

# Ryan White Part B Consumer Needs Assessment

November 2007

Southwest/Piedmont HIV Care Consortium  
Health Outreach and Wellness



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## BACKGROUND

It is estimated that in the year 2007, 33.2 million people in the world are living with HIV or AIDS (Avert, 2007). If everyone living in Virginia, West Virginia, North Carolina, South Carolina, Kentucky and Tennessee in the year 2006 had HIV+ or AIDS that number would still fall short of 33 million. In 2007, 18,814 people in Virginia were reported living with HIV or AIDS. For the Southwest Region of Virginia, 1,430 people were reported living with HIV or AIDS (VDH, 2007). People who are diagnosed as HIV+ or with AIDS face a myriad of surrounding issues such as availability of medications, health insurance, mental health and transportation, due to the disease. HIV has three methods of transmission which are- through sexual contact, blood to blood and from mother to child. Whether you are looking at prevention or care strategies, the needs of this population must be addressed. Both must run on parallel tracks if we are going to reduce the numbers of people with HIV/AIDS.

The HIV Consumer Needs Assessment provides the Southwest/Piedmont HIV Care Consortium with a management tool in maximizing the effectiveness and efficiency of HIV services. Additionally, it satisfies the requirement that the Southwest/Piedmont HIV Care Consortium, a Ryan White Part B Consortium, carry out an assessment of needs as outlined in the Ryan White HIV/AIDS Treatment Modernization Act of 2006. The Needs Assessment provides the most current information on the needs, both perceived and actual, facing individuals in the survey area. This report provides signals of need for the route to better care. For more information about legislation visit [www.HRSA.gov](http://www.HRSA.gov)

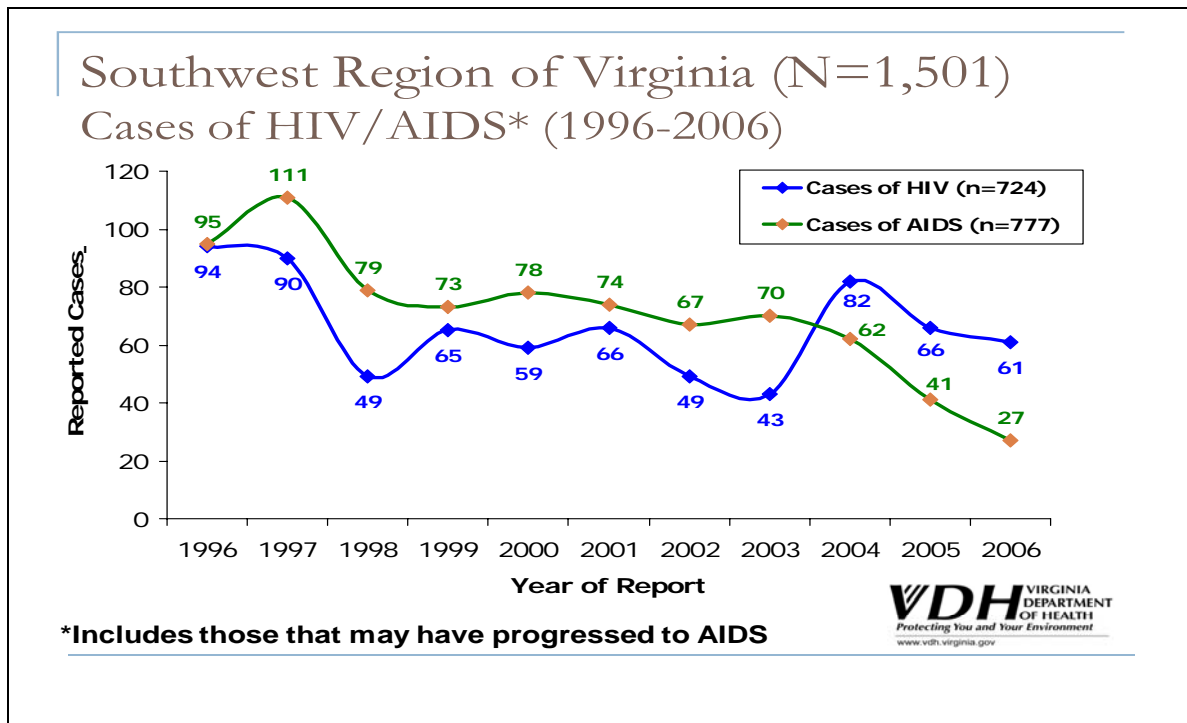
<b>2007 SOUTHWEST REGION OF VIRGINIA EPIDEMIOLOGICAL PROFILE – HIV/AIDS</b>					
		<b>SW Region</b>		<b>Virginia</b>	
<b>GENDER</b>					
	Male	1,004	70%	13,754	73%
	Female	426	29%	5,060	26%
<b>RACE</b>					
	White	663	46%	5,822	30%
	Black	724	50%	11,645	61%
	Hispanic	31	2%	1,064	5%
	Other/not reported	12	2%	283	4%
<b>AGE</b>					
	0-12	24	1%	191	1%
	13-19	53	3%	648	3%
	20-29	393	27%	5,732	30%
	30-39	553	38%	7,058	37%
	40-49	297	20%	3,783	20%
	50+	109	7%	1,398	7%
	Not reported	1	0	4	0
<b>TRANSMISSION MODE</b>					
	MSM*	508	35%	7,200	38%
	IDU	164	11%	2,413	12%
	MSM/IDU	71	4%	727	3%
	Heterosexual Contact	326	22%	3,634	19%
	Other Risks**	361	28%	4,840	28%

\*MSM: men who have sex with men; IDU: injection drug use

\*\*Other risks include hemophilia, transfusion blood/products, pediatric, multiple heterosexual contacts, undetermined/unknown, and no identified risk.

SOURCE: Division of STD/AIDS Surveillance Quarterly, Commonwealth of Virginia, Department of Health.

Second Quarter – Data reported through June 30, 2007



SOURCE: Regional Statistics HIV/AIDS and STDs (2006) (PowerPoint), Commonwealth of Virginia, Department of Health.  
<http://www.vdh.state.va.us/epidemiology/DiseasePrevention/Data/#regional>

## INTRODUCTION TO THE 2007 SURVEY

The following report documents the needs identified by consumers (individuals living with HIV) that concern the HIV Continuum of Care in Southwest Virginia.

The purpose of the HIV Consumer Needs Assessment is to identify issues and concerns of individuals living with HIV/AIDS in Health Region III. The Southwest/Piedmont HIV Care Consortium serves a total of twenty-nine (29) counties and twelve (12) city areas

The Needs Assessment provides the most current information on the needs, both perceived and actual, facing individuals in Southwest Virginia. The information contained in this report will be used by the Consortium to ensure effective and efficient planning, for implementation and evaluation of HIV health and social services in Southwest Virginia.

The data for this Assessment was obtained from a consumer survey distributed by the seven (7) Consortium subcontractors in October 2007. The four-page survey contained both closed and open-ended questions. Two hundred seventeen (217) clients completed and returned the consumer survey. The demographic characteristics of survey participants vary only slightly from the most recent Southwest Virginia statistics.

Survey respondents have the following characteristics:

- Male [58.5%]
- White [51.9%] or African American [40.3%]
- English speaking [92.1%]
- High school diploma or GED [23.6%] or Some college [29.6%]
- Income of \$0 to \$10,000 [44.4%] or \$10,001 to \$20,000 [27.3%]
- Receives public health insurance (Medicaid only) [26.4%]
- Ryan White clients [77.8%]
- Have shown symptoms of HIV infection [57.9%]
- Report physical health is about the same as last year [43.5%]
- Report mental health is about the same as last year [46.3%]

## PROCESS

The Southwest/Piedmont HIV Care Consortium contracted with the Planning and Consultation Division of the Council of Community Services in 2007 to conduct and analyze the HIV Consumer Needs Assessment.

In October 2007 Six hundred seventy four (674) Consumer Surveys (Appendix A) were distributed to Ryan White Title II subcontractors in Southwest Virginia. Surveys were then to be distributed by the case managers to clients between October 1 and October 31, 2007. The four-page survey contained both closed and open-ended questions. Self-addressed envelopes were provided for clients who chose to return the survey individually.

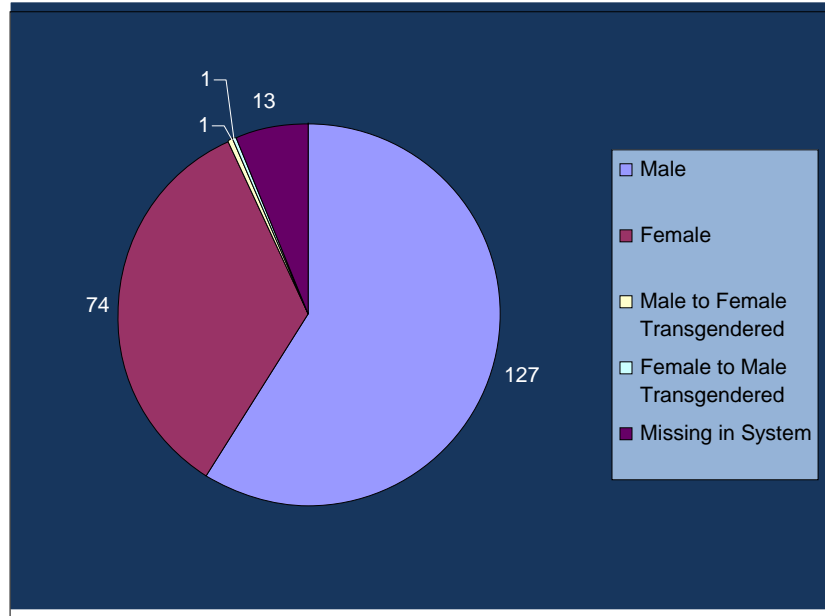
A total of two hundred seventeen (217) clients returned the consumer survey for a response rate of 32% of Ryan White clients. This return rate is a considerable increase from the response rate in 2005 which was 14%.

<b>CONSUMER EEDS ASSESSMENT SURVEY DISTRIBUTION</b>			
<b>Health District</b>	<b>Ryan White Part B Subcontractor</b>	<b>Percent Returned</b>	<b>Number Returned</b>
Lenowisco			
Cumberland Plateau	Appalachian AIDS Coalition	2.0%	13
Mount Rogers			
Alleghany	Carilion Comprehensive HIV Services*		
Roanoke City	Roanoke/Alleghany Health District	14.2%	96
Pittsyl/Dan	Piedmont ACCESS To Health Services	3.2%	22
Central Virginia	Centra Health	7.6%	51
New River	New River Health District	2.5%	17
West Piedmont	West Piedmont AIDS Task Force	2.5%	17
<b>Total</b>			<b>217</b>

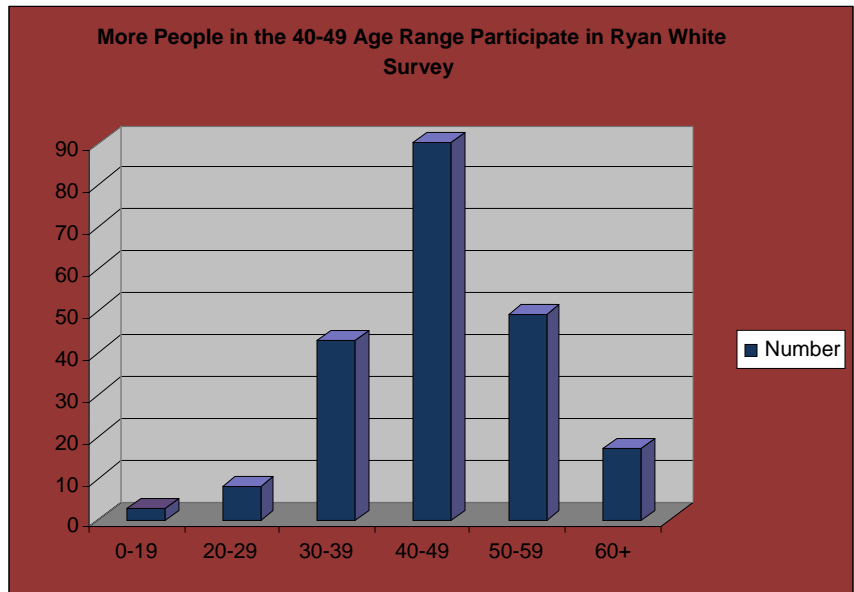
\*Carilion serves clients who reside in the health districts of Alleghany, Mount Rogers, New River, Roanoke City and West Piedmont.

# General Demographic Information of Survey Respondents

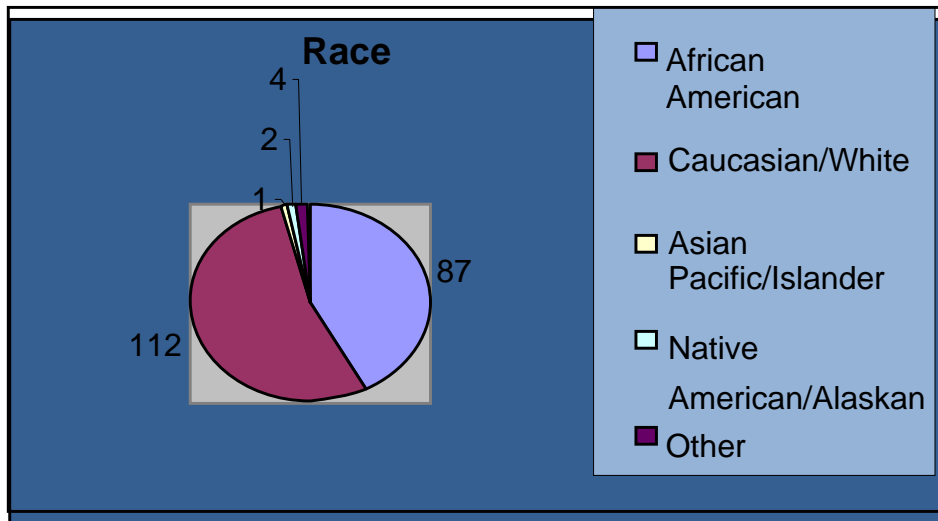
GENDER		
Male	58.8%	[127]
Female	34.3%	[74]
Trans. Male to Female	.5%	[1]
Trans. Female to Male	.5%	[1]



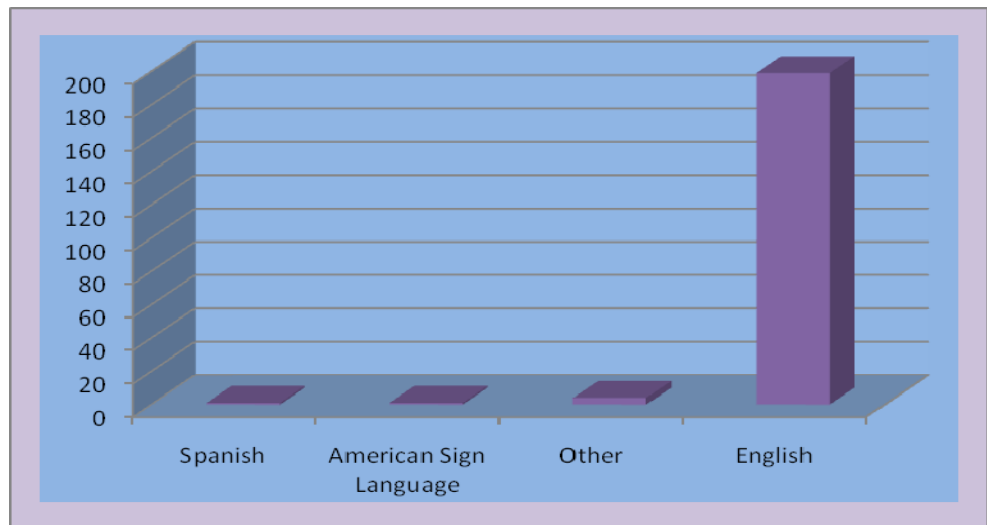
AGE	
0-19	2
20-29	7
30-39	40
40-49	83
50-59	48
60+	14



RACE		
African American	40.3%	[87]
Caucasian/White	51.9%	[112]
Asian Pacific/Islander	.5%	[1]
Native American/Alaskan	.9%	[2]
Other	1.9%	[4]

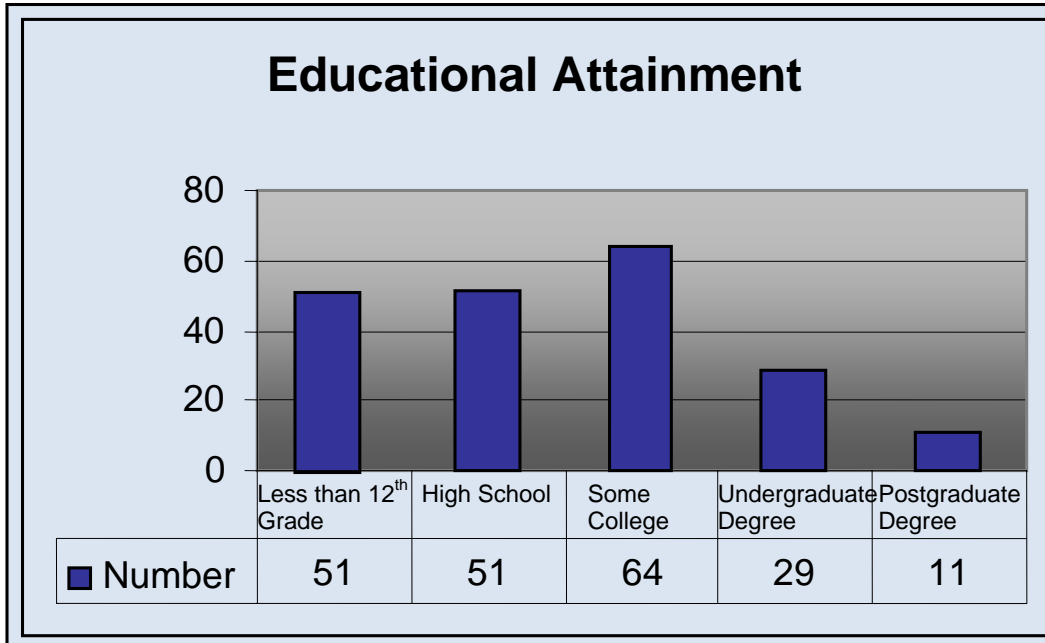


NATIVE LANGUAGE		
English	92.1%	[199]
Spanish	.5%	[1]
American Sign Lang.	.5%	[1]
Other	1.9%	[4]



**EDUCATION**

Less than 12 <sup>th</sup> grade	23.6%	[51]
High school diploma/GED	23.6%	[51]
Some college	29.6%	[64]
Undergraduate degree	13.4%	[29]
Postgraduate degree	5.1%	[11]

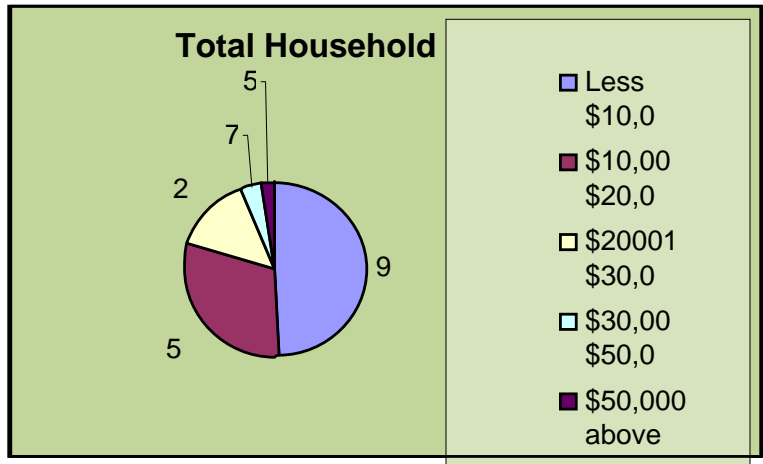




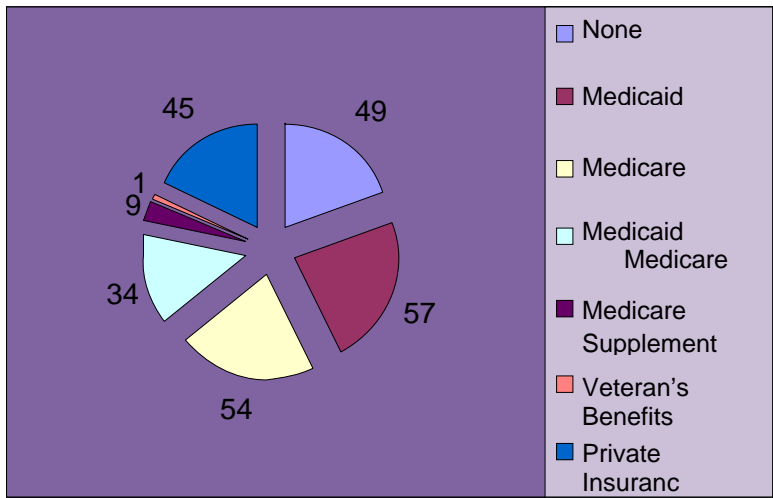
<b>EMPLOYMENT</b>		
Employed full time	22.7%	[49]
Employed part time	7.9%	[17]
Unemployed looking for work	6.9%	[15]
Unemployed waiting on disability	3.7%	[8]
Retired	4.2%	[9]
Disability	47.2%	[102]
Other unemployment	2.3%	[5]



<b>HOUSEHOLD INCOME</b>		
\$0-10,000	44.4%	[96]
\$10,001-\$20,000	27.3%	[59]
\$20,001-\$30,000	13.0%	[28]
\$30,001 and above	5.5%	[12]



\*Ryan White eligibility at time of survey was 300% of poverty level.



<b>HEALTH INSURANCE*</b>	
None	22.7% [49]
Medicaid alone	26.4% [57]
Medicare alone	25.0% [54]
Medicaid & Medicare	15.7% [34]
Medicare & Supplemental	4.2% [9]
Veteran's benefits	.5% [1]
Private insurance	20.8% [45]

\*Percentage of respondents answering "yes"

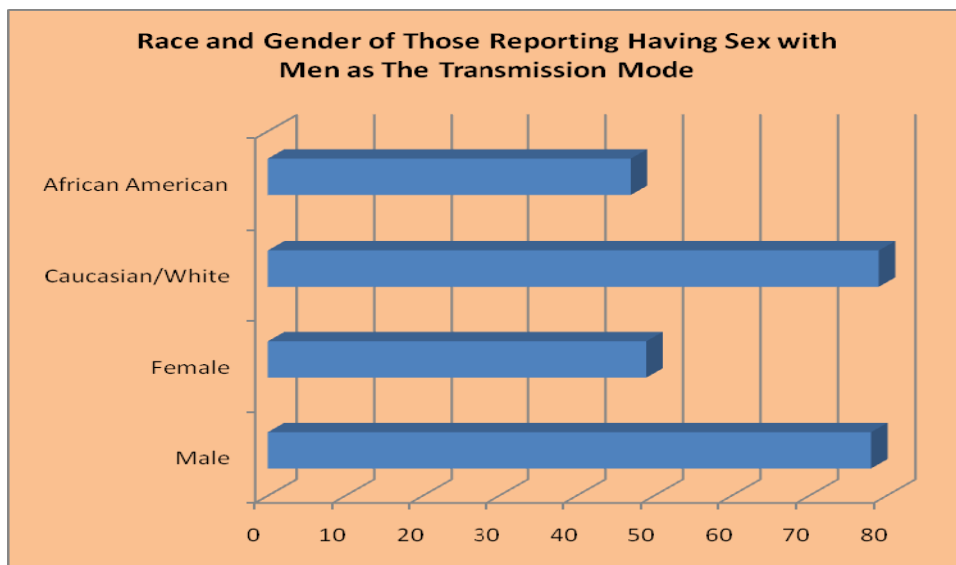
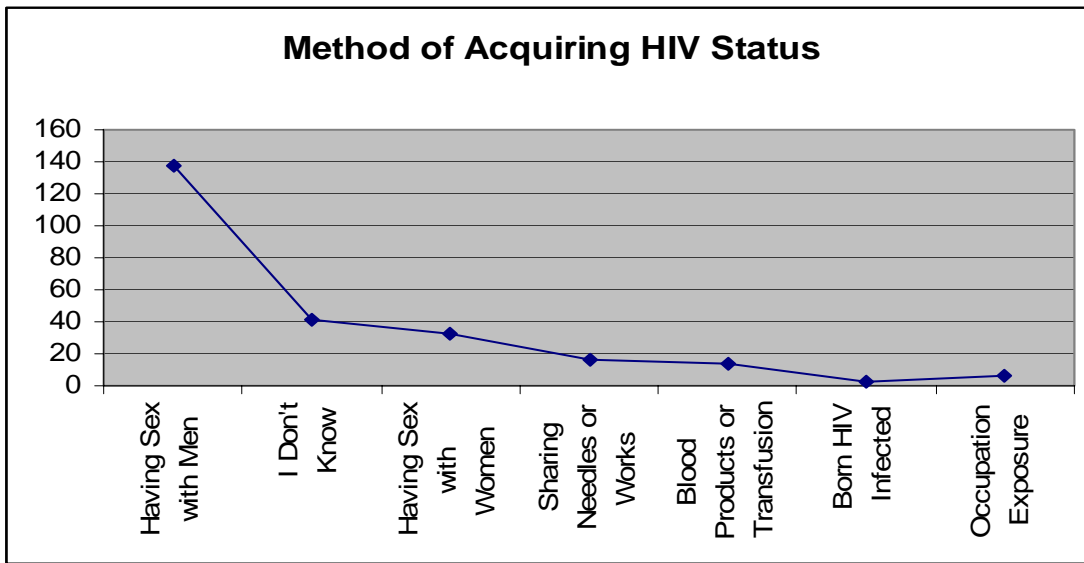
**General Demographic Information: Points of Note**

- The majority of respondents to the survey were Male- 58.8%
- The majority of respondents to the survey were between the ages of 40-49
- 51% were Caucasian and 40.3% were African American
- This left a remainder of 8.7% for all other categories
- 92.1% of the respondents reported a native language of English
- Percentages for race and native language are greatly influenced by the fact that the surveys are only printed in English.
- The majority of respondents (29.6%) have some college with a combination of 48.1% having some college to a postgraduate degree.
- The majority of respondents fell in the total income category of \$10,000.00 or less.
- 47.2% reported their employment as Disability.
- Only 1 respondent had veterans benefits as an insurance
- 22.7% had no health insurance

## Primary HIV+/ AIDS Information of Survey Respondents

<b>TRANSMISSION MODE*</b>		
Sharing needles or works	7.4%	[16]
Having sex with Men	63.4%	[137]
Having sex with Women	15.3%	[33]
Blood/blood products	6.5%	[14]
I do not know	19.0%	[41]
Other	3.7%	[8]

\*Percentage of respondents answering "yes"

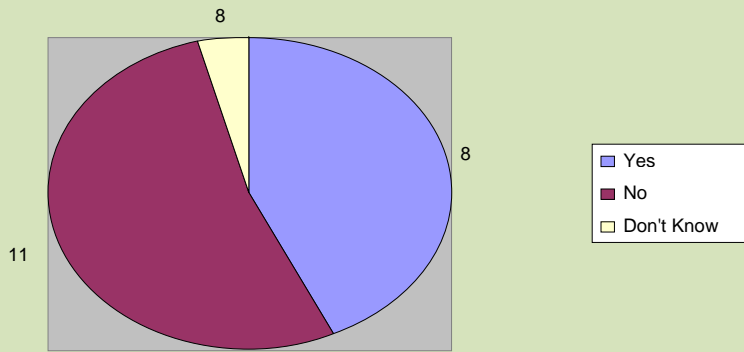


**DATE TESTED HIV+**

1977-1984*	2.4%	[5]
1985-1989	11.0%	[23]
1990-1994	19.5%	[41]
1995-1999	18.4%	[39]
2000-2004	26.8%	[57]
2005-2007	14.8%	[31]

\*HIV tests were not available until 1985. Respondents were likely to have received subjective diagnosis of AIDS.

**AIDS Diagnosed by Doctor**



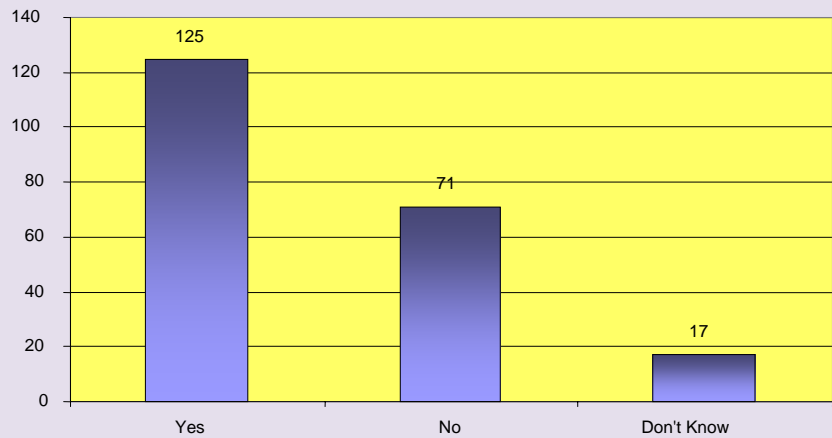
**DIAGNOSED WITH AIDS**

Yes	41.2%	[89]
No	50.9%	[110]
Don't know	3.7%	[8]

**EXPERIENCED SYMPTOMS OF HIV**

Yes	57.9%	[125]
No	32.9%	[71]

**Have Had Symptoms of**

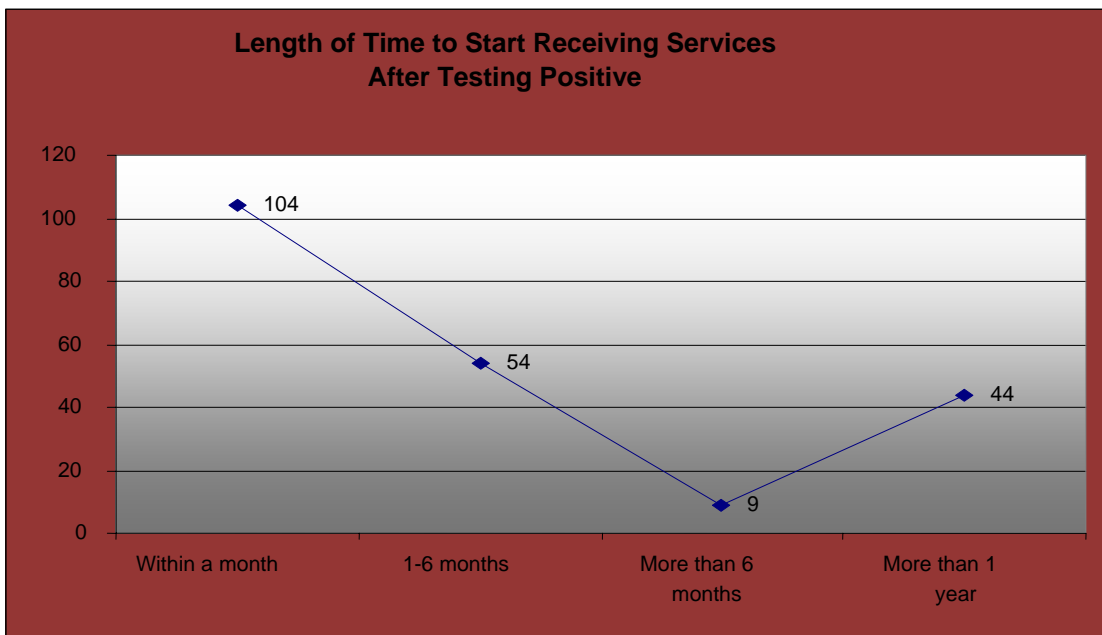


**Primary HIV+ / AIDS Information: Points of Note**

- 63.4% reported they believe they acquired HIV+ status by having sex with men.
- The greatest number testing HIV+ was during the years 2000-2004 with 28.6% and 57 people.
- It is important to note the category of 2005-2007 may have a low percentage of respondents because of only having a time window of two years instead of four.
- Almost half (41.2%) of respondents have been diagnosed with AIDS
- 58% have had symptoms of HIV.

**HIV+ / AIDS Services Information**

<b>TIME AFTER TESTING HIV+ MEDICAL CARE WAS RECEIVED</b>		
Within one month	48.1%	[104]
1 to 6 months	25.0%	[54]
More than 6 months	4.2%	[9]
More than 1 year	20.4%	[44]

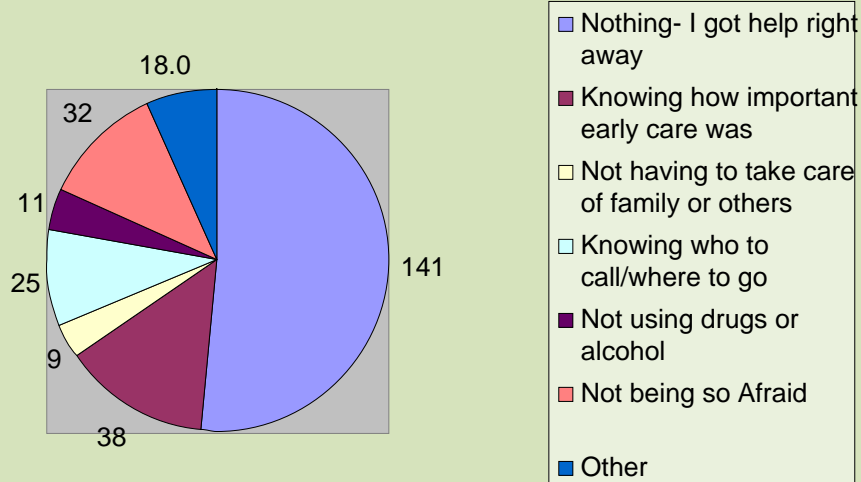


**WHAT WOULD HAVE HELPED YOU RECEIVE CARE SOONER\***

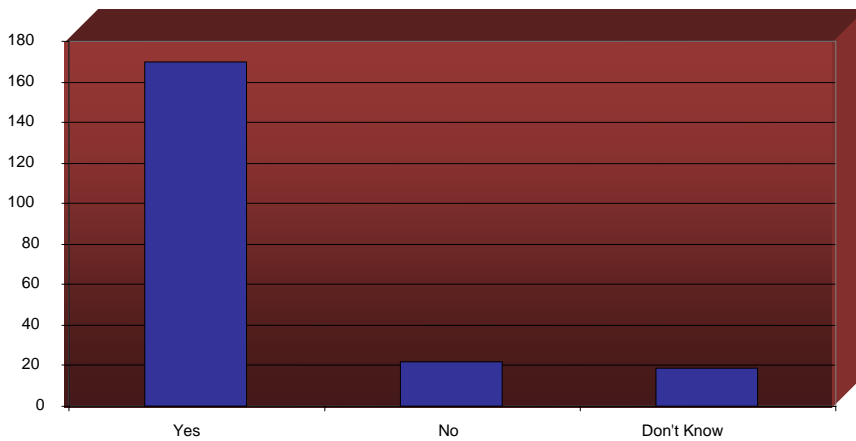
Knowing early care was important	17.6%	[38]
Knowing where to go or who to call	11.6%	[25]
Not being so afraid	14.8%	[32]
If I wasn't caring for others	4.2%	[9]
If I was not using drugs/alcohol	5.1%	[11]
Nothing – received care right away	65.3%	[141]
Unspecified other	8.3%	[18]

\*Percentage of respondents answering "yes"

**What Would have Helped to get Services Sooner**



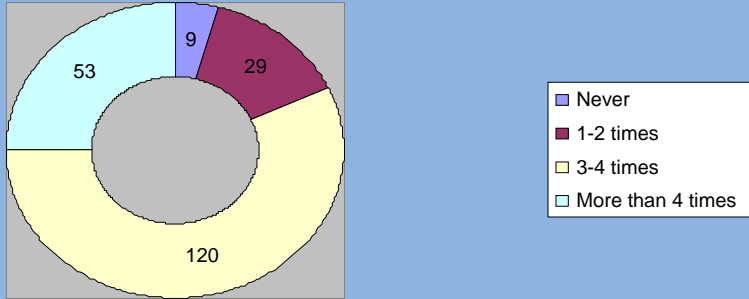
**Currently Receiving RW Services**



**RECEIVING HIV+ SERVICES**

Yes	78.7%	[170]
No	10.2%	[22]
Don't know	8.8%	[19]

**In the Last Year, How Often have You Your Doctor about HIV?**



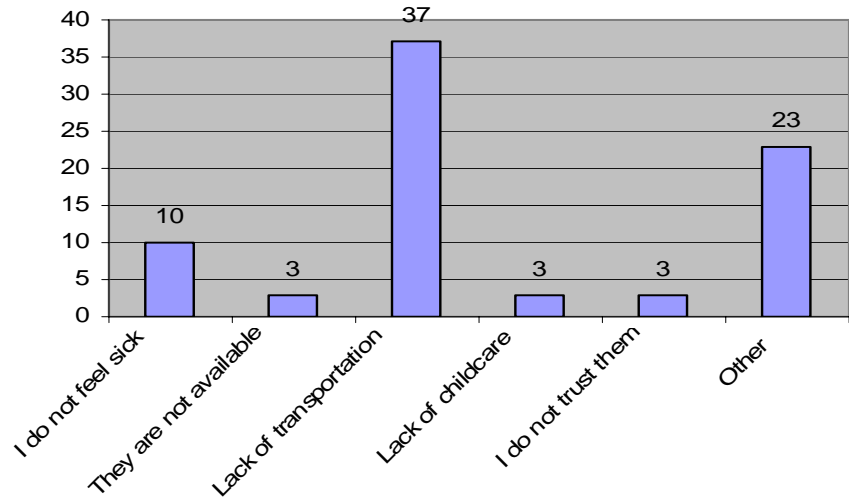
**NUMBER OF VISITS TO PHYSICIAN ABOUT HIV (within the past 12 months)**

Never	4.2%	[9]
1-2 times	13.4%	[29]
3-4 times	55.6%	[120]
More than 4 times	24.5%	[53]

**REASONS FOR NOT GOING TO SEE AN PHYSICIAN**

I do not feel sick	4.6%	[10]
They are not available	1.4%	[3]
No transportation	17.1%	[37]
I do not trust doctors	1.4%	[3]
Lack of child care	1.4%	[3]
Unspecified other	10.6%	[23]

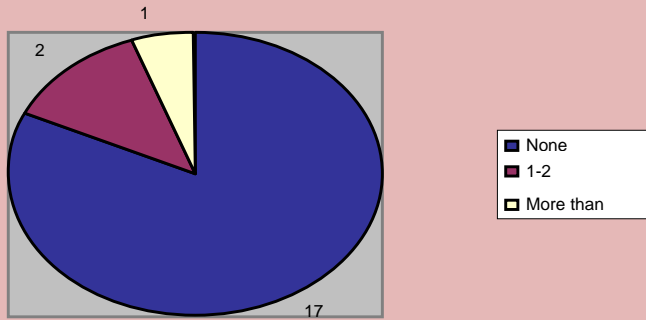
**If You have not Seen a Doctor in the Last Year, Why?**



**Zip Codes reporting lack of transportation:**

24017-5 people	24013-2 people	24541-2 people
24012-3 people	24016-2 people	12 other zip codes, each with one person,
24019-3 people	24153-2 people	reported a lack of transportation as the
24501-3 people	24540-2 people	reason for not seeing a doctor.

Emergency Room Visits Because of HIV/AIDS



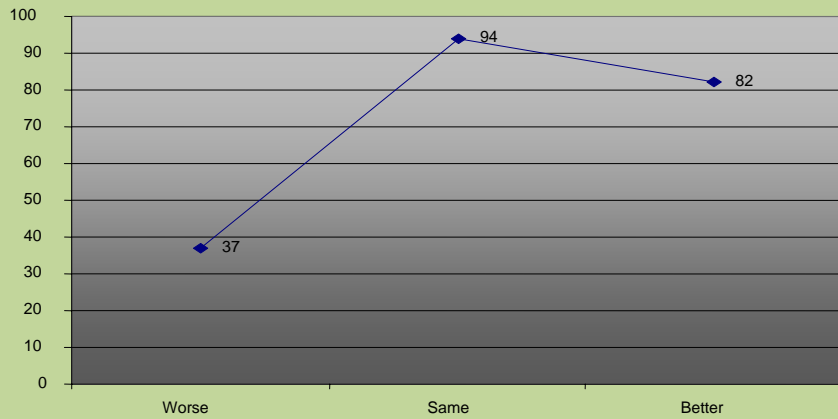
**HIV+ RELATED  
EMERGENCY ROOM  
VISITS (Last 12 months)**

None	81.5%	[176]
1-2 visits	12.5%	[27]
More than 2 visits	5.6%	[12]

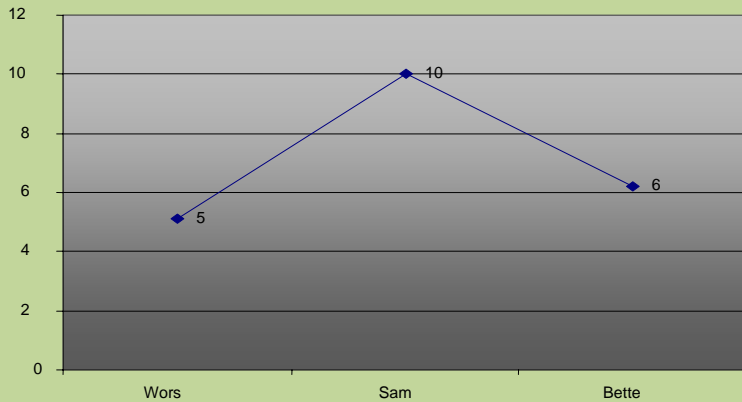
**PHYSICAL HEALTH  
AS COMPARED TO  
PREVIOUS YEAR**

Better	38.0%	[82]
The same	43.5%	[94]
Worse	17.1%	[37]

Physical Health Compared to a Year Ago



Mental Health Compared to a Year Ago



**MENTAL HEALTH AS  
COMPARED TO  
PREVIOUS YEAR**

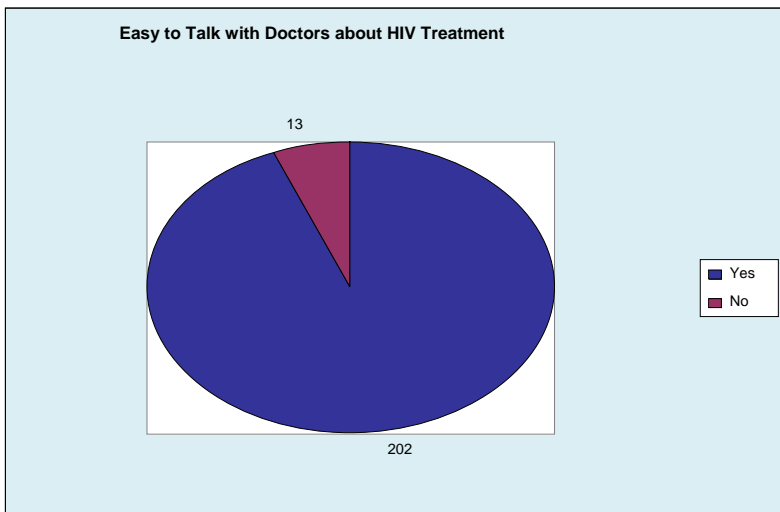
Better	28.7%	[62]
The same	46.3%	[100]
Worse	23.6%	[51]



**HIV+/AIDS Services Information: Points of Note**

- 48.1% received medical care within 1 month after testing HIV+
- 74.9% received medical care within 6 months after testing HIV+
- What would have helped to get care sooner-
  - Knowing how important early care was for my health (17.6%)
  - Not being so afraid (14.8%).
- 78.7% of those surveyed report they are receiving HIV+ services (Ryan White services)
- The majority (55.6%) of respondents visit their physician 3-4 times a year.
- 17% of those surveyed indicated that transportation is the major obstacle to physician visits.
- 18.1% of those surveyed indicated they had 1 or more emergency room visits during the year.
- When asked about physical health, 81.5% reported their physical health was the same or better.
- 75% reported their mental health being the same or better.

**Knowledge and Information about HIV+/AIDS**

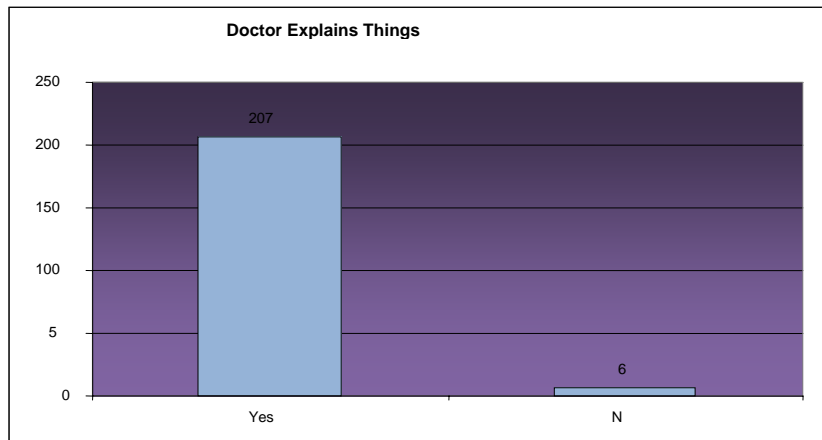


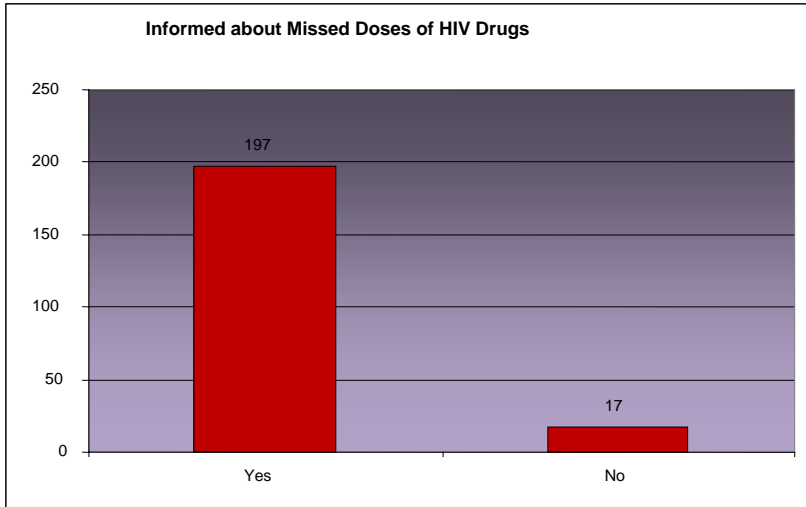
**IS IT EASY TO TALK TO YOUR DOCTORS ABOUT HIV TREATMENT?**

Yes	92.1% [199]
No	6.0% [13]

**DOCTORS EXPLAIN THINGS CLEARLY?**

Yes	79.2% [171]
No	9.3% [2]





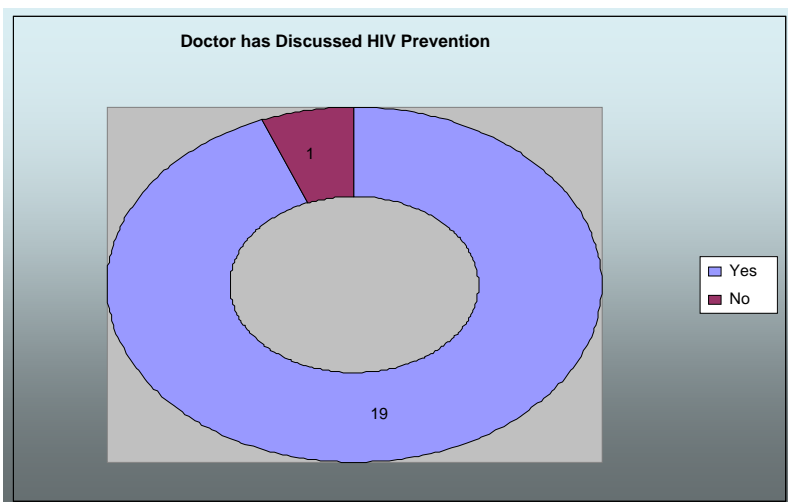
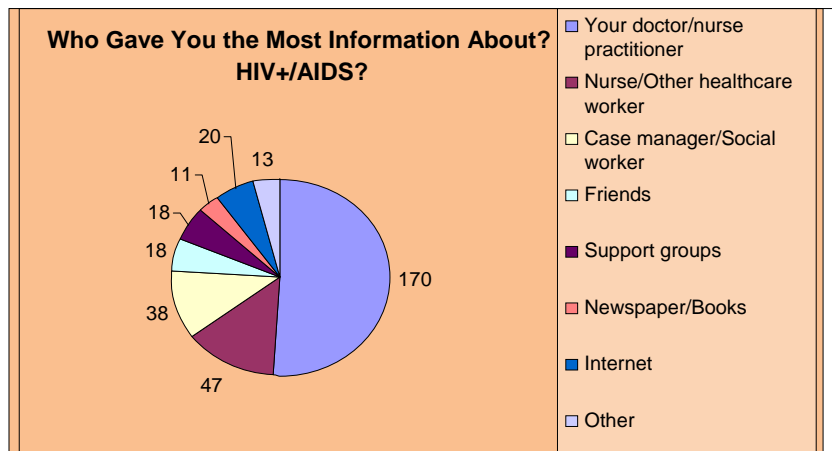
**DO YOU UNDERSTAND CONSEQUENCES OF MISSED DOSES OF HIV DRUGS?**

Yes 89.8% [88]  
 No 8.2% [8]

**RECEIVE HIV+/AIDS INFORMATION PRIMARILY FROM\***

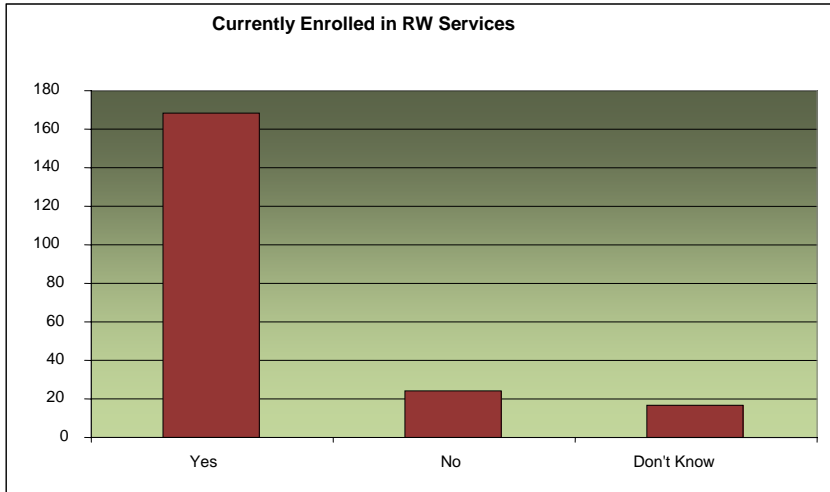
Doctors/Nurse Practitioner	78.7%	[170]
Internet	9.3%	[20]
Friends	8.3%	[18]
Support groups	8.3%	[18]
Case manager/Social Worker	17.6%	[38]
Newspapers/books/media	5.1%	[11]
Nurse/Other Healthcare Worker	21.8%	[47]
Unspecified other	6.0%	[13]

\*Percentage of respondents answering "yes"



**HAVE YOU RECEIVED HIV PREVENTION INFORMATION FROM YOUR DOCTORS?**

Yes 92.1% [199]  
 No 6.0% [13]



**ARE YOU CURRENTLY ENROLLED IN RYAN WHITE SERVICES?**

Yes	77.8%	[168]
No	11.1%	[24]
I don't know	7.9%	[17]

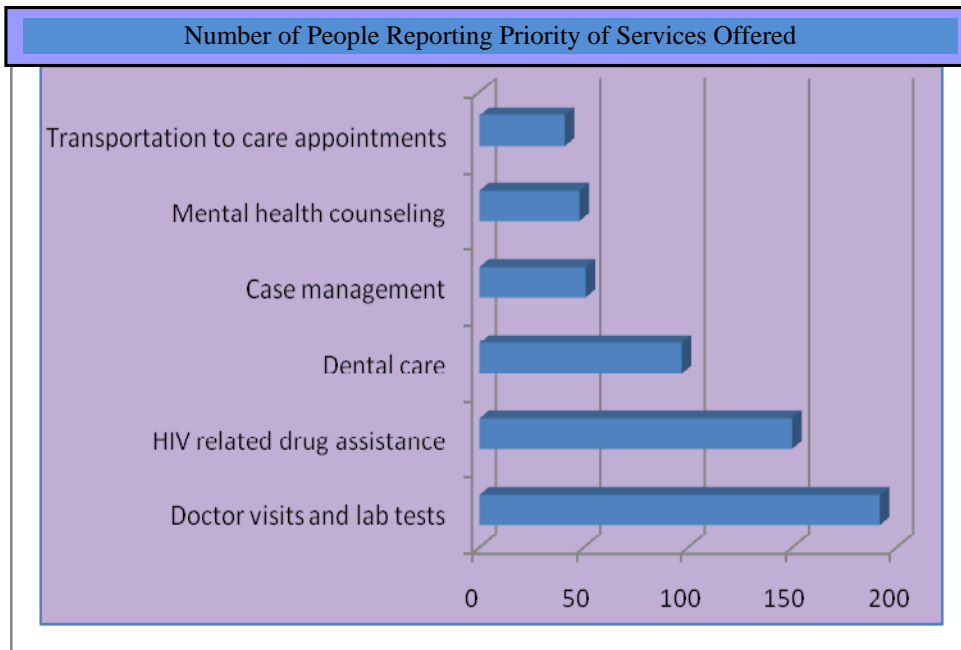
### **Knowledge and Information about HIV+/AIDS**

- 92.1% of survey respondents report they have received HIV prevention information from their doctors.
- 92.1 % report that it is easy to talk to doctors about HIV Treatment
- 79.2% report that doctors explain things clearly.
- When asked about understanding the consequences of a missed dose of HIV medication, 89.8% responded yes.
- 78.7% indicate that Doctors and Nurse Practitioners are the most prominent source of information.
- 21.8% indicated that Nurse/other healthcare worker as a source of information.
- Case manager/Social worker came in third with 17.6%.

## TOP 3 SERVICES CURRENTLY OFFERED

- When asked about the most important services offered respondents had six choices to pick as the most important. The list included Doctor visits and lab tests, HIV related drug assistance, dental care, Mental health counseling, case management and transportation to care appointments. The results of the most important services currently being received are doctor visits and lab test with 89%, HIV related drug assistance with 69.4% and Dental care with 45%.

Doctor visits and lab tests	192	88.9%
HIV related drug assistance	150	69.4%
Dental care	97	44.9%
Case management	51	23.6%
Mental health counseling	48	22.2%
Transportation to care appointments	41	19%



## TOP 3 SERVICES NOT CURRENTLY OFFERED

- When asked about the most important services not currently offered, the top three reported included help paying for insurance premiums, emergency financial assistance, and housing services. Help paying for insurance premiums was rated number one with 42%, emergency financial assistance came in second with 39% and housing services rated third in the top three choices with 26.4%.

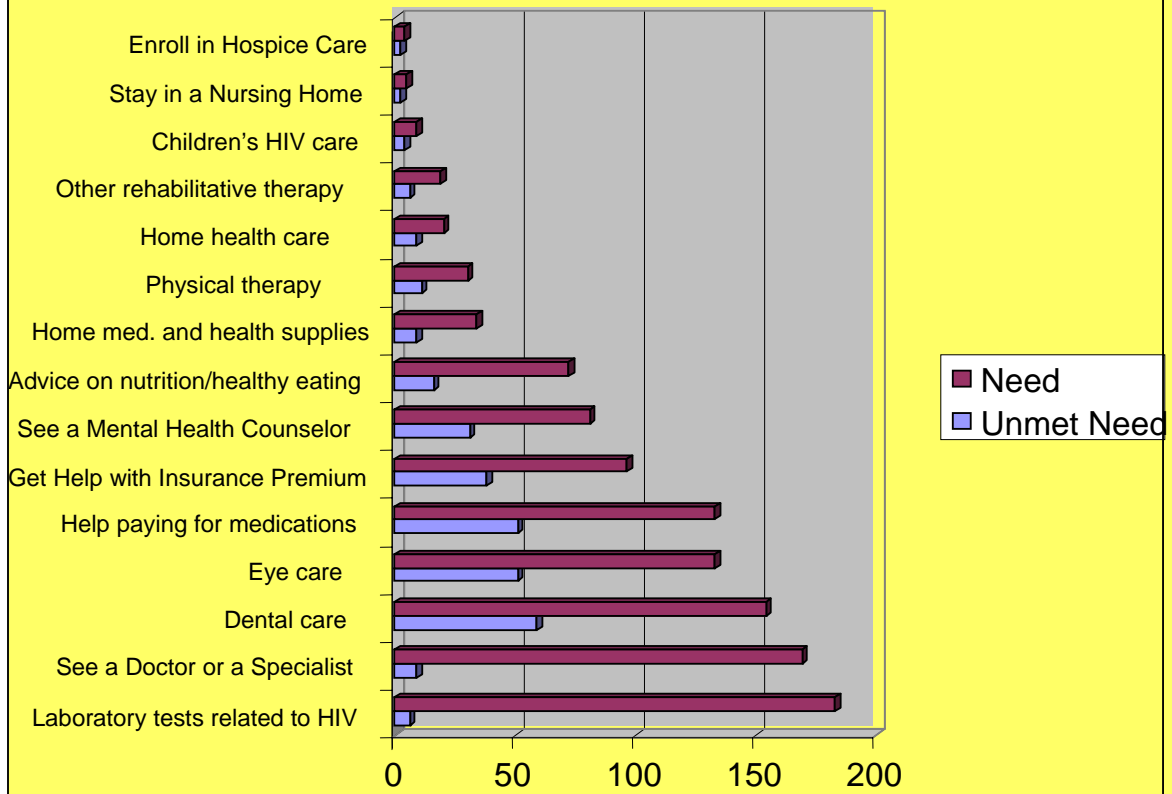
Help paying for Insurance premiums	90	41.70%
Emergency financial assistance	84	38.90%
Housing services	57	26.40%



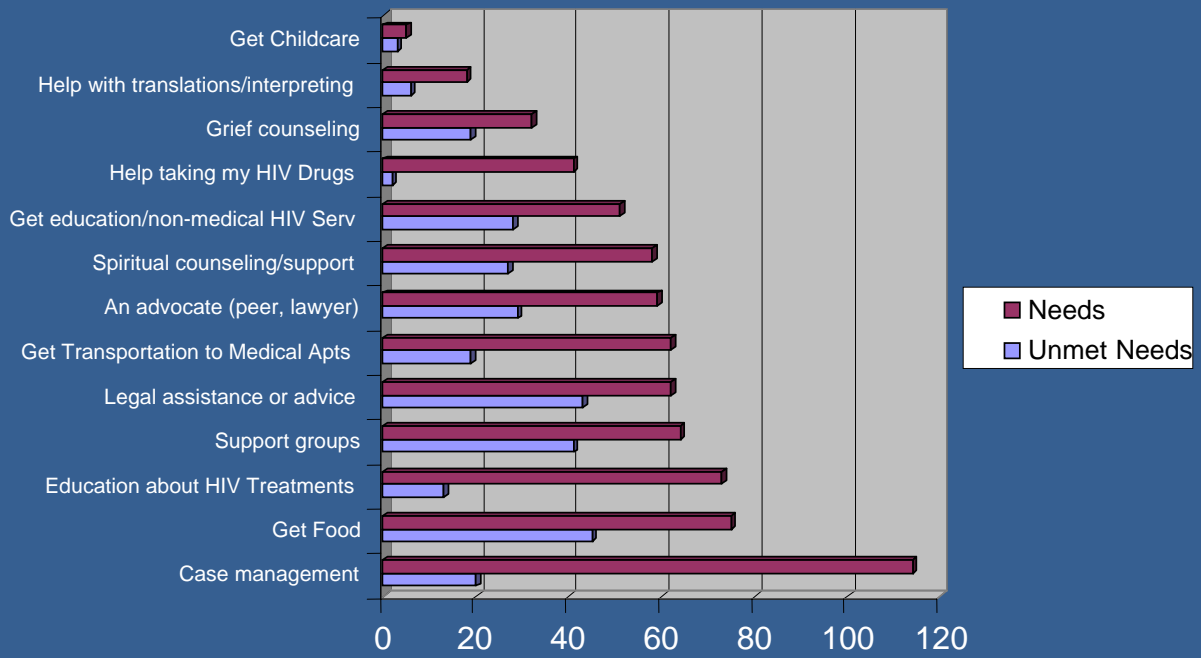
## CONSUMER NEEDS

The Consumer Needs section of the survey was divided into three categories- Health care services, Support services and Other services. Health care services are those services needed as a primary result of being diagnosed with HIV+ or AIDS. These may include things such as seeing a doctor or a specialist, getting help with insurance premiums and enrolling in hospice care. Support services are generally needs that are characterized as a secondary problem due to the seriousness of the disease. These may be needs such as case management, support groups and transportation. Other services are those that are also characterized as a secondary problem, but are not allowable expenditures by Ryan White. They are services such as: get help applying for food stamps, get help with private insurance and emergency food.

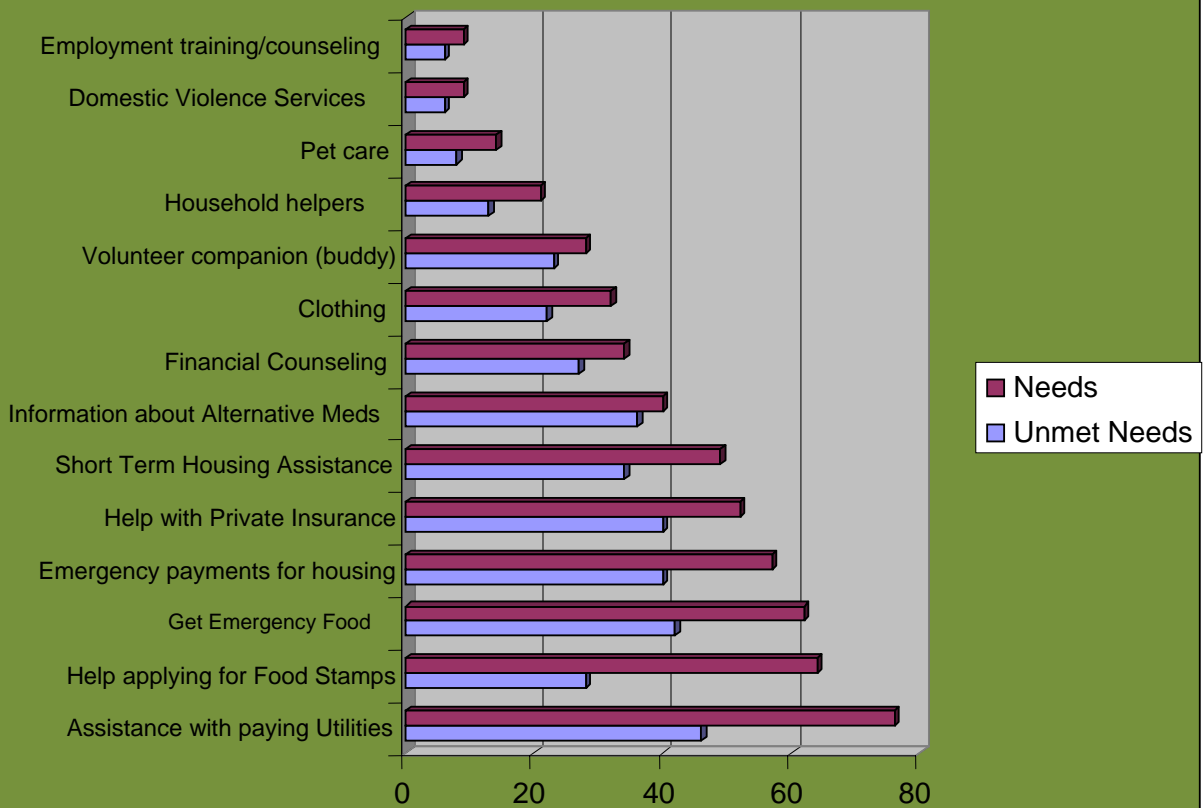
## Health Care Needs and Unmet Needs



## Support Services Needs and Unmet Needs



## Other Services Needs and Unmet Needs that are Not Currently Funded

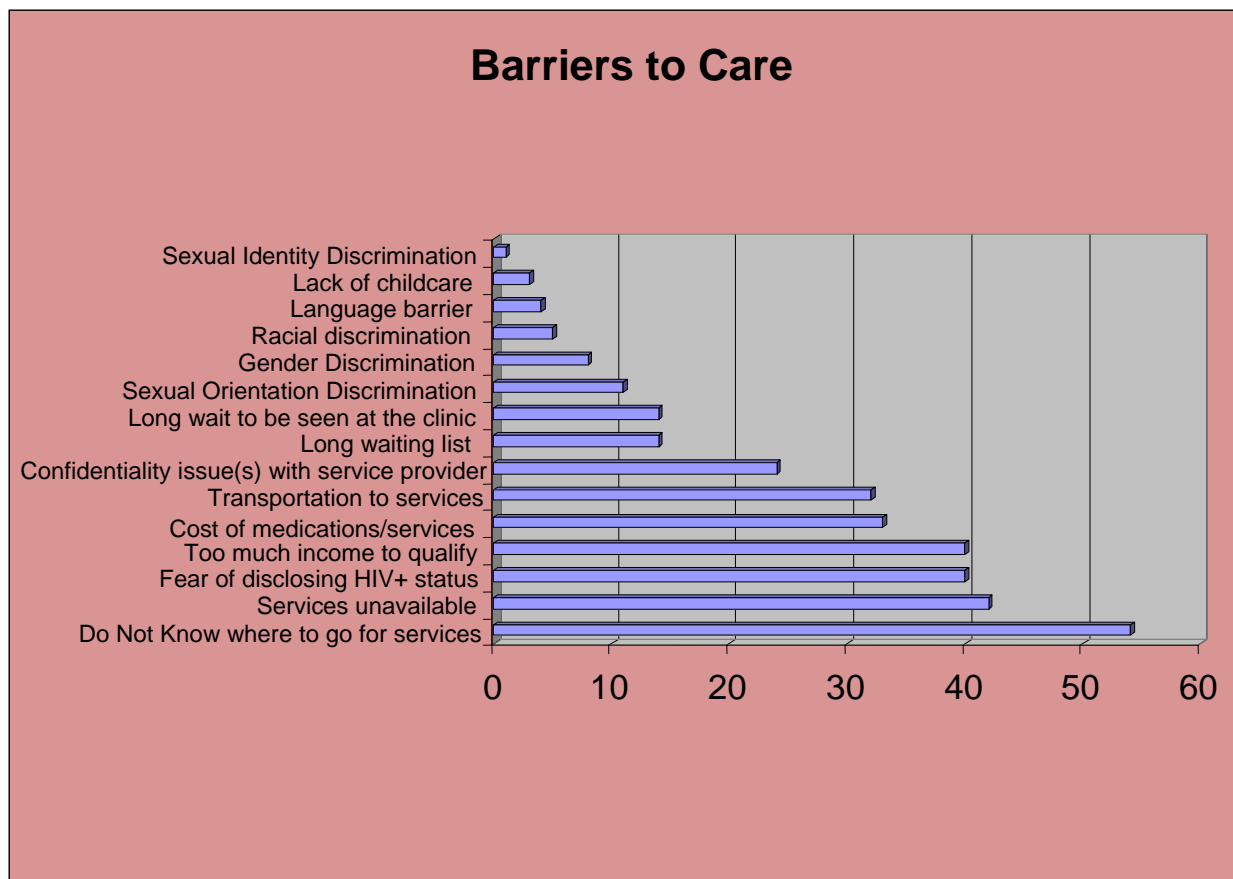




## REPORTED BARRIERS TO RECEIVING CARE\*

Cost of medications/services	15.3%	[33]
Long waiting list	6.5%	[14]
Long wait to be seen at the clinic	6.5%	[14]
Transportation to services	14.8%	[32]
Lack of childcare	1.4%	[3]
Language barrier	1.9%	[4]
Confidentiality issue(s) with service provider	11.1%	[24]
Fear of disclosing HIV+ status	18.5%	[40]
Services unavailable	19.4%	[42]
Too much income to qualify	18.5%	[40]
Gender Discrimination	3.7%	[8]
Sexual Orientation Discrimination	5.1%	[11]
Sexual Identity Discrimination	.5%	[1]
Racial discrimination	2.3%	[5]
Do Not Know where to go for services	25.0%	[54]

\*Percentage of respondents answering "yes"



# 2007 Ryan White Consumer Comments

## Ryan White survey respondents report that they worry most about:

- To have a good life with friends and family
- My health and not to get sick of having H.I.V.
- I don't worry about anything. It's all in Gods hands. With him in my life I have no worries.
- I was so educated with my disease. I don't worry
- My health
- I don't have dental care, I didn't even know it was offered and I need it  
I saw a eye doctor but not through Ryan White, do you offer that too?
- Not having health Insurance, what would happen if I was hospitalized. Pay for HIV & other medication
- Have enough Health Insurance coverage  
Dental coverage
- Being able to afford my medication and continuing to work as to not lose my insurance
- Transportation
- Money to pay bills Need for legal help (credit union card stolen – took about \$1000.00 out of savings)
- I don't. I am a very positive person. I work full time, go to school fulltime, & have a wife and three wonderful children.
- I really need Dental care but can't receive it is the state of Virginia because Medicare will not cover Dental care. IT is needed badly, because I'm missing several teeth and it makes chewing food properly very hard. Thus it limits what I can eat which affects my trying to keep my weight up, where it needs to be very difficult. Thank you for any assistance.
- I don't worry at all I guss pray for myself and others
- Life how long
- Anyone in my Family contracting the HIV VIRUS
- Finances
- I was not eligible for Ryan White services. My biggest worry is trying to pay for these expensive drugs. Otripla cost more that \$1,200.00 for 30 pills. I need help when I get in the doughnut hole of my Rx drug insurance. There seems to be no help.
- Cost of insurances and medications.
- Since I am taking care of myself, taking my medicines daily as prescribed be the doctor, I don't need to worry. And I protect myself and my family as well. I very grateful for help I found and I know scientist are working hard to find definitely a cure for trhis disease. It might take some more years, but I very confident.
- Loseing my services or doctors care for HIV and have such wonderful people help me in every way possible or not being able to get my medicines to keep my healthy. People have really helped me in every way then could at Centra Health and Ryan White.
- Whats going to happen when the money runout, whats going to happen when I no longer can take care of myself? Will someone come to my house.
- Contracting AIDS
- Finances
- If I lost my job I wouldn't have medical insurance
- I won't be financially able to have my medication  
eating the right foods
- Becoming ill longterm – and losing my job & ins. After my disability ends – not being able to pay my bills
- Financial Stability

- Nothing
- I try not to worry about too much, that alone can cause a down fall in your health. Any question I may need to be answered I ask my Doctor/Nurses promptly.
- Being financial disabled/ Getting to my appts insurance medical
- My Health Girl friend our Kids Not having money  
Not being able to maintain monthly living expenses due to illness. If I had to go to the hospital and not being able to pay bills. Doctors prescribing medication that my not be covered under Ryan White.
- I don not worry about anything.
- My Income level, How to support myself alone if I had too.
- Loosing funding for help
- Death!
- Doctors care and paying for doctor visits, tests, and buying herbs which have helped me but which I can no longer afford
- Personal safety when I am out on the streets as I am now too weak to defend myself.
- Housing and the potential of becoming homeless.
- Just making sure all medical needs are meet and medicine is available
- People finding out, and when they do the way they treat me, Bills, family, if I die where will my child go
- I do not worry about things now as much as I used too. I did wonder at first what my happen to me when this was discovered but the Ryan White Program has meet my needs greatly and I am thankful to each & every one who has a part in it. If it were not for the help I receive I couldn't take medicine for HIV & also lab care, Dr., dentist, day care. I thank the Lord each day for your help and that I am still able to do what I've always done. God is so good to me and I pray dalily for your people. My life is in His Hand's too. Thanks.
- My T cell count
- My health – more Complications with my health
- No way of calling for medical appt. or help getting a phone. Transportation. Housing.
- I used to worry a lot about death, but I'm not concerned as much now. Hey, we all have to go sooner or later.
- I worry about finances
- I'm concerned about food sometimes
- I'm not able to get a car like I use too. That really bothers
- How my medication affects me at times by being emotional, and angry, depressed
- About my health
- I am most concerned about my children when my illness declines.
- When I'm going to die. Keeping my home
- Getting to my appointment
- I worry most about being able to get the meds and health services and paying my personal expenses home clothes etc... on a limited income. The government seems to keep changing the way it provides assistance that causes a lot of stress. So I would say finances cause the most stress. My Doctors and nurses and case manager have all educated me about this chronic manageable Disease but the \$ problems persist.
- My family – my wife my children my parents my sisters and family my brothers family

### Ryan White survey respondents would like to say:

- My numbers are currently very uplifting. My last report wicH 9-01-07 was undetectable. My Doctor is Dr. Stanley at Bristol Memorial Hospital.
- The Ryan White foundation has helped me greatly. May God Bless You All Thank you!!!!!!
- So far I'm undetected for more than 2 yrs Thank God.
- I was on the Ryan White in a different state and when I came here no one knew what I was talking about. No one had heard of the "Ryan White Foundation" I was sent to internal medicine that just happened to be the foundation
- it was very frustrating to be so sick and needing help but no one in the medical field knew what to do with me.
- THERE ARE NO SERVICES IN THIS AREA. AND NOT ENOUGH ROOM TO PUT ON PAPER HELP THAT IS NEEDED IN VIRGINIA PEOPLE WITH HIV/AIDS ARE Forgotten, Discriminated against, ....."
- My COBRA runs out in 3 months. At that time I will hav NO medical insurance coverage or drug coverage or dental coverage. (which I don't have dental coverage currently). I pay \$448.00 per from my Disability monthly for COBRA coverage.
- Although, I work and have private insurance, the cost of HIV treatment is expensive and I have difficulty with that and I presently make too much money for this program. I live in the Washington DC area, but I'm staying with my sister. I'm still working status, I started work last month. I would like to see financial assistance for someone like me. The high cost of living in a major city but with treatment of my drug regime. It's hare to survive financially.
- Other that the fact I'm in dire need of Dental care and can't receive it in Va. If it is available here I haven't been able to find out where. If you have any information of this please let me know where. It would be greatly appreciated. Thank you.
- No not at the moment
- Keep up the good work!!
- need help paying \$3850.00 when you in the doughnut hole on your medicare Rx Plan. It doesn't make any difference how much you make. I am retired and on a fixed income and this big payment for drugs disrups your standard of living. I gave all my life while I worked and now I need help and can't get it.
- Please do not send this survey in the mail. Other people opens my mail sometimes. I want complete confidentiality on my condition.
- I am also infected with Chronic Hep B and Need Assistance Paying for Treatment.
- I would like to speak to someone 1 on 1
- Thank you!
- It is important for people living with HIV/AIDS to know that if they are trying to ..... There is a super system in place. No one wants to feel that ..... is in vain. It is hard to face society with all it's judgements and ridicule because of the ..... HIV/AIDS ..... knowing that you .....
- *This entry goes on much longer, but many words are undecipherable.*
- If I could get some help financial with my rent my new contact # is (434) 706-1600
- In the last two years my caseworker at P.A.T.H. was overburdened with her case load. Now that she has left and been replaced with two people, services are improving.
- For 17 months the doctor I was forced to see was terrible! From my first appointment he was condescending, arrogant, and clearly did not have any care about my health. The more sick I became the less he was. It was a nightmare but I had no other options in my area. Now I am going to Duke University Medical Center and slowly I am getting Better. P.A.T.H.S. should attempt to find other infectious disease doctors than this group.
- The Support group which the 2 new caseworkers have succeeded in getting up and going. I think is Very important!

- Thank you so much for all the help and support that is given. Without the help this would be a hard illness to deal with. Whatever I need, whatever help I get it is greatly appreciated. God bless you, and thank you again.
- Yes, I have several concerns. During this summer, my utilities were disconnected. I contacted someone from HOPWA to get help to get my utilities restored. Mrs. Anjanette Barley explained to me that she couldn't help me. I asked her were there someone else whom I could talk to. Mrs. Barley placed me on hold. She connected me to someone from Pittsylvania Community Action service. The lady from that program said my name. Mrs. Barley had had disclosed my identity to o someone who wasn't employed by HOPWA. I am very outraged by this. No, I don't trust anyone with regards for these programs. Yes, I live in a small town where people are still ignorant about HIV/AIDS. I did not appreciate what Mrs. Barley did.
- Patients are made appointment for various reason. Under the assumption that because someone from your agency make us there appoint. We are under the impression that these Dr. Appointments are being paid for my Ryan White. The patients are left and stuck with hospital/Doctor bills.
- I don't feel I need someone that since I don't accept Jesus as my Savior that that's why I have so many problems. People should be free to choose their religious preference.
- Patients need a specified list of services of what is and what is available. Why is that the people who write these grants or what have are so short sighted about the help and growing concern of people with HIV and aids.
- I think, that the "Family medical leave act" is a crying shame, for anyone, with a serious health Condition, that is forced to work and try to take care of there health also.
- I was just fired from my job, for I was out sick, with a doctors note, and because I only work'd part-time, I was not eligible for the "FMLA", due to the lack of 1250 hrs that are required. After 3 years of employment with this hospital, and them knowing of my "HIV" I was terminated, and in my termination papers, stating that the reason of termination, is due to my Call-Outs in the past 11-months (w/ doctors note everytime I got sick and call'd out) Then, my employer (Danville Regional Hospital) puts in my termination papers, that I'am not to associate with any employee at DRMC unless, I go through Human Rescources. I can not longer go there for medical treatment, unless I call Human Resourses? I was terminated for my health condition and now treated like if I'am a Criminal – and no help to be found – legal or not
- I think it may be helpful or even life saving to have something set up to help people with very low income get a phone in case of medical emergency.
- I wish the government would make these life Ins. Cos. Accept HIV patients.
- I wish the city I live in wasn't so close & narrowed minded. Quick to talk about you. I get so tired of hearing that.
- THERE IS A CURE FOR HIV/AIDS IT IS CALLED JESUS
- I have been healed – I wish there was a test to prove it
- Been undetectable for 4 YEARS!
- Because of losing my SSDI coverage in 2006, Food, Rent, Utilities, care management. Not being able to find work or assistance I don't eat regular meals. Case Management in the New River Valley is limited and can't provide for all my needs. Mental Health services are limited and the cost without insurance is hard to keep up with. I feel if possible moving to Roanoke would make my availably to services better, I've learned so much about what services are available and how they work, by trial and error! I wish there was an support group in Christiansburg/Blacksburt area so I would have better active support.
- I need help with paying my rent every month.
- Would like to contribute more to Society in regards be able to work a little but not loose Disability/Medicare most of all which is the only insurance I have. Don't want to be a burden on anyone and always wanted to pull my own weight. Would also like to see the state use more of us who are HIV to be involved in Preventive Services and education maybe in the School System or other ways

- I would like to have my .....
- I would like to get my status changed

## **Concluding Statements**

### **Educated, Middle-Aged, Poor with No Health Insurance**

Ryan White clients in Southwest Virginia are a majority white population. Nearly half of the population falls with the 40-49 age bracket. These clients are well educated with 48.1% reporting a college degree or some college education. Despite the relatively high levels of educational attainment, 44.4% reported annual household income levels of \$10,000 or less and 79.5% of all respondents had income levels of less than \$20,000 thus placing them at or below current levels of poverty. Nearly 14% of Ryan White clients were unemployed either waiting for disability or looking for work and 47.2% reported disability as their only source of income. Adding to the dire financial picture painted by the data, 22.7% of current Ryan White clients reported having no health insurance at all.

### **Method of Transmission**

Of those surveyed, 41.7% have been diagnosed by a doctor as having AIDS. Not surprisingly, sex was reported by 68.3% of respondents as the method of transmission with 63.4% indicating sex with men and 15.3% reporting sex with women.

### **Getting Care Sooner**

One out of five (20.4%) surveyed wait more than a year to get medical care after they have tested positive by their doctors. Additionally, 10.2% are still not receiving services. The data indicate that the major reasons for this delay in seeking care was 1) a lack of knowledge that early care was critical, 2) being afraid, and; 3) knowing where to go. This suggests that more emphasis needs to be placed on public awareness regarding HIV and AIDS underscoring the medical advances that have made regarding treatment. It also indicates that case managers and others are not providing basic needed information to their clients.

### **Those Who Do and Those Who Don't**

The good news found in the data is that the vast majority (78.7%) of those living with HIV and AIDS are receiving medical services. They indicate that they see their doctors on a regular basis with 82% visiting medical practitioners 3 or more times in the past year. Still, the data indicate that 4.2% did not visit their doctor in the past 12 months citing a lack of transportation (17.1%) as the major reason. Overall, respondents were positive about their current health status with 82.6% reporting their general health as the same or better than it was one year ago.

### **Mental Health Services**

Unfortunately clients surveyed are not doing well when it comes to mental health with nearly one in four (23.6%) indicating that their mental health was worse now than it was the previous year.

### **Doctors get Good Report Cards**

Those surveyed overwhelmingly indicate (92.1%) that it is easy to talk with their doctors about HIV. They told us that their doctors/nurse practitioners were their primary source of information (78.7%), that the practitioners explain things clearly (79.2%) and that they receive HIV prevention information (92.1%) as well.

### **Services Rendered**

Given the high ratings of doctors/nurse practitioners it is not surprising that respondents indicated as most important (88.9%) their visits to the doctors office and lab tests that they receive. Next in line of importance (69.4%) was HIV related drug assistance with dental care and case management falling third and fourth on the list of important services. What is surprising, given the mental health need found earlier in the report, is that mental health counseling fell next to last in terms of important services. At the bottom of the value chain was transportation to care appointments. That transportation fell to the bottom of important services is also surprising given the general economic status of Ryan White Clients and the lack of public transportation in much of rural Southwest Virginia.

### **More Financial Assistance Needed**

The dire economic status of Ryan White clients is seen in response regarding “most important services not currently provided.” All three priorities center on financial concerns with 42% of respondents asking for help with paying insurance premiums, emergency financial assistance (39%), and; housing services (26.4%).

### **Health Care Services**

In all areas of HIV health care services queried more clients indicated that they received the services needed than indicated they did not receive the services they needed. Overall in terms of Health Care Services there seems to be more satisfaction than dissatisfaction. However, data indicate additional HIV Health Care Services are needed by clients for dental care (71.3%), eye care (61.6%), getting help with insurance premiums (44.5%), and; seeing mental health counselors (37.5%).

### **Support Services**

Again, in the area of support services, in all areas queried more respondents indicated that their needs were being met than indicated their needs were not being met. These data reinforce the conclusion that the Ryan White Program in Southwest Virginia is performing well. In terms of additional support needed, respondents indicated getting food and legal assistance to be the two greatest areas of need.

### **Other Services Needed**

In all areas queried for Other Services Needed, more clients indicated their needs were being met than indicated their needs were not being met. Even though there is more satisfaction than not, clients surveyed indicated they needed additional help, primarily in areas related to money. Assistance with paying for utilities, assistance with food stamps, getting help with food and emergency payments for housing were chief among these areas of financial assistance needs.

### **Barriers**

The list of barriers to receiving care is extensive. The chart on page 29 of this report bears some study. Surprisingly, the greatest barrier to receiving care is listed as knowing where to go for services. This indicates that more effort needs to be placed on public awareness and communication with potential and existing clients. More importantly it indicates that case managers are not providing the information needed by their clients. Also surprising, given the relatively low levels of income reported is that respondents indicated “too much income to qualify for services” as a barrier. Finally, transportation falls into a relatively high level in the barriers to receiving care section of the survey. Yet, transportation fell to the bottom of the list when respondents were asked what they considered to be the most important areas of services received.

## **Summary**

Overall, the 2007 Ryan White Client Needs Survey indicates that clients are pleased with the services they are provide and that these services result in more needs being met than not. Areas of need that consistently show are financial in nature and may be a reflection of the relatively low levels of annual income reported by the respondents. Finally, more attention needs to be given to removing the barrier of “Not knowing where to go for services.”



# Appendix

## Appendix A – 2007 Ryan White Needs Survey

Have you answered this survey in the last 2 months?	<input type="checkbox"/> Yes	<input type="checkbox"/> No	<i>If yes, STOP! Do NOT continue.</i>					
What is the zip code where you live?	Zip Code:							
What is your birth date?	Day:		Month:		Year:			
Are you currently enrolled in Ryan White Services?	<input type="checkbox"/> Yes	<input type="checkbox"/> No	<input type="checkbox"/> Don't Know					
Are you currently receiving any HIV services?	<input type="checkbox"/> Yes	<input type="checkbox"/> No	<input type="checkbox"/> Don't Know					

HEALTH INFORMATION								
1. When did you first test positive for HIV?	Month:				Year:			
2. How do you think you got HIV? (Check all that apply)	<input type="checkbox"/> Having sex with men <input type="checkbox"/> Having sex with women <input type="checkbox"/> Sharing needles or works <input type="checkbox"/> Born with HIV <input type="checkbox"/> Occupational exposure <input type="checkbox"/> Blood products or transfusion <input type="checkbox"/> Don't know							
3. Have you ever had any symptoms because of HIV?	<input type="checkbox"/> Yes	<input type="checkbox"/> No	<input type="checkbox"/> Don't Know					
4. Are you currently on drugs to treat HIV?	<input type="checkbox"/> Yes	<input type="checkbox"/> No	<input type="checkbox"/> Don't Know					
5. Has a doctor ever diagnosed you with AIDS?	<input type="checkbox"/> Yes	<input type="checkbox"/> No	<input type="checkbox"/> Don't Know					
7. How long after testing positive did you start getting HIV services?	<input type="checkbox"/> Within a month <input type="checkbox"/> 1-6 months <input type="checkbox"/> More than 6 months <input type="checkbox"/> More than 1 year							
8. What would have helped you get HIV care sooner after testing? (Check all that apply)	<input type="checkbox"/> Nothing – I got help right away <input type="checkbox"/> Knowing how important early care was for my health <input type="checkbox"/> Not having to take care of family/other people <input type="checkbox"/> Knowing who to call/where to go <input type="checkbox"/> Not using drugs/alcohol <input type="checkbox"/> Not being so afraid <input type="checkbox"/> Other (specify)							
9. In the last year, how often did you see your doctor about HIV?	<input type="checkbox"/> Never <input type="checkbox"/> 1-2 times <input type="checkbox"/> 3-4 times <input type="checkbox"/> More than 4 times							
10. If you have not seen a doctor in the last year, why not?	<input type="checkbox"/> I do not feel sick <input type="checkbox"/> I do not have transportation <input type="checkbox"/> I do not have childcare <input type="checkbox"/> I do not trust them <input type="checkbox"/> They are not available <input type="checkbox"/> Other (Specify)							
11. Who gave you the MOST information about HIV treatment?	<input type="checkbox"/> Doctor/Nurse Practitioner <input type="checkbox"/> Nurse/Other Healthcare Worker <input type="checkbox"/> Case Manager/Social Worker <input type="checkbox"/> Friend(s) <input type="checkbox"/> Support groups <input type="checkbox"/> Newspapers/books <input type="checkbox"/> The Internet <input type="checkbox"/> Other (specify):							
12. When you see your case manager, does he/she explain things clearly?	<input type="checkbox"/> Yes	<input type="checkbox"/> No						
13. When you see your doctor, does he/she explain things clearly?	<input type="checkbox"/> Yes	<input type="checkbox"/> No						

14. When you go to the doctor for HIV care, has anyone ever talked to you about HIV prevention?	<input type="checkbox"/> Yes	<input type="checkbox"/> No	
15. Is it easy for you to talk with your doctors about your HIV treatment?	<input type="checkbox"/> Yes	<input type="checkbox"/> No	
16. Do you know what happens if you miss doses of HIV drugs?	<input type="checkbox"/> Yes	<input type="checkbox"/> No	
17. How is your physical health compared to a year ago?	<input type="checkbox"/> Worse	<input type="checkbox"/> Same	<input type="checkbox"/> Better
18. How is your mental health compared to a year ago?	<input type="checkbox"/> Worse	<input type="checkbox"/> Same	<input type="checkbox"/> Better
19. In the last year, how many times have you gone to the emergency room <b>BECAUSE OF HIV</b> , including follow up visits?	<input type="checkbox"/> None	<input type="checkbox"/> 1-2	<input type="checkbox"/> More than 2

20. Of the Ryan White services currently offered in southwest Virginia, what are the 3 most important to you?	<input type="checkbox"/> Doctor visits & lab tests <input type="checkbox"/> HIV related drug assistance <input type="checkbox"/> Dental care <input type="checkbox"/> Mental health counseling <input type="checkbox"/> Case management <input type="checkbox"/> Transportation to care appointments
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21. Of the Ryan White services NOT currently offered in southwest Virginia, what are the 3 most important services to you?	<input type="checkbox"/> Early intervention services <input type="checkbox"/> Help paying for health insurance premiums <input type="checkbox"/> Home Health Care <input type="checkbox"/> In Home nursing care/medical equipment <input type="checkbox"/> Hospice services <input type="checkbox"/> Dietician/Nutrition therapy <input type="checkbox"/> Outpatient substance abuse services <input type="checkbox"/> Child care services during care appointments <input type="checkbox"/> Children's HIV care services <input type="checkbox"/> Emergency financial assistance <input type="checkbox"/> Food bank/home-delivered meals <input type="checkbox"/> HIV prevention education (for positives) <input type="checkbox"/> Housing services <input type="checkbox"/> Legal services <input type="checkbox"/> Translation services. <input type="checkbox"/> Outreach services <input type="checkbox"/> Permanency planning <input type="checkbox"/> Support groups/Pastoral care <input type="checkbox"/> Information and referral to services <input type="checkbox"/> Rehabilitation services <input type="checkbox"/> Respite care <input type="checkbox"/> Treatment adherence counseling <input type="checkbox"/> Other (specify):
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22. What do you worry about the most? (You may continue on the last page if needed)
_____
_____
_____
_____
_____
_____
_____
_____
_____

<b>Healthcare Services: Tell us about your HIV healthcare service needs.</b>			
<b>In the last year did you <u>NEED</u> to...</b>	<b>Did not need</b>	<b>Needed &amp; received</b>	<b>Needed &amp; DID NOT receive</b>
23. See a doctor or a specialist	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
24. Get laboratory or other diagnostic tests	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
25. See an eye doctor	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
26. Get help paying for drugs	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
27. See a dentist	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
28. See a mental health counselor	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
29. Get help with health insurance premiums	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
30. Get in home care	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
31. Get home medical or health supplies	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
32. See a physical therapist	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
33. See a rehabilitation therapist	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
34. Talk to a nutritionist/dietician	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
35. Children's HIV care	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
36. Stay in a nursing home	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
37. Enroll in hospice care	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

<b>Support Services: Tell us about your HIV support service needs.</b>			
<b>In the last year did you <u>NEED</u> to...</b>	<b>Did not need</b>	<b>Needed &amp; received</b>	<b>Needed &amp; DID NOT receive</b>
38. See a case manager	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
39. Talk to an HIV+ peer advocate	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
40. Get legal assistance or advice	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
41. Attend a support group	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
42. Spiritual counseling or support	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
43. Grief counseling	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
44. Get education about HIV treatments	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
45. Get help taking my HIV drugs	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
46. Get help with translation/interpreting	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
47. Get education non-medical HIV services	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
48. Get food	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
49. Get childcare	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
50. Transportation to medical appointments	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Other Services:			
In the last year did you <b>NEED</b> to...	Did not need	Needed & received	Needed & DID NOT receive
51. Get help applying for disability	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
52. Get help applying for Medicaid	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
53. Get help applying for Medicare	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
54. Get help applying for a Medicare drug plan	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
55. Get help applying for Food Stamps	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
56. Get help with private insurance	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
57. Get emergency food	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
58. Get emergency payments for housing	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
50. Get short term housing assistance	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
60. Get help with paying utilities	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
61. Get clothing	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
62. Get financial counseling	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
63. Get help with housework or cooking	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
64. Volunteer companion (buddy)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
65. Get information on alternative medicine (herbs)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
66. Get domestic violence services	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
67. Get help taking care of a pet	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
68. Get employment training and/or counseling	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Barriers to care:		
69. During the past year, have you had difficulty getting HIV services for any of the following reasons?		
A. The cost of drugs or services	<input type="checkbox"/> Yes	<input type="checkbox"/> No
B. Waiting list for services	<input type="checkbox"/> Yes	<input type="checkbox"/> No
C. Long wait to be seen at office or clinic	<input type="checkbox"/> Yes	<input type="checkbox"/> No
D. Lack of transportation	<input type="checkbox"/> Yes	<input type="checkbox"/> No
E. Lack of childcare	<input type="checkbox"/> Yes	<input type="checkbox"/> No
F. Language barrier	<input type="checkbox"/> Yes	<input type="checkbox"/> No
G. Lack of trust that my care would be confidential	<input type="checkbox"/> Yes	<input type="checkbox"/> No
H. Fear of disclosing HIV status	<input type="checkbox"/> Yes	<input type="checkbox"/> No
I. Services not available	<input type="checkbox"/> Yes	<input type="checkbox"/> No
J. Did not qualify financially	<input type="checkbox"/> Yes	<input type="checkbox"/> No
K. Discrimination because of gender (male/female)	<input type="checkbox"/> Yes	<input type="checkbox"/> No
L. Discrimination because of sexual orientation (Gay/lesbian/bisexual)	<input type="checkbox"/> Yes	<input type="checkbox"/> No
M. Discrimination because of sexual identity (transgender)	<input type="checkbox"/> Yes	<input type="checkbox"/> No
N. Discrimination because of Race	<input type="checkbox"/> Yes	<input type="checkbox"/> No
O. Did not know where to go for services	<input type="checkbox"/> Yes	<input type="checkbox"/> No

DEMOGRAPHIC INFORMATION			
70. What is your racial or ethnic background?	<input type="checkbox"/> African-American/Black <input type="checkbox"/> Caucasian/White <input type="checkbox"/> Asian/Pacific Islander <input type="checkbox"/> Native American/Native Alaskan <input type="checkbox"/> Other (specify):		
71. Is your ethnic background Latino/Hispanic?	<input type="checkbox"/> Yes <input type="checkbox"/> No		
72. What is your native language?	<input type="checkbox"/> English <input type="checkbox"/> Spanish <input type="checkbox"/> American Sign Language <input type="checkbox"/> Other (specify):		
73. What is your gender?	<input type="checkbox"/> Male <input type="checkbox"/> Female <input type="checkbox"/> Transgendered Male to Female <input type="checkbox"/> Transgendered Female to Male		
74. How much education do you have?	<input type="checkbox"/> Less than 12 <sup>th</sup> grade <input type="checkbox"/> High school diploma/GED <input type="checkbox"/> Some college <input type="checkbox"/> Undergraduate degree <input type="checkbox"/> Postgraduate school/degree		
75. Are you...	<input type="checkbox"/> Employed full time <input type="checkbox"/> Employed part time <input type="checkbox"/> Unemployed looking for work <input type="checkbox"/> Unemployed waiting on disability <input type="checkbox"/> On disability <input type="checkbox"/> Retired <input type="checkbox"/> Other (specify):		
76. What is your household size (including only legally married spouse, and dependent children/adults)?	Adults:		Children:
77. What is your household income (including only legally married spouse, and dependent children/adults)?	<input type="checkbox"/> Less than \$10,000 <input type="checkbox"/> \$10,001 to \$20,000 <input type="checkbox"/> \$20,001 to \$30,000 <input type="checkbox"/> \$30,001 to \$50,000 <input type="checkbox"/> \$50,000 and above		
78. What type of health insurance do you have?	<input type="checkbox"/> None <input type="checkbox"/> Medicaid <input type="checkbox"/> Medicare <input type="checkbox"/> Medicaid + Medicare <input type="checkbox"/> Medicare + Supplemental <input type="checkbox"/> Veterans <input type="checkbox"/> Private insurance		
79. Is there anything else that you would like to tell us?	<hr/> <hr/> <hr/> <hr/> <hr/>		
Thank you very much! If you have any questions about this survey, please contact Council of Community Services, (800) 354-3388/ (540) 985-0131.			

**Appendix B- Supplemental Information for Health Care Support Graph pg. 26**

<b>Health Care Support</b>	<b>Need*</b>	<b>Unmet Need (# of clients reporting)</b>
See a Doctor or a Specialist	78.3% [169]	9
Laboratory tests related to HIV	84.7% [183]	6
Eye care	61.6% [133]	51
Help paying for medications	67.9% [133]	51
Dental care	71.3% [154]	59
See a Mental Health Counselor	37.5% [81]	31
Get Help with Insurance Premiums	44.5% [96]	38
Home health care	9.3% [20]	9
Home medical and health supplies	15.8% [34]	9
Physical therapy	13.9% [30]	11
Other rehabilitative therapy	8.8% [19]	6
Advice on nutrition/healthy eating	33.3% [72]	16
Children's HIV care	4.2% [9]	4
Stay in a Nursing Home	2.3% [5]	2
Enroll in Hospice Care	1.8% [4]	2

**Appendix C- Supplemental Information for Support Services Graph pg. 27**

<b>Support Services</b>	<b>Need*</b>	<b>Unmet Need (# of clients reporting)</b>
Case management	52.8% [114]	20
An advocate (peer, lawyer)	27.3% [59]	29
Legal assistance or advice	28.7% [62]	43
Support groups	29.6% [64]	41
Spiritual counseling/support	26.9% [58]	27
Grief counseling	14.2% [14]	7
Education about HIV Treatments	33.8% [73]	13
Help taking my HIV Drugs	19.0% [41]	2
Help with translations/interpreting	2.0% [2]	1
Get education/non-medical HIV Serv	23.6% [51]	28
Get Food	34.7% [75]	45
Get Childcare	2.3% [5]	3
Get Transportation to Medical Apts	28.7% [62]	19



**Appendix D- Supplemental Information for Other Services Graph on pg. 28**

<b>Other Services</b>	<b>Need*</b>		<b>Unmet Need (# of clients reporting)</b>
Help applying for Food Stamps	29.7%	[64]	28
Help with Private Insurance	24.1%	[52]	40
Get Emergency Food	28.7%	[62]	42
Emergency payments for housing	26.4%	[57]	40
Short Term Housing Assistance	22.6%	[49]	34
Assistance with paying Utilities	35.2%	[76]	46
Clothing	14.8%	[32]	22
Financial Counseling	15.7%	[34]	27
Household helpers	9.7%	[21]	13
Volunteer companion (buddy)	12.9%	[28]	23
Information about Alternative Meds	18.6%	[40]	36
Domestic Violence Services	4.2%	[9]	6
Pet care	6.5%	[14]	8
Employment training/counseling	19.4%	[9]	6

**2007 Ryan White  
Subcontractors Survey**

## Process and Methodology

The Southwest/Piedmont HIV Care Consortium contracted with the Planning and Consultation Division of the Council of Community Services in 2007 to conduct and analyze the HIV Care Consortium Survey of Needs. The process began with the design of a survey to gather data regarding HIV services that subcontractors of HIV services believe to be important.

The 2007 Southwest/Piedmont HIV Care Consortium Survey of Needs was created and distributed to the seven subcontractors of the Southwest/Piedmont HIV Care Consortium in November of 2007. All seven surveys were completed and returned for a 100% return rate via email to the Council of Community Services.

The following report is broken into four sections following the format of the survey itself:

Section One	Ranking of Services
Section Two	Services Not Offered
Section Three	If Funds were available
Section Four	Comments on Other Barriers to Services

### Section One

The following services were given in a list and the subcontractors were asked to rank in order of importance with one being the most important and twenty-eight being the least important.

#### Results for Priority of Services:

<b>Ranking</b>	<b>Service</b>
1	AIDS pharmaceutical assistance (local)
2	Case management, medical (including treatment adherence)
3	Case management, non-medical
4	Oral health care
5	Mental health services
6	Outpatient /Ambulatory health services
7	Medical transportation services
8	Health insurance premium & cost sharing assistance
9	Treatment adherence counseling
10	Emergency financial assistance
11	Housing services
12	Substance abuse services–outpatient
13	Referral for health care/supportive services
14	Health education/risk reduction
15	Medical nutrition therapy
16	Psychosocial support services
17	Food bank/home-delivered meals
18	Outreach services
19	Substance abuse services – residential
20	Home and community-based health services
21	Early intervention services
22	Legal services
23	Rehabilitation services

24	Linguistics services
25	Home health care
26	Hospice services
27	Respite care
28	Child care services

**Points of Interest Regarding Ranking**

- Subcontractors ranked existing Ryan White Services as top seven most important
- Subcontractors and clients agree in ranking services
  - Pharmaceutical assistance (HIV related drug assistance for clients) ran # 1 for subcontractors and #2 for clients
  - Oral health (Dental Care for clients) ranked 3 for clients and 4 for subcontractors
  - Case management ranked #4 for clients and 2<sup>nd</sup> and third for subcontractors
  - Transportation also placed high in importance for both clients and subcontractors
- Contractors and clients agree that of the services not offered the following rank as most important:
  - Help paying for insurance premiums
  - Emergency financial assistance
  - Housing Services
- Treatment adherence counseling was the only service where disagreement appeared where contractors ranked it 9<sup>th</sup> most important and clients ranked it 14<sup>th</sup> in conjunction with 14<sup>th</sup> ranked in-home nursing care/medical equipment and out-patient substance abuse services.

## Section Two

The seven [7] subcontractors were asked- Of the services not offered during 2007-2008, which best describes how you would offer the service if funds were available during 2008-2009? The options for each subcontractor to choose from were 1) provide service 2) Provide referrals only to another Ryan White subcontractor 3) Provide referrals only-another Non-Ryan White program or 4) Service not available, will not/can not provide service. If an option was not chosen by the survey respondents then it is not represented in the tables below.

### Results

<b>Child Care Services</b>	
Provide Referrals only-another Non-RW program	3
Service not available, will not/can not provide service	3
Missing in the System	1
Total	7

<b>Early Intervention Services</b>	
Provide Service	3
Provide Referrals only-another Non-RW program	3
Missing in the System	1
Total	7

<b>Emergency Financial Assistance</b>	
Provide Service	1
Provide Referrals only to another RW subcontractor	2
Provide Referrals only- another Non-RW program	4
Total	7

<b>Food Bank/Home-Delivered Meals</b>	
Provide Service	1
Provide Referrals only to another RW subcontractor	2
Provide Referrals only-another Non-RW program	4
Total	7

<b>Health Education/Risk Reduction</b>	
Provide Service	5
Provide Referrals only to another RW subcontractor	1
Missing in the System	1
Total	7

<b>Health Insurance Premium &amp; Cost Sharing Assistance</b>	
Provide Service	4
Provide Referrals only to another RW subcontractor	1
Provide Referrals only-another Non-RW program	1
Missing in the System	1
Total	7

<b>Home Health Care</b>	
Provide Referrals only-another Non-RW program	6
Service not available, will not/can not provide service	1
Total	7

<b>Home and Community-Based Health Services</b>	
Provide Service	1
Provide Referrals only to another RW subcontractor	5
Missing in the System	1
Total	7

<b>Hospice Services</b>	
Provide Referrals only-another Non-RW program	6
Service not available, will not/can not provide service	1
Total	7

<b>Housing Services</b>	
Provide Service	3
Provide Referrals only to another RW subcontractor	1
Provide Referrals only-another Non-RW program	3
Total	7

<b>Legal Services</b>	
Provide Referrals only to another RW subcontractor	1
Provide Referrals only-another Non-RW program	6
Total	7

<b>Linguistic Services</b>	
Provide Service	4
Provide Referrals only-another Non-RW program	3
Total	7

<b>Medical Nutrition Therapy</b>	
Provide Service	3
Provide Referrals only to another RW subcontractor	2
Provide Referrals only-another Non-RW program	1
Missing in the System	1
Total	7

<b>Outreach Services</b>	
Provide Service	3
Provide Referrals only-another Non-RW program	2
Service not available, will not/can not provide service	1
Missing in the System	1
Total	7

<b>Psychosocial Support Services</b>	
Provide Service	2
Provide Referrals only to another RW subcontractor	2
Provide Referrals only-another Non-RW program	3
Total	7

<b>Referral for Health Care/Supportive Services</b>	
Provide Service	5
Provide Referrals only to another RW subcontractor	1
Provide Referrals only-another Non-RW program	1
Total	7

<b>Rehabilitation Services</b>	
Provide Referrals only to another RW subcontractor	1
Provide Referrals only-another Non-RW program	6
Total	7

<b>Respite Care</b>	
Provide Referrals only to another RW subcontractor	1
Provide Referrals only-another Non-RW program	5
Service not available, will not/can not provide service	1
Total	7

<b>Substance Abuse Services-Residential</b>	
Provide Referrals only-another Non-RW program	4
Service not available, will not/can not provide service	1
Missing in the System	2
Total	7

<b>Substance Abuse Services-Outpatient</b>	
Provide Referrals only-another Non-RW program	4
Missing in the System	3
Total	7

<b>Treatment Adherence Counseling</b>	
Provide Service	3
Provide Referrals only-another Non-RW program	2
Missing in the System	2
Total	7

### Summary Chart

Of services not offered which best describes how you would offer the service if funds were available?				
	Provide Service W/RW	Referral to other RW	Referral to other non RW	Will/can not provide Service
Child Care Services	0	3	0	3
Early Intervention Services	3	0	3	0
Emergency Financial Assistance	1	2	4	0
Food Bank/Home-Delivered Meals	1	2	4	0
Health Education/Risk Reduction	5	1	0	0
Health Insurance Premium/Cost Sharing	4	1	1	0
Home/Community-Based Health Services	1	5	0	0
Home Health Care	0	0	6	1
Hospice Services	0	0	6	1
Housing Services	3	1	3	0
Legal Services	0	1	6	0
Linguistic Services	4	0	3	0
Medical Nutrition Therapy	3	2	1	0
Outreach Services	3	0	2	1
Psychosocial Support Services	2	2	3	0
Referral for Health Care/ Support Services	5	1	1	0
Rehabilitation Services	0	1	6	0
Respite Care	1	5	1	0
Substance Abuse Services-Residential	0	0	4	1
Substance Abuse Services-Outpatient	0	0	4	0
Treatment Adherence Counseling	3	0	2	0
<b>Total</b>	<b>38</b>	<b>23</b>	<b>64</b>	<b>8</b>

#### Points of Interest – Section Two

- Subcontractors would provide or refer most services if funding were available
- In areas of financial assistance, health insurance and housing assistance which were high priorities for clients, subcontractors would either provide the service or make referrals.
- There were only 8 areas of service that subcontractors would not provide or refer



## Section Three

Based on best estimations for service or sub-service contractors were asked whether clients have 1) received service through my Agency with RW funds 2) Received from another RW program referred by my agency 3) Received from another Non-RW program referred by my agency or 4) Requested but were unable to receive from any program.

### Results

<b>AIDS Pharmaceutical Assistance</b>	
Received service through my agency with RW funds	4
Missing in the System	3
Total	7

<b>Case Management, Medical (including treatment adherence)</b>	
Received service through my agency with RW funds	3
Received from another RW program referred by my agency	3
Missing in the System	1
Total	7

<b>Case Management, Non-Medical</b>	
Received service through my agency with RW funds	6
Missing in the System	1
Total	7

<b>Child Care Services</b>	
Received from another RW program referred by my agency	2
Requested but were unable to receive from any program	1
Missing in the System	4
Total	7

<b>Early Intervention Services</b>	
Received service through my agency with RW funds	1
Received from another Non-RW program referred by my agency	2
Missing in the System	4
Total	7

<b>Emergency Financial Assistance</b>	
Received from another Non-RW program referred by my agency	4
Missing in the System	3
Total	7

<b>Food Bank</b>	
Received from another Non-RW program referred by my agency	6
Missing in the System	1
Total	7

<b>Home-Delivered Meals</b>	
Received from another Non-RW program referred by my agency	2
Requested but were unable to receive from any program	3
Missing in the System	2
Total	7

<b>Food Vouchers</b>	
Received service through my agency with RW funds	1
Received from another Non-RW program referred by my agency	3
Missing in the System	3
Total	7

<b>Health Education/Risk Reduction</b>	
Received service through my agency with RW funds	4
Received from another Non-RW program referred by my agency	1
Missing in the System	2
Total	7

<b>Health Insurance Premium &amp; Cost Sharing Assistance</b>	
Received service through my agency with RW funds	4
Received from another Non-RW program referred by my agency	2
Missing in the System	1
Total	7

<b>Home and Community-Based Health Services</b>	
Received service through my agency with RW funds	1
Received from another Non-RW program referred by my agency	3
Requested but were unable to receive from any program	1
Missing in the System	2
Total	7

<b>Home Health Care</b>	
Received from another RW program referred by my agency	1
Received from another Non-RW program referred by my agency	2
Requested but were unable to receive from any program	2
Missing in the System	2
Total	7

<b>Hospice Services</b>	
Received from another Non-RW program referred by my agency	3
Requested but were unable to receive from any program	2
Missing in the System	2
Total	7

<b>Housing Services</b>	
Received from another RW program referred by my agency	1
Received from another Non-RW program referred by my agency	4
Missing in the System	2
Total	7

<b>Legal Services</b>	
Received from another Non-RW program referred by my agency	6
Missing in the System	1
Total	7

<b>Linguistic Services</b>	
Received service through my agency with RW funds	2
Received from another Non-RW program referred by my agency	1
Requested but were unable to receive from any program	1
Missing in the System	3
Total	7

<b>Dietician Services Out Side Primary Care</b>	
Received from another RW program referred by my agency	1
Received from another Non-RW program referred by my agency	1
Requested but were unable to receive from any program	2
Missing in the System	3
Total	7

<b>Nutritional Supplements</b>	
Received from another RW program referred by my agency	1
Received from another Non-RW program referred by my agency	3
Requested but were unable to receive from any program	1
Missing in the System	2
Total	7

<b>Mileage Based Transports</b>	
Received service through my agency with RW funds	4
Requested but were unable to receive from any program	1
Missing in the System	2
Total	7

<b>Taxi Based Transports</b>	
Received service through my agency with RW funds	2
Requested but were unable to receive from any program	3
Missing in the System	2
Total	7

<b>Bus Tickets/Passes</b>	
Received service through my agency with RW funds	1
Received from another Non-RW program referred by my agency	1
Requested but were unable to receive from any program	2
Missing in the System	3
Total	7

<b>Mental Health Services</b>	
Received service through my agency with RW funds	3
Received from another Non-RW program referred by my agency	3
Missing in the System	1
Total	7

<b>Oral Health Care</b>	
Received service through my agency with RW funds	4
Received from another RW program referred by my agency	1
Received from another Non-RW program referred by my agency	1
Missing in the System	1
Total	7

<b>Physician Visits and Specialty Care</b>	
Received service through my agency with RW funds	3
Received from another RW program referred by my agency	2
Received from another Non-RW program referred by my agency	1
Missing in the System	1
Total	7

<b>Laboratory and Diagnostic Services</b>	
Received service through my agency with RW funds	3
Received from another RW program referred by my agency	2
Received from another Non-RW program referred by my agency	1
Missing in the System	1
Total	7

<b>Outreach Services</b>	
Received from another Non-RW program referred by my agency	2
Requested but were unable to receive from any program	2
Missing in the System	3
Total	7

<b>Psychosocial Support Services</b>	
Received from another Non-RW program referred by my agency	6
Missing in the System	1
Total	7

<b>Referral for Health Care/Supportive Services</b>	
Received service through my agency with RW funds	3
Received from another Non-RW program referred by my agency	2
Missing in the System	2
Total	7

<b>Rehabilitation Services</b>	
Received from another Non-RW program referred by my agency	2
Requested but were unable to receive from any program	2
Missing in the System	3
Total	7

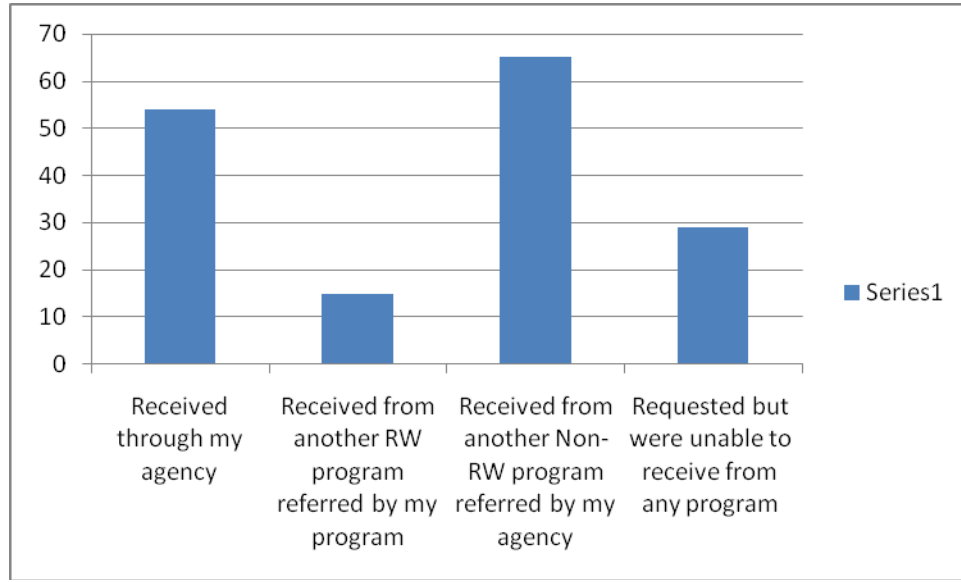
<b>Respite Care</b>	
Received from another Non-RW program referred by my agency	3
Requested but were unable to receive from any program	2
Missing in the System	2
Total	7

<b>Substance Abuse Services-Residential</b>	
Received from another Non-RW program referred by my agency	2
Requested but were unable to receive from any program	3
Missing in the System	2
Total	7

<b>Substance Abuse Services-Outpatient</b>	
Received service through my agency with RW funds	1
Received from another RW program referred by my agency	1
Received from another Non-RW program referred by my agency	2
Requested but were unable to receive from any program	1
Missing in the System	2
Total	7

<b>Treatment Adherence Counseling</b>	
Received service through my agency with RW funds	4
Missing in the System	3
Total	7

### Summary Chart



### Points of Interest Section Three

- More services (39.9%) are provided through referrals to non-Ryan White programs than any other category
- Subcontractors are managing services using both Ryan White programs and non-Ryan White programs – only 17.8% of services were not available from any source

## **Section Four: Comments on Barriers**

When the subcontractors were asked about any other barriers to providing services, they responded with:

- There are so few CBO's\* in the Danville area to refer clients for assistance with housing, utilities and employment issues. The lack of these available resources, often times create various inadequate medical follow-up. HIV meds often are contributors to poor dental hygiene more funds are needed for clients to receive adequate dental care. More funds are also needed to provide transportation for clients to dental appointments.

\*CBO-Community Based Organizations

- lack on-going support group in New River Valley  
housing is a major issue; funds are too limited to help with rent  
nutritional supplements would be helpful, i.e. Boost  
limited medical/mental health care providers  
distance to existing medical health care providers

- I have a rural area with very limited resources. It is hard to get companies to agree to wait 90 days for payment and that limits the providers that we have.
- Our clients not having transportation to and from any appointment is an issue because in order to provide transportation someone in our office must do the transport. If in the future we are unable to transport clients to non-related HIV appointments our client's will not be able to keep those appointments. This would include dental appointments, substance abuse treatment, eye care and intake appointments along with others.
- I have had a hard time completing this section. It seems to me that today we have issues that are related more to how we provide services and assist clients in receiving the medical and financial assistance they need. HIV/AIDS providers/grantees work harder and harder to produce measurable results, clients increasingly are complacent about participating in care yet complain when a service can't be provided, and grant paperwork and data requirements are getting more cumbersome every day.

Grant funding is a very necessary help for HIV/AIDS patients but is a double-edged sword for subcontractors. Limited staffing to handle the rising caseload strains the ability of our employees. We realize grants have more paperwork involved, but it is harder and harder to meet the demands of the clients, watch the budgets and stretch the dollars, but still effectively handle the paperwork/grant related requirements. Staff have to consider each patient's situation before offering referrals or scripts, things that clinical staff in other practices seldom have to concern themselves with. In Part B grant applications, reviewers criticize how much of our Part B funding goes into case management salaries, without considering the staff-to-patient ratios of our clinic versus others in our region. Today we have four persons in our clinic to provide services to nearly 300 persons (RW and private, Lynchburg and Danville). We have 2 employees funded through Part B, and one of those is seriously ill. There are no other grant funded employees. We have 2 employees to assist in granting writing, data management, and administration.

Clients are increasingly complacent about services, that is to say, our experience is that most do not want to participate in the planning or delivery of their care. We have tried many ways to involve clients, provide education to them, offer incentives like food or gift cards for completing appointments, plus solicit opinions about their care. We have maybe 12-15 clients at each education/advocacy meeting – less than 10% of the caseload. This is an added burden for clinical staff to try to involve clients in their own care. *Another* aspect of grant-related clinical care that other medical providers do not have to perform. If we provided pickup and delivery, we think more would attend. However, there is no funding for that.

An example of this complacency is trying to place and read TB tests. Although we have made efforts to increase TB testing as a part of the standard of care for HIV/AIDS patients, the patients apparently do not care if they receive this testing. We have dedicated days to offering nothing but TB clinics; few patients participate. We suspect that if we offered transport for patients to and from, it would improve the chances of more willing participants; however, we do not have the manpower nor the time to do this on an ongoing basis. This looks bad on peer reviews and data submission.

We constantly struggle with finding willing providers to see clients who need specialty care. Often we are asked to pay the fee 'up front' before the provider will see the client. This week we



had an ENT provider who refused to see an uninsured patient even though RW funds could pay for the care. It was subtly managed by saying there were no appointments available for months after learning of the patient's insurance status. Again, as medical providers, the onus is on us to get clients into care somewhere or even pay funds up front so that a client can be seen for evaluation. Smaller agencies simply cannot do this; hence there is an uneven access to care across the state and rural HIV clients in particular suffer this lack of access to care compared to their peers in larger cities/organizations.

How Part B funds are utilized varies from region to region. Programs in Tidewater and Richmond provide funding that the Southwest does not (such as durable medical equipment, nutritional supplements, sometimes better drug coverage or substance abuse services). Even subcontractors within a region disagree on what Part B funding provides to clients and, thus, a client in one city may receive copay assistance that a client 60 miles away does not. This is also true for clients moving to our region from larger metropolitan areas, who question why we do not provide a service they received it in another part of the state. They wonder why the care is not standardized, that is, the same range of services available in throughout the State.

I do not think any of our comments are new to those in the HIV/AIDS field and indeed common to most in the Southwest region. We earnestly feel that providing care to HIV/AIDS clients is a community benefit, something we ought to do, and we want to provide the best care possible. We struggle from lack of staffing, limited funds, client complacency, non-standardized levels of service often creating further disparities for our rural clients, provider prejudices/ dislike of Medicaid/Medicare reimbursement rates, organizational capacity to handle rising data and paperwork requirements, organizational lack of funds to provide 'up front' fees to other medical providers to get clients evaluated, piled on top of very complex medical management and care for a specialized infectious disease which shifts and evolves with changes in medications or knowledge of the disease.

Many clients have mental or substance abuse issues, societal/cultural issues or issues that complicate or hinder their treatment. We offer them treatment for mental/SA issues but few clients accept or finish the treatments. Medical providers are not able to change social or cultural issues surrounding clients in their communities. We can and do offer a high level of medical care. At times we despair of making a dent in the AIDS pandemic because we are realizing medical providers can only offer care to the client. More help is needed from other community, cultural, and societal issues in order to change the course of AIDS. We can make access to care available – and we do – but we can't make the clients accept it.

Barriers, then, are: Complacency or disinterested clients, uneven access to care, limited funding for staffing, lack of referral providers, provider restrictions on accepting Medicaid/Medicare clients, rising caseloads that tax the capacity of our medical providers, and the increasing burdens of grant-related paperwork and data collection.