PHOENIX EMA RYAN WHITE PART A HIV Health Services Planning Council

Needs Assessment of "Newly Diagnosed/New to Care" PLWHA in Maricopa and Pinal Counties, Arizona

2009 REPORT OF FINDINGS

Prepared by

COLLABORATIVE RESEARCH

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2009 "In Care" Newly Diagnosed PLWHA Needs Assessment

Phoenix EMA HIV Health Services Planning Council *September 2009*

Executive Summary

OVERVIEW OF PHOENIX HIV/AIDS EPIDEMIC

The Phoenix EMA's estimated population is 4,172,462, representing 66% of the state's population. Arizona is the second fastest growing state in the nation and Maricopa County is the fourth most populous county in the nation. Pinal County is the 7th fastest growing county in the nation among those counties with populations greater than 10,000 persons. The EMA accounts for 74% of the prevalent cases of HIV/AIDS and 77% of the emergent cases of HIV/AIDS. Pinal County has the highest emergent rate in the state (17 versus state rate of 13.3) and third highest HIV/AIDS prevalence rate (203.28) next to Maricopa and Pima (Tucson) counties. *Approximately 30% of the prevalent cases and 60% of the emergent cases of HIV/AIDS in Pinal County are attributable to the incarcerated persons housed there.* The EMA's population is predominantly White with a significant and increasing Hispanic minority. According to 2004 population estimates from the Arizona Department of Economic Security (DES), the EMA's demographics are as follows: 60% White, 4% African-American, 30% Hispanic, 2% American Indian, 3% Asian/Pacific Islander, and approximately 2% other or multiple races.

RELEVANCE OF THE PHOENIX EMA NEWLY DIAGNOSED "IN CARE" NEEDS ASSESSMENT STUDY

The Phoenix EMA has a combined HIV/AIDS prevalence of 9,205 persons representing an 854 case increase (or greater than 10% increase) reported in the 2009 Part A grant application. *A total of 52% of emergent cases are among minorities. Of prevalent cases, 87% are among men, 13% are among women, 58% are White; 13.5% are African-American, 23.4% are Hispanic, 3% are American Indian and 1% Asian/Pacific Islander* (ADHS, 2007). *In Arizona's HIV/AIDS reporting, estimates of incidence are based upon the sum of new HIV cases, and new AIDS cases which were not diagnosed as HIV infections in any prior calendar year. These cases are referred to as* emergent *cases and are used as an estimate of incidence. Cases of HIV/AIDS can only be counted as emergent in the year they were first diagnosed with HIV infection. Persons who were emergent as HIV and diagnosed as AIDS in the same calendar year are counted as emergent AIDS to avoid double counting. This method is the most straightforward method available for estimating incidence. (Arizona, Executive Summary, HIV/AIDS Annual Report, 2007)*

The increase in total cases of HIV/AIDS by race, risk, gender and age group, from 2006 to 2007, is illustrated in the table below:

TABLE 1. INCREASES IN TOTAL HIV/AIDS CASES

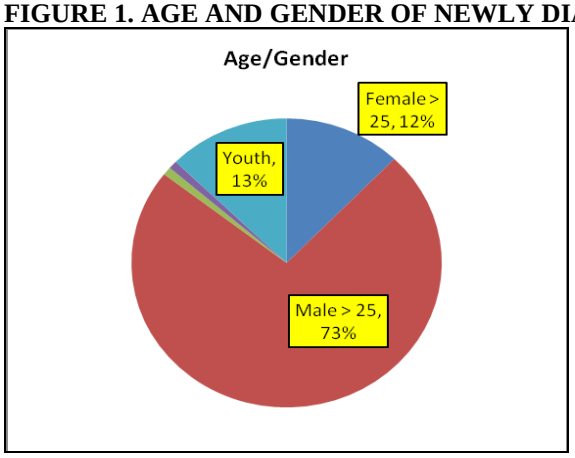
PLWHA				
	2006	2007	Increase	Increase
White	5027	5464	437	9%
AA	1006	1137	131	13%
Hispanic	1882	2147	265	14%
AI	267	267	0	0%
MSM	5106	5564	458	9%
Hetero	851	907	56	7%
IDU	1023	1062	39	4%
MSM/IDU	722	781	59	8%
Male	7246	7989	743	10%
Female	1095	1216	121	11%
<13	36	35	-1	-3%
13-19	46	46	0	0%
20-44	4805	5087	282	6%
45+	3454	4024	570	17%

The tremendous increases in the numbers of the newly diagnosed and clients newly entering care for the first time prompted the Planning Council to name this emerging population as one of the Phoenix EMA's priority Severe Need Groups. The Planning Council authorized the commission of this needs assessment study, with the goal for the Planning Council to learn more about the special service needs of this emerging population and, specifically, to determine the pathways to HIV testing and ultimately primary medical care, with linkage of the needs assessment findings back to the HIV prevention and the CPG.

'IN CARE' PROFILE OF NEWLY DIAGNOSED/NEW TO CARE PLWHA (*Recorded in CAREWare with a diagnosis date between March 1, 2008 through February 28, 2009)*

As evidenced in the graphic below, almost ¾ of the total number of 'Newly Diagnosed/New to Care' (who were recorded in CAREWare as receiving one or more Ryan White funded services during the 2008/2009 project year) are males over the age of 25 years (73%); 12% are females 25+ years of age; and 13% are youth, 13-24 years of age.

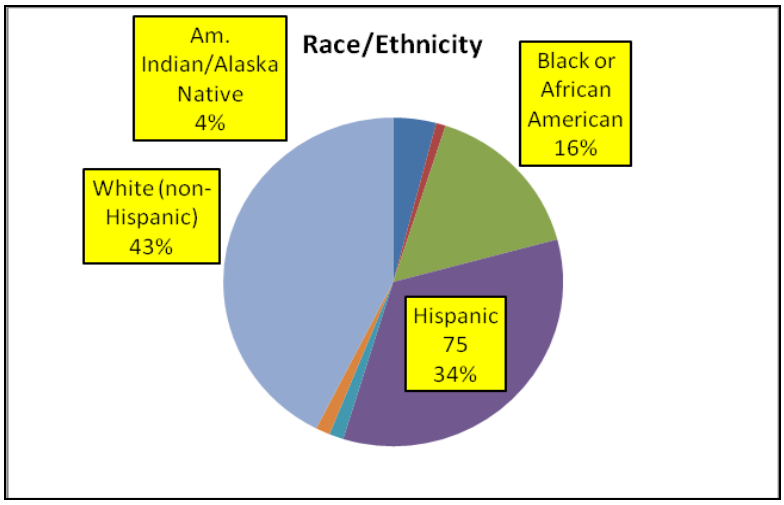
FIGURE 1. AGE AND GENDER OF NEWLY DIAGNOSED PLWHA



'IN CARE' PROFILE OF NEWLY DIAGNOSED/NEW TO CARE PLWHA (CONTINUED)

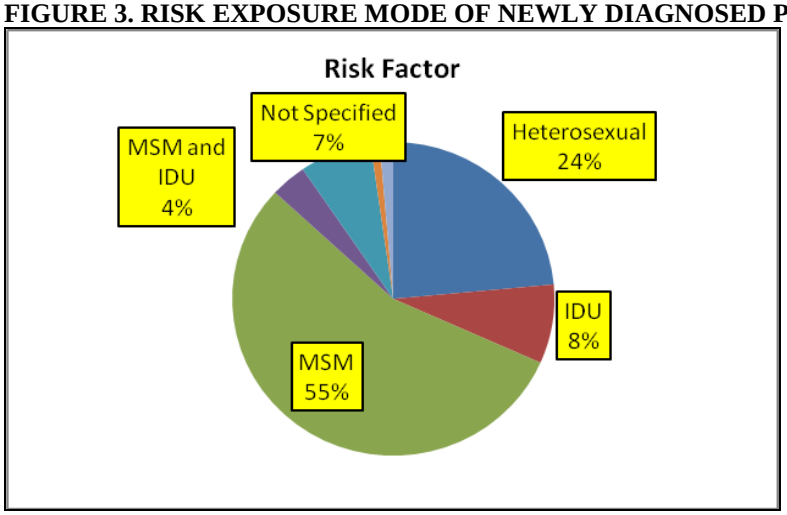
The largest number of the 2008/2009 Phoenix EMA 'In Care' newly diagnosed/new to care PLWHA are whites (43%), followed by Hispanics (34%); African Americans (16%); and then American Indians (4%). *(CAREWare, 2008-2009)*

FIGURE 2. RACE/ETHNICITY OF NEWLY DIAGNOSED PLWHA



By risk exposure mode, the majority of the newly diagnosed/new to care PLWHA who entered care in the Phoenix EMA over the past year are MSM (55%); followed by 24% Heterosexual contact; 8% IDU; 7% not specified; and 4% MSM/IDU. *(CAREWare, 2008-2009)*

FIGURE 3. RISK EXPOSURE MODE OF NEWLY DIAGNOSED PLWHA



By HIV/AIDS status, over 16% of the newly diagnosed PLWHA had a concurrent diagnosis of HIV and AIDS, representing a substantial 'late to care' fraction among these new-to-care PLWHA. Almost 84% were reported with HIV infection/not AIDS.
By income, this new Severe Need Group evidences substantial levels of poverty, with almost 2/3 reporting incomes at or below 100% of the federal poverty level. *(CAREWare, 2008-2009)*

OVERVIEW OF NEWLY DIAGNOSED/NEW TO CARE 'IN CARE' STUDY FINDINGS

The 2009 Newly Diagnosed/New to Care "In Care" Needs Assessment surveyed 70 PLWHA in the Phoenix EMA whose top expressed Needs for HIV-related services evidence a strong mix of core medical and supportive services including:

TABLE 2. 2009 'NEWLY DIAGNOSED/NEW TO CARE' NEED, USE, GAP, & BARRIER MATRIX

Service Category	Need Rank	Use Rank	Gap Rank	Barrier Rank
Housing Assistance	1	5	1	1
Medications	2	4	2	3
Primary Medical Care	3	2	NR	NR
Food Bank Services	4	7	NR	NR
Medical Transportation	5	3	NR	6
Mental Health Services	6	6	NR	2
Substance Abuse Services	7	NR	NR	NR
Emergency Financial Assistance	8	NR	NR	5
Health Insurance	9	8	NR	NR
Case Management	10	1	4	4
Health Education/Information/Referral	NR	910	3	NR
Oral Health Care	NR	NR	NR	7

The 'Newly Diagnosed/New to Care' survey respondents ranked the following service NEEDS:

1. Housing Assistance
2. Medications
3. Primary Medical Care
4. Food Bank Services
5. Medical Transportation
6. Mental Health Services
7. Substance Abuse Services
8. Emergency Financial Assistance
9. Health Insurance
10. Case Management

The 'Newly Diagnosed/New to Care' survey respondents ranked the following service GAPS (services that are perceived to be unavailable):

1. Housing Assistance
2. Medications
3. Health Education/Information & Referral/Living with HIV Disease Education
4. Case Management

The 'Newly Diagnosed/New to Care' survey respondents ranked the following service Barriers (services "hard to get"):

1. Housing Assistance
2. Mental Health services
3. Medications
4. Case Management
5. Emergency Financial Assistance
6. Medical Transportation
7. Oral Health Care

SUMMARY OF OTHER 'NEWLY DIAGNOSED/NEW TO CARE' NEEDS ASSESSMENT FINDINGS:

The services reported as used <u>prior to their entry into PMC</u> by the 2009 'Newly Diagnosed' PLWHA include the following:

1. Case Management
2. Transportation tied with Food
3. Housing assistance tied with Mental Health Counseling, and Peer Advocate
4. Outreach Case Management tied with Substance Abuse Counseling
5. Other--Support Groups

Thirty-nine percent (39%) of the 2009 respondents report not accessing any other services prior to their entry into PMC. It is not known how many of these (39%) PLWHA actually knew about or were offered any services prior to their PMC entry, however, ***10% of the PLWHA respondents reported not knowing about these services available in the Phoenix EMA*** and 10% report not needing these services.

When queried about what would have helped these PLWHA to enter care earlier, ***almost half reported that an advocate/peer to accompany them to their first medical appointment,*** followed by transportation assistance (27%); more information/health education upon testing positive, a peer to talk with (27%), mental health counseling (18%), and "being clean and sober"-substance abuse counseling (9%) were viewed as the most supportive factors they could identify that may have speeded their initial entry into care.

The services reported as needed and used by the 'Newly Diagnosed' upon entry into PMC included:

1. Case Management (86%);
2. Food (57%);
3. Transportation (54%);
4. Mental Health counseling (48%);
5. Housing Assistance (43%);
6. Peer Advocate (36%);
7. Substance Abuse counseling (21%)
8. 'Other-Dental Care (7%); and
9. Outreach Case Manager (4%)

In rank order, the kinds of health information needed right now, as reported by the 2009 'Newly Diagnosed' PLWHA respondents include:

1. How to take better care of myself (64%)
2. How to reduce the side effects of HIV medications (64%)
3. How to disclose their status to others (59%)
4. How to find social support groups (59%0
5. Basic HIV health education information (46%)
6. How to take HIV meds (treatment adherence education) (41%)
7. How to negotiate safer sex with partners (32%)
8. How to prevent HIV transmission to others (32%)
9. How to get mental health counseling services (32%), and
10. How to get substance abuse counseling services (9%).

Chapter 1: Introduction

BACKGROUND

A special focus of the Phoenix EMA Planning Council in 2009 was to better understand and respond to the complex HIV prevention and service needs of the newest Severe Need Group: the Newly Diagnosed/New to Care PLWHA. The emergent cases of HIV/AIDS continue to grow at alarming rates, ranging from 10-15% increases among the sub-populations of this SNG, and therefore, represent a population of substantial concern to the Phoenix EMA HIV Services Planning Council.

This special needs assessment study was undertaken to determine the priority service needs, barriers, and gaps in the continuum of care for 'Newly Diagnosed/New to Care PLWHA. A special focus of this needs assessment study was to perform an in-depth survey of the HIV risk behaviors and prevention needs of this SNG population, along with survey items intended to clarify what system level changes may be necessary in order to strengthen the prevention-to testing-to care linkages, so that persons living with HIV disease may learn their HIV status and be assisted in entering care at earlier stages of their disease process.

Results of this client-centered activity will be used to establish Ryan White funded service priorities, document the need for specific prevention and care services, determine barriers to accessing HIV testing and care, provide baseline data for comprehensive prevention and care planning including capacity building, and help providers improve the accessibility, acceptability and quality of both prevention and care services that are delivered to this newly designated 'Severe Need Groups/Special Population'.

A comprehensive assessment of the HIV care and prevention service needs, gaps and barriers of the emerging population of 'Newly Diagnosed/New to Care' PLWHA within the Phoenix EMA was conducted in the summer of 2009. This assessment of need included the quantitative review and analysis of CAREWare data for all newly entering PLWHA over the last project year, along with a qualitative survey of the 'Newly Diagnosed' (defined as having received a first diagnosis of HIV or AIDS in 2007 or 2008). A new and comprehensive survey tool was developed, inclusive of 85 detailed survey items relative to the complex HIV prevention and care needs, uses, barriers and gaps for the Newly Diagnosed/New to Care PLWHA in the EMA.

The 'Newly Diagnosed/New to Care' survey questionnaire was administered via a toll free 1-800 telephone survey questionnaire of newly diagnosed male and female PLWHA. The survey opportunity was marketed heavily through the Ryan White funded primary medical care providers, (including MIHS, HIS, CPLC, Care Directions, Ebony House, and Private Doctors (Pueblo/Cunningham; Spectrum/Vanig) and involved the wide distribution of palm cards and flyers as well as a mailing to all of the RW clients, marketing the availability of the survey, to English and Spanish speaking PLWHA, (with the use of an interpreter). Each PLWHA Respondent received a $15 gift card for participating in the needs assessment study.

RELEVANCE OF THE PHOENIX EMA PART A COMPREHENSIVE 'NEWLY DIAGNOSED/NEW TO CARE' NEEDS ASSESSMENT

The Phoenix EMA has a combined HIV/AIDS prevalence of 9,205 persons representing an 854 case increase (or greater than 10% increase) reported in the 2009 Part A grant application. *A total of 52% of emergent cases are among minorities. Of prevalent cases, 87% are among men, 13% are among women, 58% are White; 13.5% are African-American, 23.4% are Hispanic, 3% are American Indian and 1% Asian/Pacific Islander* (ADHS, 2007). *In Arizona's HIV/AIDS reporting, estimates of incidence are based upon the sum of new HIV cases, and new AIDS cases which were not diagnosed as HIV infections in any prior calendar year. These cases are referred to as* emergent *cases and are used as an estimate of incidence. Cases of HIV/AIDS can only be counted as emergent in the year they were first diagnosed with HIV infection. Persons who were emergent as HIV and diagnosed as AIDS in the same calendar year are counted as emergent AIDS to avoid double counting. This method is the most straightforward method available for estimating incidence. (Arizona, Executive Summary, HIV/AIDS Annual Report, 2007)*

The increase in total cases of HIV/AIDS by race, risk, gender and age group, from 2006 to 2007, is illustrated in the table below:

TABLE 3. INCREASES IN TOTAL HIV/AIDS CASES

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As evidenced above, Whites experienced the greatest number of cases, but Hispanics evidenced the greatest increases in HIV/AIDS cases in 2006/2007. Males, MSM, and PLWHA 45 years of age or older evidenced the greatest increases in HIV/AIDS cases over the same time period. The tremendous increases in the numbers of the newly diagnosed and clients newly entering care for the first time prompted the Planning Council to name this emerging population as one of the Phoenix EMA's priority Severe Need Groups. The Planning Council authorized the commission of this needs assessment study, with the goal for the Planning Council to learn more about the special service needs of this emerging population and, specifically, to determine the pathways to HIV testing and ultimately primary medical care, with linkage of the needs assessment findings back to the HIV prevention and the CPG.

PROJECT DESIGN FOR THE NEWLY DIAGNOSED/NEW TO CARE PLWHA NEEDS ASSESSMENT STUDIES

The objectives of the comprehensive 'Newly Diagnosed/New to Care' Needs Assessment Study were:

1) To identify the extent and types of HIV service Needs among Newly Diagnosed & New to Care PLWH/A in the Phoenix EMA;
2) To identify the HIV service Gaps and Barriers to care as perceived by Newly Diagnosed & New to Care PLWHA in the Phoenix EMA;
3) To determine the pathways to HIV testing and ultimately care for the Newly Diagnosed/New to Care PLWHA in the Phoenix EMA; and
4) To determine the current HIV prevention service Needs of the Newly Diagnosed and how may the HIV Testing-to-Care linkages be strengthened?

The sample for surveying the 'In Care' population was first determined by establishing a target goal for a representative sampling for the needs assessment study of the new Severe Need Group of 'Newly Diagnosed/New to Care' PLWHA receiving Ryan White funded services. Based upon the total number of 'New to Care' (N=221) it was determined that at least 30% of the 'Newly Diagnosed/New to Care' Survey Respondents should be targeted (N=66).

The actual number of 'Newly Diagnosed/New to Care PLWHA who participated in the survey process was 70 (107% of goal). The survey process was implemented under the direction of Collaborative Research. The survey sites for the survey process included the HIV prevention/testing providers and Ryan White funded service providers, in order to maximally access those PLWHA who were recently diagnosed with HIV or AIDS over the past project year and who were currently receiving RW funded services. Each PLWHA Respondent received a $15 HEB food card for participating in the survey process.

Chapter 2: 'Newly Diagnosed/New to Care Needs Assessment Findings

DEMOGRAPHIC PROFILE OF 2009 NEWLY DIAGNOSED PLWHA RESPONDENTS

Age Ranges of the 'Newly Diagnosed' PLWHA Respondents

Overall, the demographic profile of the 2009 'Newly Diagnosed' survey respondents mirror those of the total number of Newly Diagnosed/New to Care demographics recorded in CAREWare, with 13% of the survey respondents among youth, ages 13-24 years. The largest segment of respondents reported their ages between 35 and 44 years of age (36%); followed by the 25-34 age groups (26%). Almost 26% of the respondents reported their age as 45+ years.

TABLE 4. AGE RANGES OF NEWLY DIAGNOSED PLWHA SURVEY RESPONDENTS

Range of Birth Year	Age Range	#/% Newly Diagnosed PLWHA
1996-85	13-24	9/12.9%
1984-75	25-34	18/25.7%
1974-65	35-44	25/35.7%
1964-55	45-54	12/17.1%
1954-45	55-64	4/5.7%
1944 before	65+	2/2.9%
TOTAL		70/100%

The 2009 'Newly Diagnosed/New to Care' survey respondents reported a total of 25 different zip codes for their location of residence. The zip codes most frequently reported include: 85013 (15%); 85009 (11%); and 8%, respectively from 85004, 85007, 85016, 85029, 85033, and 85051. Table 5 below evidences 43% long-term residents of the EMA (greater than 10years); with 17% reporting their length of residence from 5-10 years. However, a substantial minority (40%) of the total 'Newly Diagnosed/New to Care' PLWHA respondent group reports a relatively recent move into the Phoenix EMA, with residence reported as five or fewer years..

FIGURE 4. ZIP CODE OF RESIDENCE OF NEWLY DIAGNOSED PLWHA

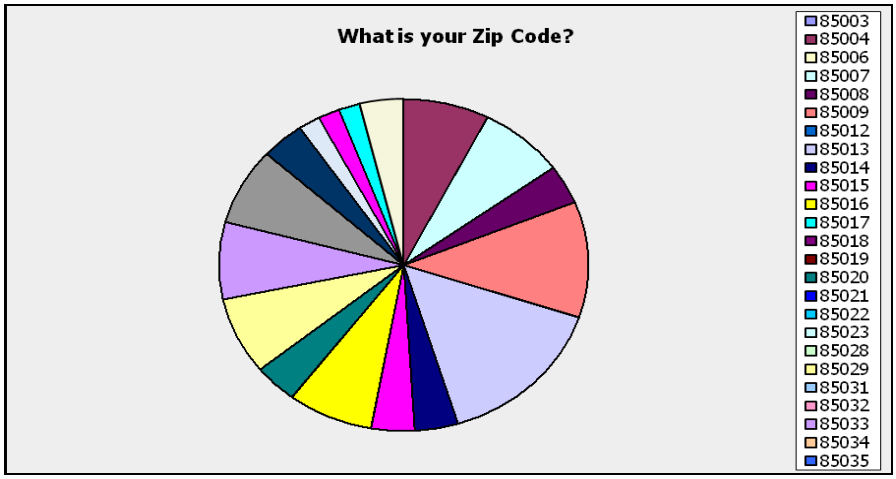

TABLE 5. LENGTH OF RESIDENCE IN PHOENIX EMA

How long have you lived in the Phoenix area?		
Answer Options	**Percent**	**Count**
I just moved here.	2.9%	2
Past 6-12 months.	8.6%	6
Past 12-24 months.	11.4%	8
Past 2-3 years.	2.9%	2
Past 3-5 years.	14.3%	10
Past 5-10 years.	17.1%	12
More than 10 years.	42.9%	30
	answered question	**70**

For those 'Newly Diagnosed' PLWHA who had not lived in Phoenix all their lives, they reported that they had moved both from within Arizona: reporting previous residence in Tucson, Navajo and Bullshead, AZ; as well as immigrated from another state, including moves from Ohio, Connecticut, Colorado, North Dakota, Maryland, Montana, Illinois, Wisconsin, Nevada, Louisiana, Hawaii, Nebraska, Utah, Oregon, Washington, Missouri, California, Alabama, and Washington, DC

Almost 83% of the Respondents report their gender as male and 14% as female, with almost 3% reporting transgender.

TABLE 6. GENDER OF NEWLY DIAGNOSED PLWHA RESPONDENTS

Gender		
Answer Options	**Percent**	**Count**
Male	82.9%	58
Female	14.3%	10
Transgender	2.9%	2
	answered question	**70**

Almost half of the 2009 'Newly Diagnosed' survey respondents report their race as white (46%); with almost 29% reporting Hispanic; 14% reporting African American; almost 3% American Indian; and 9% reporting multiracial.
(See Table 7 below and Figure 5 on the following page)
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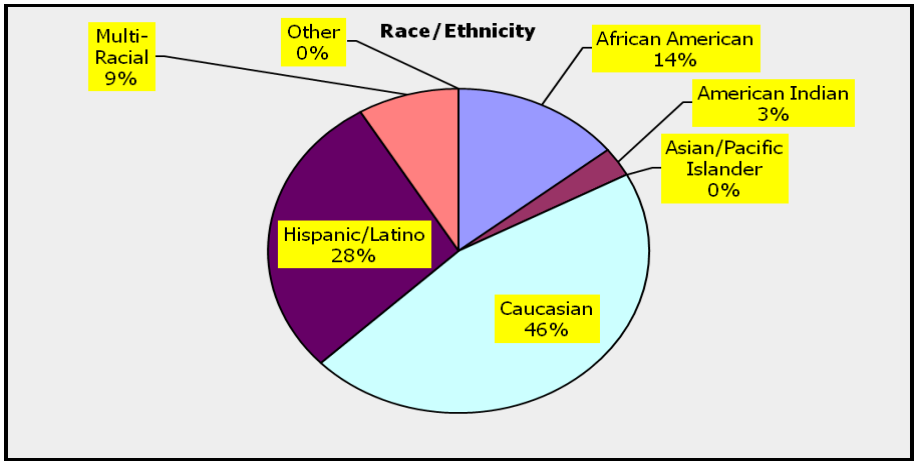
TABLE 7. RACE/ETHNICITY OF NEWLY DIAGNOSED PLWHA RESPONDENTS

Ethnicity		
Answer Options	**Percent**	**Count**
African American	14.3%	10
American Indian	2.9%	2
Asian/Pacific Islander	0.0%	0
Caucasian	45.7%	32
Hispanic/Latino	28.6%	20
Multi-Racial	8.6%	6
	answered question	**70**

FIGURE 5. RACE/ETHNICITY OF NEWLY DIAGNOSED PLWHA SURVEY RESPONDENTS



The majority of the 2009 'Newly Diagnosed' PLWHA survey respondents report their risk exposure mode as MSM (60%); followed by 17% Heterosexual contact; 14% IDU; 3% sexual assault; and 11% report their HIV transmission mode as unknown.

TABLE 8. RISK EXPOSURE MODES OF NEWLY DIAGNOSED PLWHA RESPONDENTS

Do you know how you may have acquired HIV/AIDS?		
Answer Options	**Percent**	**Count**
Male sex w/male	60.0%	42
Heterosexual Sex	17.1%	12
Injection Drug Use	14.3%	10
Sexual Assault	2.9%	2
Unknown	11.4%	8
	answered question	**70**

FIRST POSITIVE HIV TEST, REFERRALS TO AND LINKAGES WITH PMC

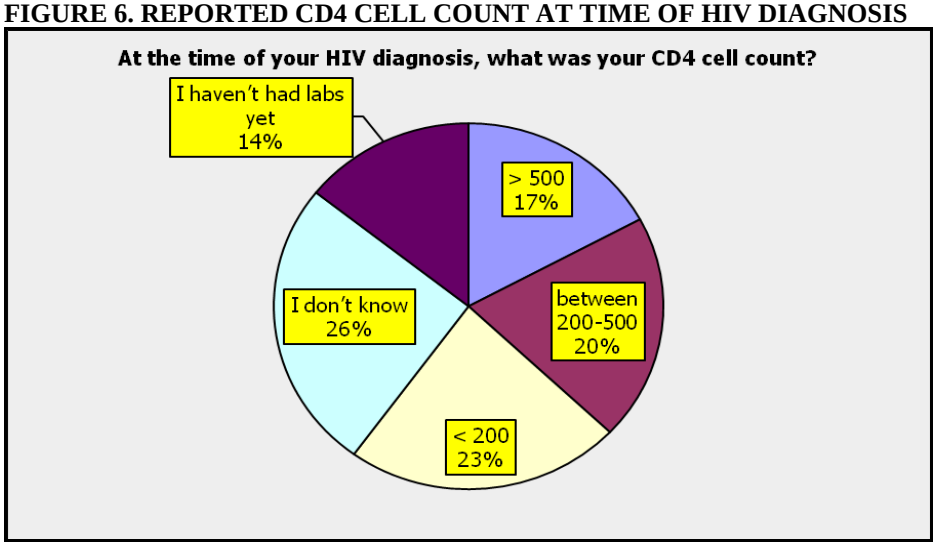
All of the 'Newly Diagnosed/New to Care' PLWHA reported receiving their first positive HIV test in either 2008 (31 PLWHA) or 2009 (39 PLWHA). A total of 12 respondents reported a concurrent AIDS diagnosis (eight PLWA in 2008 and four PLWA in 2009).

As evidenced in Figure 6 on the following page, only 17% of this respondent group reported CD4c cell counts above 500 cells/mm at the point of their diagnosis, with another 20% reporting CD4 cell counts between 200-500 cells/mm upon entry into care.

Almost ¼ of the 'Newly Diagnosed/New to Care' PLWHA reported CD 4 cell counts below 200 (evidencing an AIDS diagnosis upon first diagnosis). Forty percent (40%) of the 2009 respondents reported they had not yet had labs drawn or did not yet know their laboratory monitoring results.

(See FIGURE 6. REPORTED CD4 CELL COUNT AT TIME OF HIV DIAGNOSIS on the following page)

FIGURE 6. REPORTED CD4 CELL COUNT AT TIME OF HIV DIAGNOSIS



While the majority of the Newly Diagnosed PLWHA respondents reported a direct referral into HIV primary medical care (71%), **almost 21% report that they did not receive this important PMC referral.** Another 38% report referral for medical care for a condition other than HIV; 38% report referral for HIV/Health education classes; 35% report a mental health referral, and almost 21% report a substance abuse treatment referral.

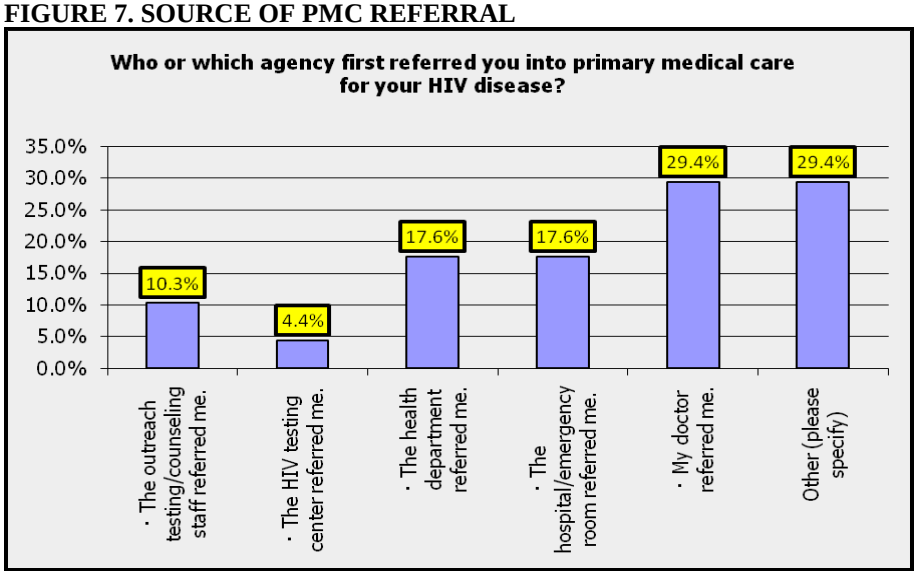
TABLE 9. SERVICE REFELLALS UPON DIAGNOSIS

At the time of your HIV diagnosis were you referred for any of the following services?		
Answer Options	**Percent**	**Count**
o Medical care related to the HIV diagnosis	70.6%	48
o Medical care for a condition other than HIV	38.2%	26
o Health/HIV education class	38.2%	26
o Mental health services (other than substance abuse)	35.3%	24
o Substance abuse counseling service	20.6%	14
o No, I was not referred for services	20.6%	14
Other (please specify): OB/GYN and Housing	5.9%	2
answered question		**70**

The 2009 'Newly Diagnosed' PLWHA respondents report a variety of PMC referral sources. Almost 30% report that their physician referred them and another 30% report a variety of other health provider sources for their initial referral into PMC (see list of 'other' referral sources below). Another 18% of the respondents, respectively, report the hospital/ER and the Health Department as their initial PMC referral sources.

Finally, 10% report that the outreach testing/counseling staff referred them into primary medical care, and only 4% report that the HIV testing center referred them into PMC services.
(See Figure 7 on the following page)

FIGURE 7. SOURCE OF PMC REFERRAL



Other referral sources:

- A friend referred me to the health department
- Blood testing center
- Clinic - Body Positive
- Clinic doctor sent me after positive gonorrhea test
- Maricopa County Health Department
- OB/GYN
- Southwest Center
- Southwest center/body positive
- Tarros: Maricopa Care Planner Book

The vast majority of this respondent group reports immediate entry into PMC (within 1-3 months following diagnosis). Another 9% of respondents report entry into care within six months. ***However, over 11% of the 'Newly Diagnosed' PLWHA reports that they have yet to enter PMC services.*** Two PLWHA report 'other' answers to this question, including "snuck in to have labs done, but have not yet seen the doctor"; and "20 days before graduating from high school".

TABLE 10. LENGTH OF TIME TO ENTER PMC

How soon after your diagnosis did you receive medical care related to HIV?		
Answer Options	**Percent**	**Count**
o Immediately	77.1%	54
o Within 6 months	8.6%	6
o Within a year	0.0%	0
o I have never received medical care for my HIV	11.4%	8
Other (please specify): *had labs done but have not seen a doctor yet; 20 days before I graduated from high school*	7.1%	2
	answered question	**70**

For those reporting a delay into primary medical care, the most frequently offered reasons for their delay include lack of insurance and lack of transportation, followed by reports of concerns about

disclosure of their status to partners/family members, fears about others finding out they were positive, concerns about confidentiality, not feeling ready to deal with their diagnosis, the general stigma surrounding HIV disease, and they 'feel well'. Other reasons for the delay into care included practical barriers related to prison release and information/insurance/scheduling issues. *(See list of 'other' reasons for delay below.)*

TABLE 11. REASONS FOR CARE ENTRY DELAY

If you delayed entry into medical care for HIV, what were your reasons for not getting treated?		
Answer Options	**Percent**	**Count**
o No insurance	33.3%	6
o No transportation	22.2%	4
o Worry about how to tell partner/family I was positive	11.1%	2
o Not ready to deal with it	11.1%	2
o General stigma surrounding HIV disease	11.1%	2
o Felt well	11.1%	2
o Fear of others finding out I was HIV positive	11.1%	2
o Concerns about confidentiality/privacy	11.1%	2
Other (please specify)	27.8%	5
	answered question	**13**

Other Reasons for Delay into PMC:

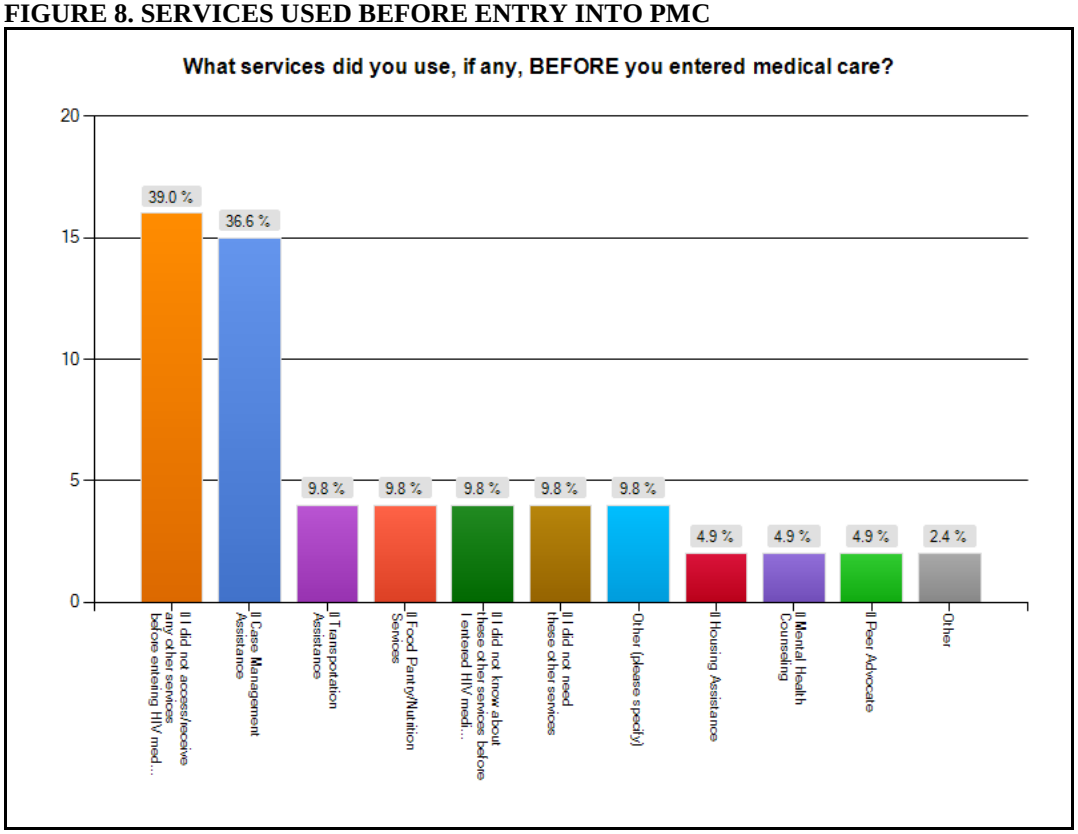
- In prison, couldn't get care until released
- Doctor couldn't see me until 6 months because only available Tues-Thurs 8-10am
- Trouble getting enrolled in insurance programs like ACCCHS
- Was going on vacation
- Waiting for information (doctors list) from Care Directions

The services reported as used <u>prior to their entry into PMC</u> by the 2009 'Newly Diagnosed' PLWHA include the following:

1. Case Management
2. Transportation tied with Food
3. Housing assistance tied with Mental Health Counseling, and Peer Advocate
4. Outreach Case Management tied with Substance Abuse Counseling
5. Other--Support Groups

Thirty-nine percent (39%) of the 2009 respondents report not accessing any other services prior to their entry into PMC. It is not known how many of these (39%) PLWHA actually knew about or were offered any services prior to their PMC entry, however, ***10% of the PLWHA respondents reported not knowing about these services available in the Phoenix EMA*** and 10% report not needing these services. *(See Figure 8 on the following page)*

FIGURE 8. SERVICES USED BEFORE ENTRY INTO PMC



When queried about *what would have helped PLWHA to enter care earlier*, ***almost half reported that an advocate/peer to accompany them to their first medical appointment,*** followed by transportation assistance (27%); more information/health education upon testing positive, a peer to talk with (27%), mental health counseling (18%), and "being clean and sober"-substance abuse counseling (9%) were viewed as the most supportive factors they could identify that may have speeded their initial entry into care.

TABLE 12. SERVICES WHICH WOULD HELP SPEED ENTRY INTO CARE

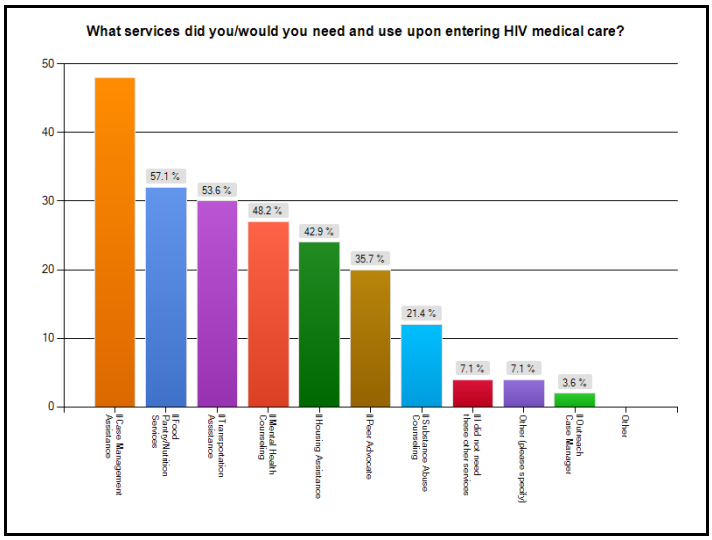
What services would have helped you to enter into medical care earlier?		
Answer Options	**Percent**	**Count**
o An advocate to come with me to my first appointment	45.5%	10
o Transportation assistance	27.3%	6
o More information/health education at the time of my HIV test	27.3%	6
o A peer to talk with about it	27.3%	6
o Mental health counseling at the point of testing positive	18.2%	4
o Being clean and sober	9.1%	2
Other (please specify): List of services/doctors the day you test	9.1%	2
answered question		**22**

<u>The services reported as needed and used by the 'Newly Diagnosed' upon entry into PMC included:</u>

1. Case Management (86%);
2. Food (57%);
3. Transportation (54%);
4. Mental Health counseling (48%);
5. Housing Assistance (43%);
6. Peer Advocate (36%);
7. Substance Abuse counseling (21%)
8. 'Other-Dental Care (7%); and
9. Outreach Case Manager (4%).

(See Figure 9 on the following page)

FIGURE 9.SERVICES NEEDED/USED UPON ENTRY INTO PMC



Over 1/3 of the 2009 'Newly Diagnosed' PLWHA respondents reported first learning their HIV status upon a voluntary request for testing. Most of the newly diagnosed, however, learned they were HIV positive while being treated for something else, including during general physical exams, upon STD diagnosis, ER/hospital visits, or testing for a blood donation, or while in jail/prison.

TABLE 13. MEANS OF FIRST DIAGNOSIS/LEARNING HIV STATUS

How did you find out you were HIV positive?		
Answer Options	**Percent**	**Count**
o When I requested a test for HIV	35.3%	24
o Part of a physical examination or doctor's visit.	23.5%	16
o When I went to the hospital/ER for something else	20.6%	14
o Part of a street/community outreach testing event.	5.9%	4
o When I was in jail or prison	2.9%	2
o When I donated blood	2.9%	2
Other (please specify): HD for skin problem; Gonorrhea; HIS Clinic; Gay youth school group; Dr, recommended upon diagnosis of Shingles	14.7%	10
	answered question	**68**

TABLE 14. PROMPTERS OF VOLUNTARY HIV TESTING

If you voluntarily requested a test for HIV, what prompted you to get tested for HIV?		
Answer Options	**Percent**	**Count**
o I wanted to know my status.	61.1%	33
o I did not feel well and thought I should get checked for HIV.	44.4%	24
o I wanted to confirm my suspicion that I was positive.	37.0%	20
o My partner tested positive.	18.5%	10
o I needed screening/treatment for an STD.	7.4%	4
o I had unprotected sex with someone who was HIV positive.	7.4%	4
o A friend tested positive.	3.7%	2
o My partner asked me to get tested.	1.9%	1
Other (please specify): *See list below*	12.9%	7
	answered question	**54**

Other HIV Testing Prompts:

My doctor recommended the test
Terribly sick
Always get tested every 6-8 months since age 12
Donated blood and was rejected, waited several months to be mentally ready for test and result
Doctor recommended an HIV test - I was sick
Doctor recommended it
My partner told me he was negative and then after sex told me he was positive

TABLE 15. FREQUENCY OF HIV TESTING

How many times were you tested for HIV before you tested positive?		
Answer Options	**Percent**	**Count**
o I had not been tested before.	44.1%	26
o I generally got tested every six months or so.	23.7%	14
o I generally got tested on an annual basis or so.	10.2%	6
o I got tested every two years or so.	10.2%	6
Other (please specify)	11.8%	7
	answered question	**59**

Other Reported Patterns of HIV Testing

Once during pregnancy
Randomly
Only one other HIV test at age 18
Once 10 years ago
Just tested twice in my life
On occasion - no specific time frame
I got tested when I felt I needed to

As evidenced in Table 16 below, almost half or 46% of the 'Newly Diagnosed' PLWHA reported thinking/believing they were already HIV positive for more than one year (14.3%) or more than 1-3 years (31.4%) before they formally learned their status upon testing positive.

TABLE 16. LENGTH OF TIME THOUGHT TO BE LIVING WITH HIV PRIOR TO TESTING

How long do you think you may have been HIV positive (living with HIV) before you received your first positive test?		
Answer Options	**Percent**	**Count**
o 1-3 months	14.3%	10
o 3-6 months	5.7%	4
o 6-12 months	17.1%	12
o More than 1 year	14.3%	10
o More than 2-3 years	31.4%	22
o I do not know	17.1%	12
	answered question	**70**

The reasons reported by the 2009 PLWHA respondents for not getting tested for HIV are similar, overall, to the reasons given by the newly diagnosed for their delay into primary medical care. However, with regard to the delay in seeking HIV testing, the most frequently reported reasons include: "Not ready to deal with it" (68%), "Not ready to know" (53%), and "Felt well" (53%). The remaining reasons cited for their delay in getting tested revolve around similar issues that act as barriers to care, including fears surrounding disclosure, confidentiality concerns and stigma.

TABLE 17. REASONS FOR DELAYS IN GETTING TESTED

If you delayed getting tested for HIV, what were your reasons for not getting tested?		
Answer Options	**Percent**	**Count**
o Not ready to deal with it	68.4%	26
o Not ready to know	52.6%	20
o Felt well	52.6%	20
o General stigma surrounding HIV disease/ Fears about discrimination	31.6%	12
o Concerns about confidentiality/privacy	31.6%	12
o Fear of others finding out I was HIV positive	26.3%	10
o Worry about how to tell partner/family if I came up positive	21.1%	8
o No insurance	15.8%	6
Other (please specify): *See list below*	13.3%	5
	answered question	**38**

Other reasons for delaying HIV testing:
Incarcerated, didn't want to think about it until I got out
Didn't think I was at risk
Didn't care
Doctor did not include in regular screening
Was in the window period

HIV PREVENTION, RISK BEHAVIORS AND THE 'NEW LY DIAGNOSED' PLWHA

BEFORE testing HIV positive 88.2% of the survey sample affirmatively reports having received some form of HIV prevention message. The various sources of these prevention messages are listed in Table 18 below.

TABLE 18. SOURCES OF HIV PREVENTION MESSAGES

If before testing HIV positive, where did you see/hear these HIV prevention messages?		
Answer Options	**Percent**	**Count**
o TV or radio	93.3%	56
o Books, magazines, newspapers	56.7%	34
o Other HIV/AIDS providers: prevention workers, street outreach	26.7%	16
o My doctor or other health care provider	26.7%	16
o Internet web-sites	26.7%	16
o Friends or family	26.7%	16
o Internet chat rooms	13.3%	8
o Support Groups	6.7%	4
Other (please specify): School, pamphlets, posters, billboards, bars & clubs, testing counselor	28.3%	17
answered question		**60**

The table below depicts the various perceptions of the impact of the current HIV prevention messages as reported by the 2009 'Newly Diagnosed' PLWHA respondents. ***A notable finding is that 50% of the respondents reported that the prevention messages are credited with creating personal risk awareness.*** Another positive finding is that existing prevention messages were the source of information for many of the PLWHA respondents as to how they could obtain free condoms (13%) and why they should start using condoms (37%). Fully 30% reported that these messages were the motivating force behind their seeking HIV testing.

A substantial minority of the PLWHA respondents reported that the messages did not seem to pertain to them, with 10% reporting they "I did not think they were at risk for HIV" and another 13% reporting "I did not think the messages related to me". Another 10% reported that they were already using safer sex practices, so did not believe they were at risk.

TABLE 19. PERCEIVED IMPACT OF HIV PREVENTION MESSAGES

Were these HIV prevention messages helpful in increasing your awareness/reducing your risk for HIV?		
Answer Options	**Percent**	**Count**
o No, I did not think I was at risk for HIV	10.0%	6
o No, I did not think the messages related to me	13.3%	8
o No, I already used safer sex practices	10.0%	6
o Yes, that is how I learned I might be at risk for HIV	50.0%	30
o Yes, that is how I started using condoms	36.7%	22
o Yes, that is why I got tested for HIV	30.0%	18
o Yes, that is how I learned where I could get free condoms	13.3%	8
Other (please specify): But I didn't think it would happen to me; I was using drugs and didn't care; My Mom told me about prevention; My partner was positive—I didn't care; Knew risks & consequences; Did not care	10%	6
answered question		**60**

The following reported barriers to the use or access of existing HIV prevention messages may be helpful in creating newly crafted messages and/or altering some of the ways that HIV prevention services are delivered in the Phoenix EMA.

TABLE 20. BARRIERS TO USING HIV PREVENTION SERVICES

What gets in the way of using HIV prevention services?		
Answer Options	**Percent**	**Count**
o People fear that someone they know would see them	**76.7%**	**46**
o They feel they don't need/want any services	**63.3%**	**38**
o People get tired of hearing the same old messages about safer sex	**61.7%**	**37**
o People don't know where to go	**56.7%**	**34**
o Too many things going on in people's lives	**60.0%**	**36**
o They are afraid they would be turned in to the police or immigration	26.7%	16
o Not open during times they would go	23.3%	14
o Services are too far away/not in their community	15.0%	9
o Not provided in their language	13.3%	8
Other (please specify)	10.0%	6
answered question		**60**

The 2009 'Newly Diagnosed/New to Care' PLWHA respondents report exceptionally high risk behaviors, overall. The next set of survey items pertain to the reported venues for the location of sexual partners over the past three years, the numbers of reported sexual partners located through these various venues, the numbers of male and female sexual partners over the past six months, and the reported frequency of barrier protection during sexual activity. As evidenced, the internet is the most heavily trafficked means of 'hook-up', followed by bars/clubs, adult bookstores and bathhouses/sex clubs. *(See Figure 10 and Table 21 below)*

FIGURE 10. VENUES FOR LOCATION OF SEXUAL PARTNERS AND FREQUENCY OF VISITATION

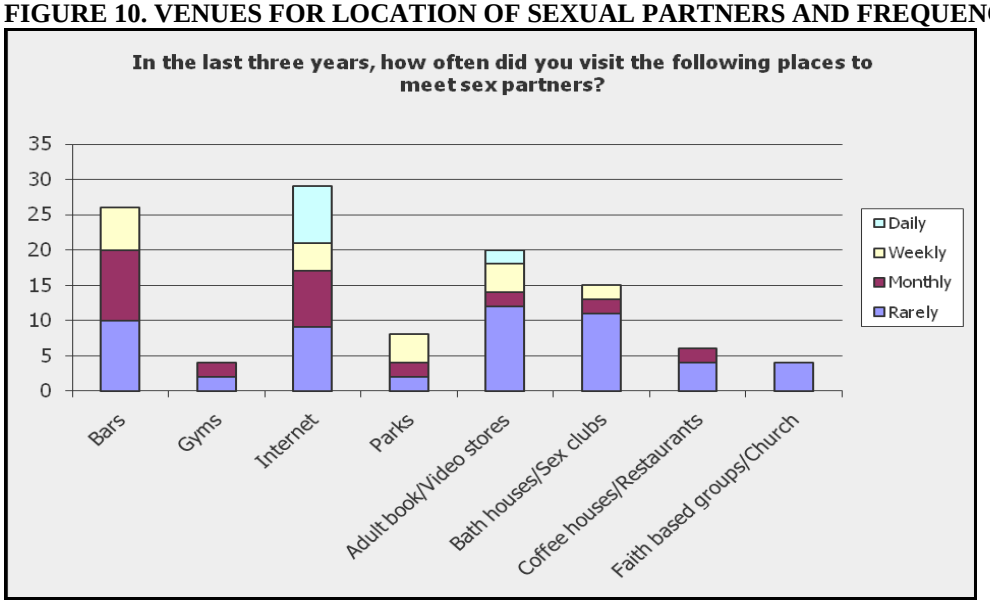


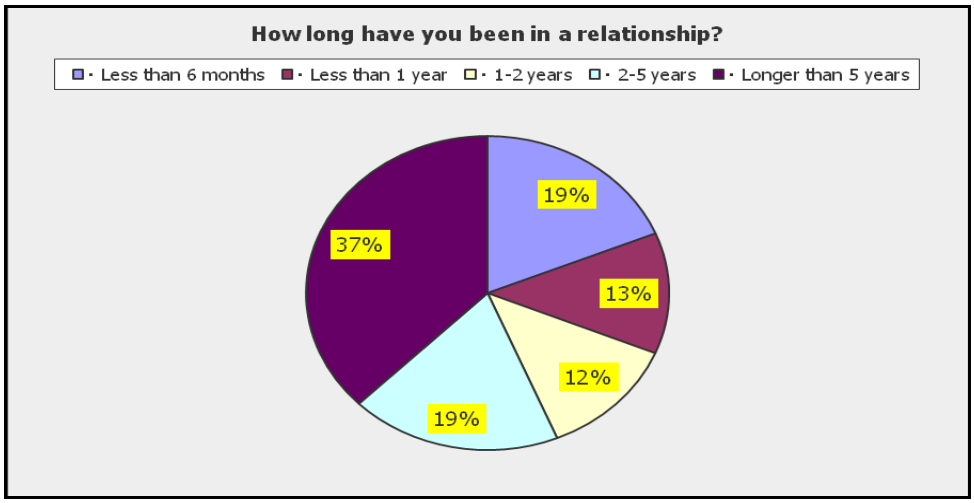
TABLE 21. VENUES FOR LOCATION OF SEXUAL PARTNERS AND FREQUENCY OF VISITATION

In the last three years, how often did you visit the following places to meet sex partners?					
Answer Options	**Daily**	**Weekly**	**Monthly**	**Rarely**	**Count**
Bars	0	**6**	**10**	**10**	**26**
Gyms	0	0	2	2	4
Internet	**8**	**4**	**8**	**9**	**29**
Parks	0	4	2	2	8
Adult book/Video stores	**2**	**4**	**2**	**12**	**20**
Bath houses/Sex clubs	0	**2**	**2**	**11**	**15**
Coffee houses/Restaurants	0	0	2	4	6
Faith based groups/Church	0	0	0	4	4
NA (haven't tried to find sex partners):					24
				answered question	**45**

The number of sex partners identified through Internet hook-ups ranged from 1 to 175, typically anonymous partners, as reported by the 'Newly Diagnosed' PLWHA respondents.

Over one quarter (26%) of the 2009 respondents reports having had sex for money or drugs And, over 11% report having paid for sex with money or drugs.
Of the total number of 'Newly Diagnosed' PLWHA respondents, (N=70), almost half or 46% report they are currently in a relationship: 69% of those reporting a current relationship, report a monogamous relationship at present (with 31% reporting a non-monogamous or 'open' relationship presently). The figure below depicts the reported lengths of partnered relationships as reported by the 2009 respondents.

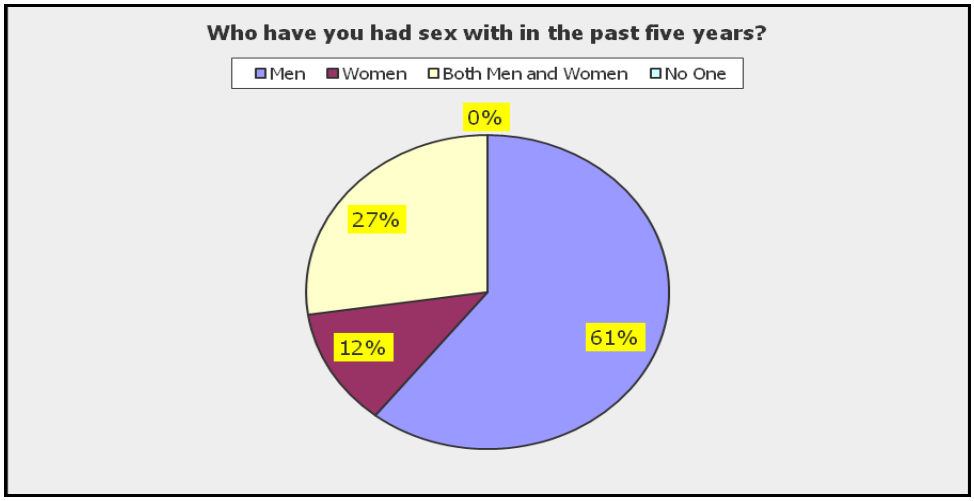
FIGURE 11. REPORTED LENGTH OF RELATIONSHIP



The number of sexual partners reported by the 'Newly Diagnosed' PLWHA respondents over the past year ranged from 1-100, with an average of 9.2 sexual partners per respondent. (Total of 622 partners reported by 68 respondents). The total number of male sexual partners reported by 60 respondents was 541, averaging 9 male sexual partners each over the past year.

The total number of female sexual partners reported by 68 respondents was 63, yielding an average of <1 female sexual partner per respondent over the past year. As evidenced in Figure 12 below, 27% of the respondents report sex with both males and females in the past five years.

FIGURE 12. GENDER OF SEXUAL PARTNERS IN PAST FIVE YEARS

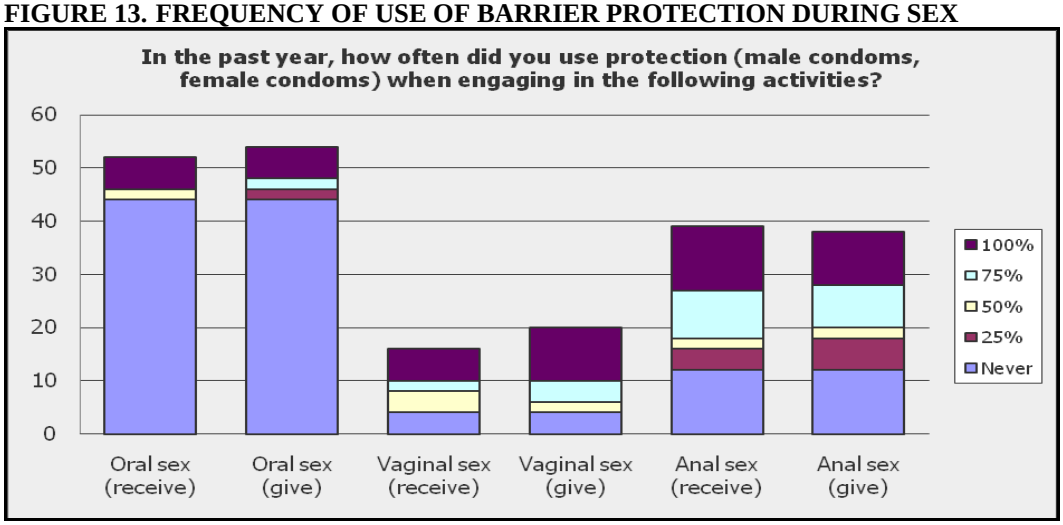


According to the reported frequency of use of barrier protection for various sexual activities, it is evident that there is a substantial level of unprotected sexual intercourse among the newly diagnosed PLWHA respondents. Of particular concern are the numbers reporting "never" or "rarely" (25%) use condoms for receptive anal intercourse. *(See Table 22 and Figure 13 below)*

TABLE 22. FREQUENCY OF USE OF BARRIER PROTECTION DURING SEX

In the past year, how often did you use protection (male condoms, female condoms) when engaging in the following activities?						
Answer Options	**100%**	**75%**	**50%**	**25%**	**Never**	**Count**
Oral sex (receive)	6	0	2	0	44	52
Oral sex (give)	6	2	0	2	44	54
Vaginal sex (receive)	6	2	4	0	4	16
Vaginal sex (give)	10	4	2	0	4	20
Anal sex (receive)	12	9	2	**4**	**12**	39
Anal sex (give)	10	8	2	**6**	**12**	38
Other: *Have not has sex over past year*						2
					answered question	**60**

FIGURE 13. FREQUENCY OF USE OF BARRIER PROTECTION DURING SEX



The most frequently reported reasons for NOT using condoms during sexual activities include:

o My partner does not like using condoms or barriers
o I don't like using condoms or barriers
o I didn't know I had HIV or AIDS at the time
o I am sometimes high or buzzed during sex/forget to use one
o Condoms or barriers are not always available
o I didn't think my partner was HIV positive

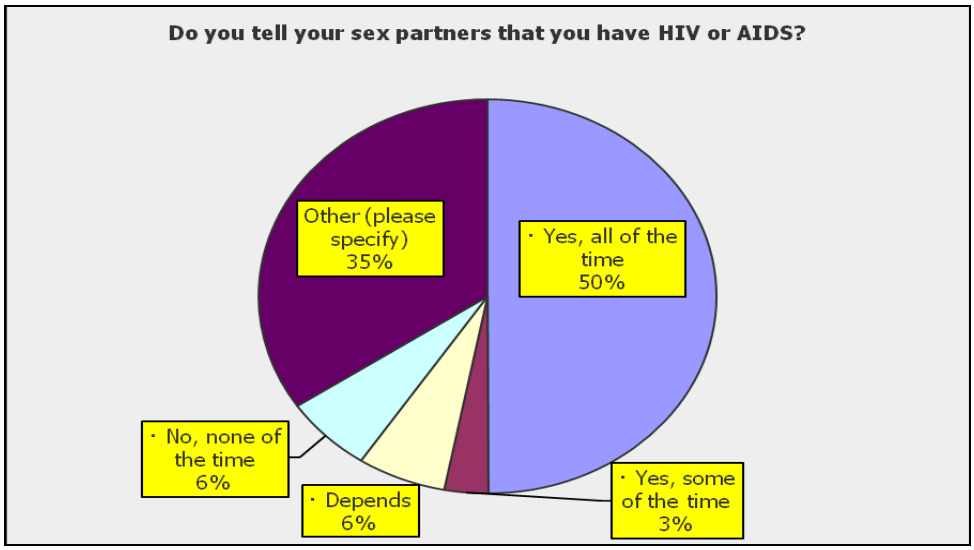
Each of these barriers to condom usage may potentially be overcome and are amenable to directed intervention. These findings underscore the critical importance of delivering HIV prevention messages to newly diagnosed PLWHA, upon entry into care and for all providers to continuously reassess risk behaviors and provide all indicated prevention with positives programming. (See Table 23 on the following page)

TABLE 23. REASONS FOR NOT USING CONDOMS/BARRIER PROTECTION FOR SEX

If you do NOT use condoms every time you have sex, please check all the reasons why.		
Answer Options	**Percent**	**Count**
o My partner does not like using condoms or barriers	72.7%	32
o I don't like using condoms or barriers	54.5%	24
o I didn't know I had HIV or AIDS at the time	54.5%	24
o I am sometimes high or buzzed during sex/forget to use one	45.5%	20
o Condoms or barriers are not always available	40.9%	18
o I didn't think my partner was HIV positive	38.6%	17
o My partner is also HIV positive	18.2%	8
o I didn't want my partner to know I had HIV or AIDS	18.2%	8
o I don't know how to talk to my partner about using condoms/barriers	13.6%	6
o My HIV/AIDS is undetectable	9.1%	4
o I want to have a baby	9.1%	4
o I don't care if I get a different strain of HIV	9.1%	4
answered question		**44**

It is of concern that only 50% of the 2009 'Newly Diagnosed/New to Care' PLWHA respondents reports disclosing their HIV status to sexual partners. This finding indicates an unmet need for education and counseling for the development of disclosure skills and building confidence in sexual negotiation skills. Over 17% of the respondents report that they are unsure about how to protect their sexual partners from acquiring HIV, and 3% report that they do not know what to do to keep their partner(s) from getting HIV/AIDS. Over ¼ (26%) of the 2009 'Newly Diagnosed' PLWHA respondents affirmatively report the need for information, education and counseling about how to tell their partners their HIV/AIDS status. Over half of the respondent group (56%) report that they do tell their partners to get tested for HIV and 18% reported they do not (with 28% reporting non-applicable, presumably because their partner is already living with HIV/AIDS).

FIGURE 14. DISCLOSURE OF HIV STATUS TO SEXUAL PARTNERS



***Other**: Many Respondents reported "No sex since diagnosis" (comprising vast majority of 'other' responses) or reported "monogamous"

TABLE 24. NEED FOR INFORMATION REGARDING SEXUAL NEGOTIATION SKILLS

Do you need information on how to get your sex partner(s) to use condoms?		
Answer Options	**Percent**	**Count**
o Yes	21.2%	14
o No	78.8%	52
	answered question	**66**

As evidenced in the table above, over 1/5 of the 2009 'Newly Diagnosed' PLWHA respondents report the need for more information, education and counseling about how to effectively negotiate the use of barrier protection with sexual partners. The vast majority of respondents (97%) report that they DO know where to get free male and female condoms. However, over 18% of the females reported that they do not feel comfortable asking for free condoms for their male sexual partners. Furthermore, 20% of women respondents reported that they are not comfortable asking their male sexual partners to wear condoms.

Most males and females reported they would be comfortable asking their case manager for free condoms (only 14.5% stated they would not be comfortable asking). 77% of respondents report

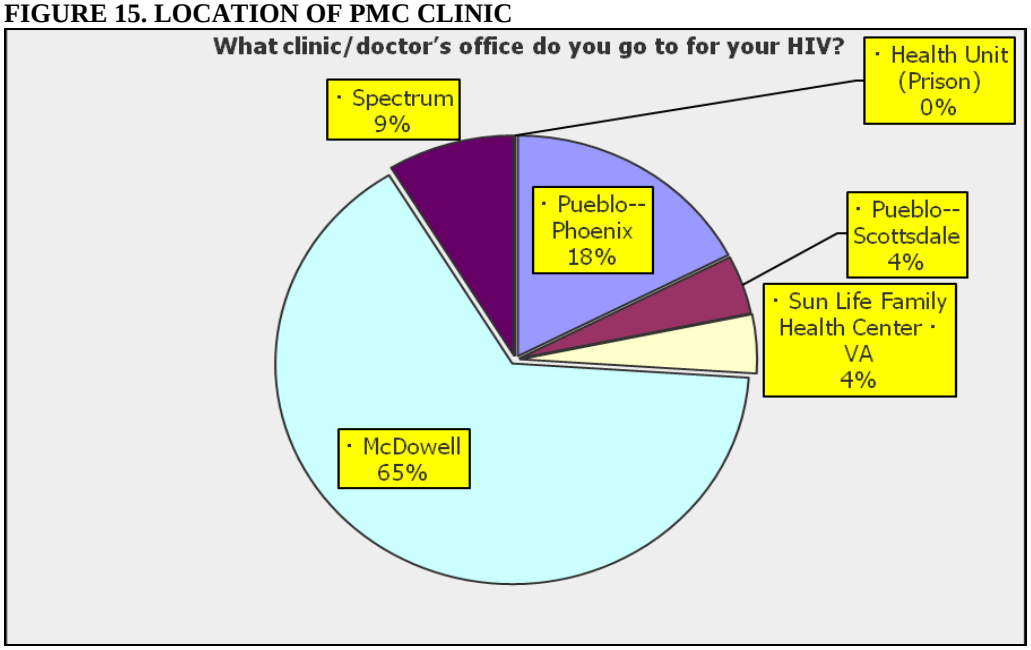
they believe their case manager to be knowledgeable about helping them learn safer sex practices (and 8% do not; with 15% who stated they "did not know").

ENTRY INTO CARE ISSUES FOR NEWLY DIAGNOSED PLWHA

Location of Primary Medical Care Clinic and Insurance Status

The majority of the 2009 'Newly Diagnosed/New to Care' PLWHA respondents report their HIV primary care home as McDowell Health Center (65%). The remainder of the PMC sites reported by the 2009 respondents include: Pueblo-Phoenix (18%); Spectrum (9%); Pueblo-Scottsdale (4%); and Sun Life Family Health Center (4%).

FIGURE 15. LOCATION OF PMC CLINIC

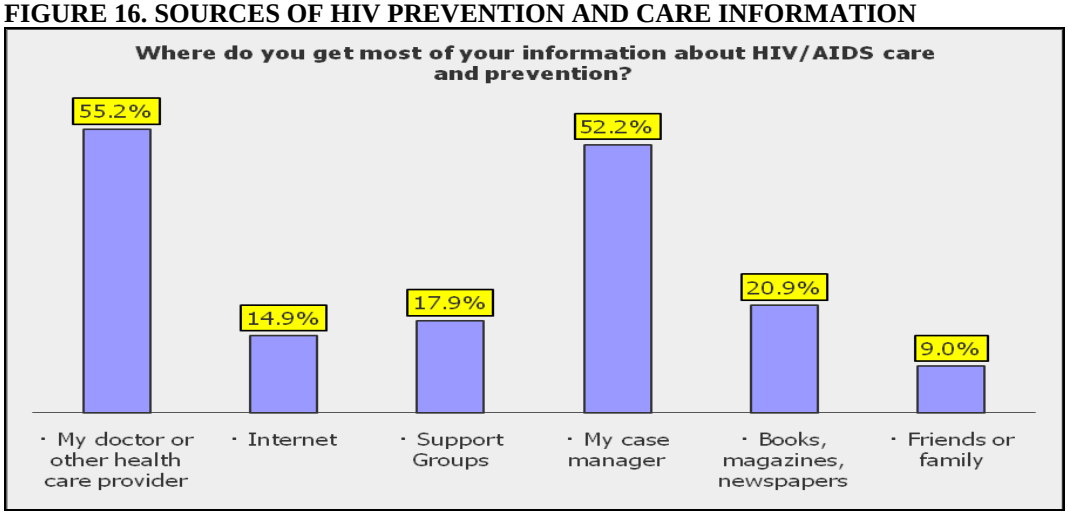


The vast majority of the 2009 'Newly Diagnosed' PLWHA respondents report Medicaid as their primary source of health insurance for primary medical care (73%). Only 17% of the 2009 respondents report private insurance; 3% report VA benefits; and only 7% of this respondent group reports no form of health benefit.

Sources of HIV Prevention and Care Health Information

As evidenced in Figure 16 below, the 2009 respondents rely most heavily for their HIV/AIDS-related health information from their primary medical care provider (55%) and case manager (52%). Other reported sources of HIV care and prevention information include books, periodicals and newspapers; support groups (18%); the Internet (15%); and friends or family (9%).

FIGURE 16. SOURCES OF HIV PREVENTION AND CARE INFORMATION



Current Health Information Needs

In rank order, the <u>kinds of health information needed right now</u>, as reported by the 2009 'Newly Diagnosed' PLWHA respondents include:

1. How to take better care of myself (64%)
2. How to reduce the side effects of HIV medications (64%)
3. How to disclose their status to others (59%)
4. How to find social support groups (59%0
5. Basic HIV health education information (46%)
6. How to take HIV meds (treatment adherence education) (41%)
7. How to negotiate safer sex with partners (32%)
8. How to prevent HIV transmission to others (32%)
9. How to get mental health counseling services (32%), and
10. How to get substance abuse counseling services (9%).

TABLE 25. CURRENT HEALTH INFORMATION NEEDS

What kinds of HIV information do you need right now?		
Answer Options	**Percent**	**Count**
o How to take better care of myself	63.6%	28
o How to reduce the side effects of HIV meds	63.6%	28
o How to tell others my HIV status	59.1%	26
o How to find social support groups	59.1%	26
o Basic HIV education	45.5%	20
o How to take HIV meds	40.9%	18
o How to talk to partners about safer sex	31.8%	14
o How to prevent HIV transmission to others	31.8%	14
o How to get mental health counseling services	31.8%	14
o How to get substance abuse counseling services	9.1%	4
Other (please specify)		16
	answered question	**44**

Level of Satisfaction with HIV Testing/Counseling, Primary Medical Care and Medical Case Management Services

Overall, the 2009 'Newly Diagnosed/New to Care' PLWHA respondents reported their level of satisfaction with the HIV Testing/Counseling services as "excellent" (29%); "good" (34%; "fair" (17%); or "poor" (9%). Over 11% reported this survey item as non-applicable (owing to diagnosis learned through other means than HIV testing/counseling provider).

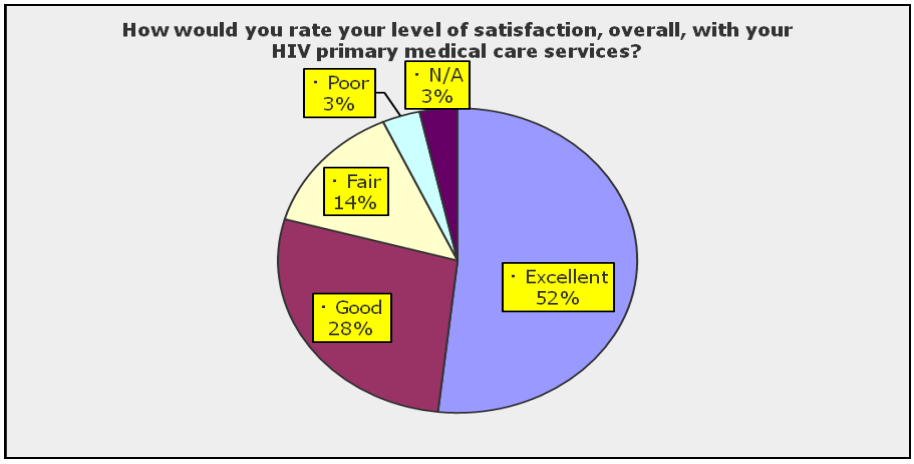
TABLE 26. LEVEL OF SATISFACTION WITH HIV TESTING/COUNSELING SERVICES

How would you rate your level of satisfaction, overall, with your HIV testing/counseling services?		
Answer Options	**Percent**	**Count**
o Excellent	28.6%	20
o Good	34.3%	24
o Fair	17.1%	12
o Poor	8.6%	6
o N/A	11.4%	8
Comments:		8
answered question		**70**

HIV Testing/Counseling Satisfaction Survey Comments:

Told my status, told to be quiet, no referrals for service, medical care or meds
In hospital for pneumonia
Told me to call in for results but wouldn't give results on phone
It was difficult to get my results. I was told to call in for results and then told results aren't given over phone.
Just told me I had HIV, gave me a letter and then sent me to find a clinic
Needed counseling, not just a blue book of phone numbers
In hospital diagnosis, hospital provided limited information.
Lost paperwork while waiting for results so had trouble getting results.

FIGURE 17. LEVEL OF SATISFACTION WITH PRIMARY MEDICAL CARE SERVICES



Overall, the 2009 'Newly Diagnosed/New to Care' PLWHA respondents reported their level of satisfaction with PMC services, to date, as "excellent" (52%); "good" (28%); "fair" (14%); and with only 3% reporting their level of satisfaction as "poor".

Primary Medical Care Satisfaction Survey Comments:
Doctor forgets to give shots, no explanations on medications and disease about my VL/CD4. Hard to get appointment to see doctor. He is out of the office a lot. I see a lot of PA's and other medical staff.

TABLE 27. LEVEL OF SATISFACTION WITH HIV CASE MANGEMENT SERVICES

How would you rate your level of satisfaction, overall, with your HIV case management services?		
Answer Options	**Percent**	**Count**
o Excellent	39.4%	26
o Good	18.2%	12
o Fair	12.1%	8
o Poor	12.1%	8
o N/A	18.2%	12
	answered question	**66**

Overall, the 2009 'Newly Diagnosed/New to Care' PLWHA respondents reported their level of satisfaction, to date, with their case management services as excellent (39%); "good" (18%); "fair" (12%)' and "poor" (12%). *(18% answered the question as "non-applicable")*

Case Management Satisfaction Survey Comments
Poorly organized process and poor communication about what to expect. The one good thing is she walked me through the process of going window to window in HD.
She has an attitude, pries into my personal life and won't talk about my need to see a doctor. My fiancé is HIV+ too and she sees a doctor already.
CM not engaging me, not helping facilitate me making med appoint, won't help me get a bus pass, reluctant to assist me in addressing and resolving my issues-alcohol, disability enrollment

SERVICE NEEDS

TABLE 28. TOP RANKING SERVICE NEEDS OF 2009 NEWLY DIAGNOSED/NEW TO CARE PWLHA RESPONDENTS

TOP RANKING SERVICE NEEDS		
Answer Options	**Percent**	**Count**
Housing Assistance	59.6%	28
Medications	55.3%	26
Primary Medical Care	46.8%	22
Food Bank Services	31.9%	15
Medical Transportation	21.3%	10
Mental Health Counseling	12.8%	6
Substance Abuse counseling	8.5%	4
Emergency Financial Assistance/ Money	6.4%	3
Health Insurance	4.3%	2
Medical Case mgmt	4.3%	2
Health Education	0.0%	0
Oral Health Care/ Dental	0.0%	0
Co-pays	0.0%	0
	answered question	**47**

The' Newly Diagnosed/New to Care' survey respondents ranked the following service NEEDS:

1. Housing Assistance
2. Medications
3. Primary Medical Care
4. Food Bank Services
5. Medical Transportation
6. Mental Health Services
7. Substance Abuse Services
8. Emergency Financial Assistance
9. Health Insurance
10. Case Management

'Other' Service Needs"

Support (emotional) and good nutrition
Social events - support groups and social gatherings
Love, empathy, connection, human contact, and to be empowered for the rest of life
HIV specific counseling
Clothing, a job, food stamps
Nutritional counseling
Group counseling

TABLE 29. PART A SERVICES UTILIZED BETWEEN MARCH 1, 2008 AND FEBRUARY 28, 2009

NEWLY DIAGNOSED/NEW TO CARE SERVICE UTILIZIATION	
SERVICE CATEGORY	**%Clients**
Medical Case Management	27.96%
Oral Health Care	18.36%
Case Management (non-medical)	16.13%
Legal Services	10.01%
Medical Transportation Services	5.84%
Food Bank/Home-delivered Meals	5.29%
Psychosocial Support	4.73%
Mental Health Services	3.34%
Medical Nutrition Therapy	3.20%
Service Outreach	2.92%
Health Insurance Program (HIP)	1.53%
Substance Abuse: Outpatient	0.70%

SERVICE USES

TABLE 30. TOP RANKING SERVICE USES

TOP RANKING SERVICE USES		
Answer Options	**Percent**	**Count**
Case mgmt	65.4%	34
PMC	57.7%	30
Trans	46.2%	24
Meds	38.5%	20
Housing	38.5%	20
Mental health	26.9%	14
Food bank	15.4%	8
Insurance	11.5%	6
Education	7.7%	4
Dental	7.7%	4
Substance abuse counseling	3.8%	2
Money	3.8%	2
Co-pays	0.0%	0
Other (please specify)		17
	answered question	**52**

'Other' Uses

Acupuncture
Applying for entitlements
Katrina relocation
Medicaid and HOPWA
Support groups - social support

SERVICE BARRIERS

The 'Newly Diagnosed/New to Care' survey respondents ranked the following service Barriers (services "hard to get"):

1. Housing Assistance
2. Mental Health services
3. Medications
4. Case Management
5. Emergency Financial Assistance
6. Medical Transportation
7. Oral Health Care

TABLE 31. TOP RANKING SERVICE BARRIERS

TOP RANKING SERVICE BARRIERS		
Answer Options	**Percent**	**Count**
Housing	41.2%	14
Mental health	17.6%	6
Meds	17.6%	6
Case mgmt	17.6%	6
Money	14.7%	5
Trans	5.9%	2
Dental	5.9%	2
	answered question	**34**

'Other' Service Barriers

Can't save money to get security for an apartment
A job
Only HIV Meds are covered by Ryan White and ADAP, but i need to get psych meds
Medications other than for HIV like antibiotics and ulcer medications
Money for doctor and medication co-pay and food stamps
Money for housing - too high, can't save money to get security for an apartment
Cost and coverage in care for people who work versus those on disability
Schedule changes for support group, job counseling, and group therapy

Service Barrier Reasons

Too long a waiting list and funding is low so lines for services is long
Case manager is a barrier and hasn't helped me
CM-inability to assist and housing-many complicated steps to get access to services – background checks, etc.
Waiting for section 8 list to open up
No work available
Need birth certificate to get food stamps. Waiting for my birth certificate to arrive from Illinois.

SERVICE GAPS

The 'Newly Diagnosed/New to Care' survey respondents ranked the following service GAPS (services that are perceived to be unavailable):

1. Housing Assistance
2. Medications
3. Health Education/Information & Referral/Living with HIV Disease Education
4. Case Management

TABLE 32. TOP RANKING SERVICE GAPS

TOP RANKING SERVICE GAPS (SERVICES THEY CAN'T GET)		
Answer Options	**Percent**	**Count**
Housing	71.4%	10
Meds	14.3%	2
Education	14.3%	2
Case mgmt	14.3%	2
Other (please specify)		8
answered question		**14**

'Other' Service Gaps

Specialized support group
Support groups
Job counseling
Jobs/employment assistance

Service Gap Reasons

Application process is long/waiting
After diagnosis i didn't know where to turn. Found out about the southwest center.
There is a newly diagnosed program now but there should be more.
Most support groups are for those diagnosed for a long time, very scary.
There needs to be more outreach and support for newly diagnosed.
Section 8 is only for elderly and disabled and worker told me I don't qualify.
Can't afford housing with my social security disability.
Most support groups are filled with people on ACCCHS or Ryan White.
I want a support group for people with jobs, health insurance, and not in the public assistance system.
Don't know about services, just diagnosed last week.
Hoping my case manager will tell me about what help i can get for housing and medications.
Waiting for social security to be approved
A lot of support groups are at night, and buses don't run at night.
Hard for me to walk, bad legs and have trouble getting a ride home.
Need case managers who are aware of HIV and its effects and meds and substance abuse issues
Pharmacy wouldn't accept medication card (co pay benefit program card Bristol Myers Squib) to reduce co-pay – Caused me to stop meds for a week -

SUMMARY OF PATHWAYS TO TESTING AND CARE

PRIOR TO PMC ENTRY SERVICE TRAJECTORY

The services reported as needed/used by the 'Newly Diagnosed/New to Care' prior to PMC entry included:

1. Case Management
2. Transportation tied with Food and 'other'
3. Housing assistance tied with Mental Health Counseling, and Peer Advocate
4. Outreach Case Manager tied with Substance Abuse Counseling
5. Support groups

ENTRY INTO PMC SERVICE TRAJECTORY

The services reported as needed and used by the 'Newly Diagnosed' upon entry into PMC included:

1. Case Management (86%);
2. Food (57%);
3. Transportation (54%);
4. Mental Health counseling (48%);
5. Housing Assistance (43%);
6. Peer Advocate (36%);
7. Substance Abuse counseling (21%)
8. 'Other-Dental Care (7%); and
9. Outreach Case Manager (4%).

Chapter 4: Recommendations for Comprehensive Strategic Plan

I. Address the Top Ranking Service Gaps of 'Newly Diagnosed/New to Care' PLWHA

The 'Newly Diagnosed/New to Care' survey respondents ranked the following service GAPS (services that are perceived to be unavailable):

1. Housing Assistance
2. Medications
3. Health Education/Information & Referral/Living with HIV Disease Education
4. Case Management

II. Address the Top Ranking Service Barriers of 'Newly Diagnosed/New to Care' PLWHA

The 'Newly Diagnosed/New to Care' survey respondents ranked the following service Barriers (services "hard to get"):

1. Housing Assistance
2. Mental Health services
3. Medications
4. Case Management
5. Emergency Financial Assistance
6. Medical Transportation
7. Oral Health Care

III. Address the Top Ranking Health Information Needs of 'Newly Diagnosed/New to Care' PLWHA

In rank order, the kinds of health information needed right now, as reported by the 2009 'Newly Diagnosed' PLWHA respondents include:

1. How to take better care of myself (64%)
2. How to reduce the side effects of HIV medications (64%)
3. How to disclose their status to others (59%)
4. How to find social support groups (59%0
5. Basic HIV health education information (46%)
6. How to take HIV meds (treatment adherence education) (41%)
7. How to negotiate safer sex with partners (32%)
8. How to prevent HIV transmission to others (32%)
9. How to get mental health counseling services (32%), and
10. How to get substance abuse counseling services (9%).

IV. Address the HIV Prevention Needs of the 'Newly Diagnosed/New to Care' PLWHA

V. Strengthen the HIV Testing-to Care Linkages in the EMA

VI. Consider further exploration of the level of dissatisfaction expressed by newly diagnosed PLWHA with the HIV Testing/Counseling services. Continue to improve the quality of Case Management services delivery in the EMA.