months ago Six months ago
 One year I do not go to the doctor
 Other: Please explain _____