Chapter 9 Special Study: African American Men who have Sex with Men Living with HIV/AIDS

Importance

HIV/AIDS remains a disproportionate burden for African Americans, representing the 6th leading cause of death for African American males as late as 1999, and the 10th leading cause of death for African American females.

The rate of new AIDS cases among African Americans was 20 times higher than among non-Hispanic whites in 2000. For African American females, 55% of these cases were related to injection drug use or sex with an injecting drug user.

Epidemiologic/Demographic Profile

The Houston Area 2002 Epidemiological Profile produced by the Houston Regional HIV/AIDS Resource Group in April 2002 provides population based data for living, reported PLWH/A. This data is compared to the full surveyed population and to survey responses from African American MSM. African American response to the Needs Assessment was slightly lower (45.8%) than their composition in the EMA/HSDA (46.5%). See Table 9-1.

Table 9-1: ETHNICITY - AFRICAN-AMERICAN MSMs

Ethnicity	All Respondents	AA MSM	ALL PLWH/A (EMA/HSDA)
Non Hispanic Anglo	31.9%	0.0%	35.6%
African-American	45.8%	100.0%	46.5%
Hispanic	21.1%	0.0%	17.3%
Other	1.2%	0.0%	0.6%
Total	100.0%	100.0%	100.0%

Of the African American Men Having Sex with Men (AA MSM), 58.1% reported as HIV Positive (No Symptoms), 28.9% HIV Positive (Symptomatic) and 20.7% Living With AIDS as shown in Table 9-2. This high asymptomatic rate is 6.6 percentage points higher than all respondents who are HIV Positive (No Symptoms), and dramatically higher (35 percentage points) than all MSM.

Table 9-2: HIV STATUS - AA MSM

HIV Status	All Respondents	AA MSM	EMA/HSDA All MSM
HIV Negative	NA	1.1%	NA
HIV Positive (No Symptoms)	51.5%	58.1%	23.1%
HIV Positive (Symptoms)	31.4%	28.9%	
Living With AIDS	30.4%	20.7%	76.9%
Total*	113%	108.9%	100.0%

*Note: Totals of surveyed individuals include "double responses" by some individuals

African American MSM had slightly lower HIV Positive (Symptomatic) than All Respondents (2.5 percentage points). Similarly, AA MSM living with AIDS reported an almost ten percentage point lower rate of HIV positive symptoms than all respondents.

These HIV status reports indicate an improved health status as compared to all respondents though not as favorable as all males having sex with males (MSM).

Sexual Orientation

The high rate (25%) of self-reported bisexuality is an important factor in prevention and transmission of the disease. (See Table 9-1) This is higher than the general respondent rate of 13%, and indicates the need to educate the African American community about heterosexual transmission.

"Women are a real concern in our area. Many of them are with men we know are bisexual, they know their lifestyle is shaky but they still sleep with us." (AA MSM)

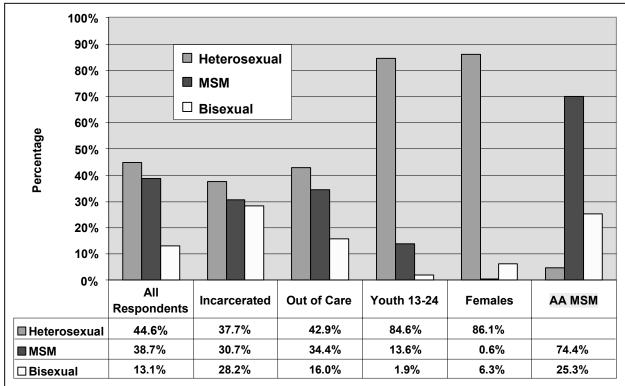


Figure 9-1: Sexual Orientation by Special Study Group

Educational Level

The AA MSM group has the highest degree of educational attainment at the high school/technical and college/graduate levels, see Figure 9-2. AA MSM are a group that can digest information, with significant potential for effective health education and prevention efforts.

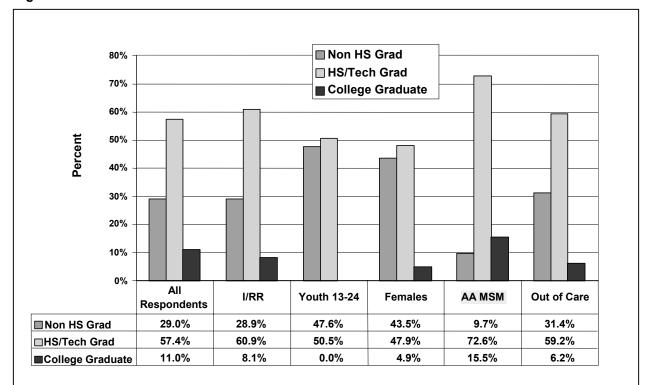


Figure 9-2: HIGHEST EDUCATION LEVEL ACHIEVED

SOCIOLOGIC AND HEALTH OBSERVATIONS - AA MSM

Care Status

PLWH/A in the African American segment were slightly less likely to be "in-care" than all respondents. They were only 1 percentage point higher than all respondents to be "out-of-care", and 3 percentage points higher than all respondents to be "never-in-care" as shown below in Table 9-3.

Table 9-3: CARE STATUS

Care Status	All Respondents	AA MSM
In-care	81%	77%
Out-of-care	12%	13%
Never-in-care	7%	10%
Total	100%	100%

The reasons offered for "out-of-care" were either provider advice that they not be in care or misperception of that doctor's instructions. Some may have low viral loads that do not require aggressive antiretroviral therapy, but still meet the need for primary care (HRSA definition of "in-care": accessing primary care within the past 6 months). See Figure 9-3.

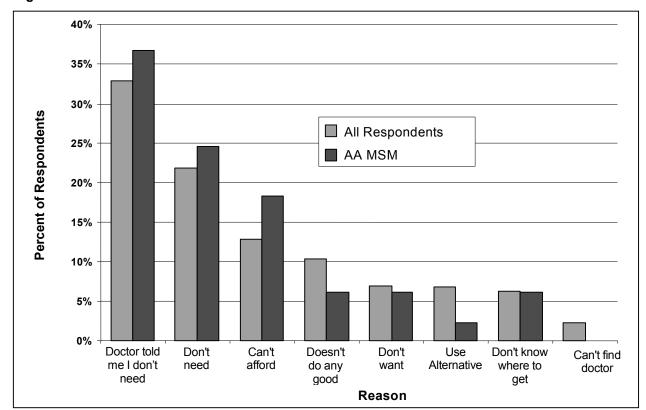


Figure 9-3: REASONS OUT OF CARE - AA MSM VS ALL RESPONDENTS

Viral Load

AA MSM were less likely than All Respondents to know their viral load (42%), with only youth and "out-of-care" surpassing them in their lack of awareness. The AA MSM group was among the highest (12%) to have 'no answer' vs. 'not know' their viral load, which may reflect their unwillingness to respond to this question. See Figure 9-4.

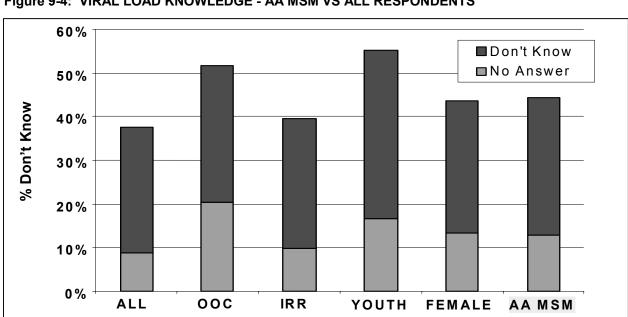


Figure 9-4: VIRAL LOAD KNOWLEDGE - AA MSM VS ALL RESPONDENTS

AA MSM reported 'don't know' with the highest percentage lack of awareness of their lowest, highest and current viral load as Figure 9-5 illustrates. A 30% non-detectable ranking for lowest reported viral load is significantly less than the best practice of 86%.

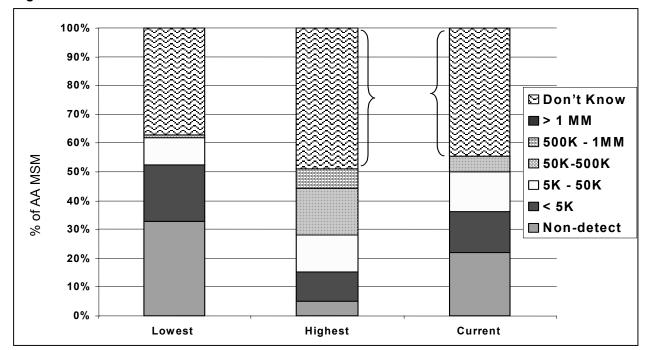


Figure 9-5: VIRAL LOAD PROFILES - AA MSM

Testing History

Most AA MSM found out that they were HIV positive by directly accessing HIV testing (65.5%). The rest found out they were HIV positive by means other than direct testing (33.4%). Of this third, 17.4% visited the Emergency Room and discovered that they were HIV Positive, 11.1% found out by Physical Examination, and almost 5% via Blood Donation as Figure 9-6 illustrates.

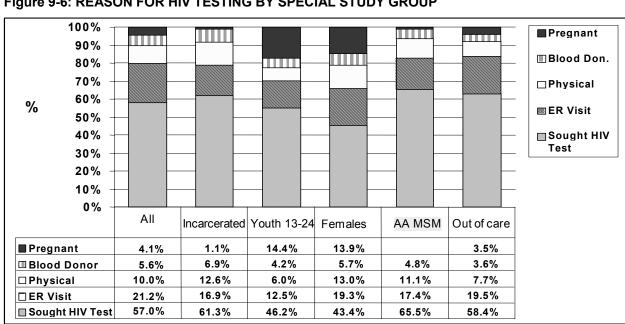
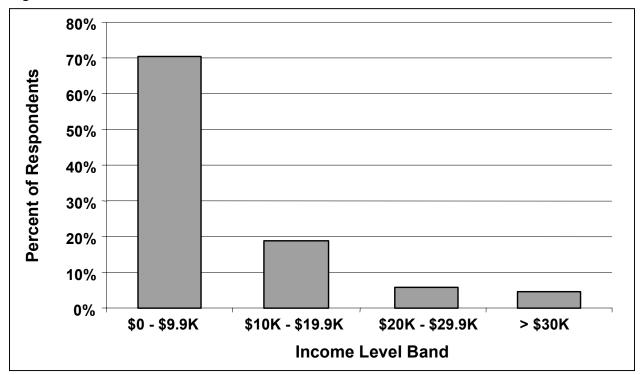


Figure 9-6: REASON FOR HIV TESTING BY SPECIAL STUDY GROUP

Income

Income averaged under \$10,000, with 80% of AA MSM reporting under \$20,000 annual income as illustrated in Figure 9-7.

Figure 9-7: INCOME LEVEL - ALL RESPONDENTS



Insurance

AA MSM were less likely to be uninsured than any other special study group as shown in Figure 9-8. The rate of 35% uninsured is still much higher than the national 17% figure.

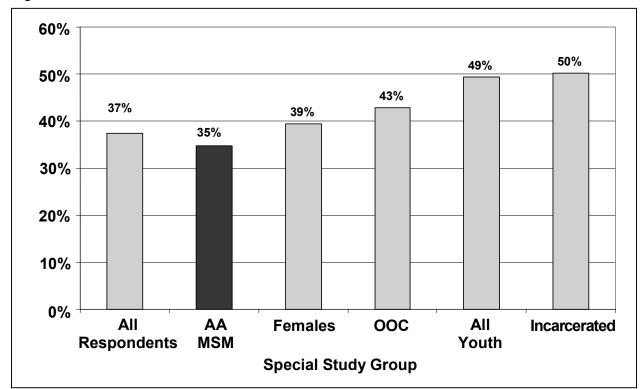


Figure 9-8: PERCENT UNINSURED BY SPECIAL STUDY GROUP

Chapter 9: AFRICAN-AMERICAN MSM LIVING WITH HIV/AIDS

[&]quot;Despite two consecutive years of declines in the number of uninsured Americans at the end of the 1990s boom, essentially the same percentage of the U.S. population was uninsured in 2000 as was in 1994 — about 17 percent."

¹ Pohl, Mary Beth and John Holahan, "Changes in Insurance Coverage: 1994-2000 and Beyond" - <u>Health Affairs</u>, April 3, 2002.

Medicare is the key source of insurance for AA MSM (32.9%), followed by Medicaid (31%) or 63.9% covered by public sector insurance. 14.8% receive public health assistance and 11.1% have some form of commercial or COBRA insurance. 2.2% receive Veteran's Administration coverage. See Figure 9-9.

AA MSM are the special study group most likely to have commercial insurance or COBRA, slightly higher than even all respondents.

50% 45% 40% 35% 30% 25% 20% 15% 10% 5% 0% ΑII All Youth 13 Respondent Incarcerated **AA MSM** OOC **Females** 24

44.4%

8.3%

1.9%

8.3%

0.0%

42.1%

20.8%

13.3%

5.5%

1.5%

31.0%

32.9%

14.8%

11.1%

2.2%

30.6%

22.2% 11.3%

9.2%

7.0%

33.4%

11.5%

9.0%

7.0%

1.7%

Figure 9-9: HEALTH INSURANCE SOURCE BY SPECIAL STUDY GROUP (insured only)

33.4%

28.9%

12.4%

10.9%

4.0%

■ Medicaid

■ Medicare

□Public Health Assistance

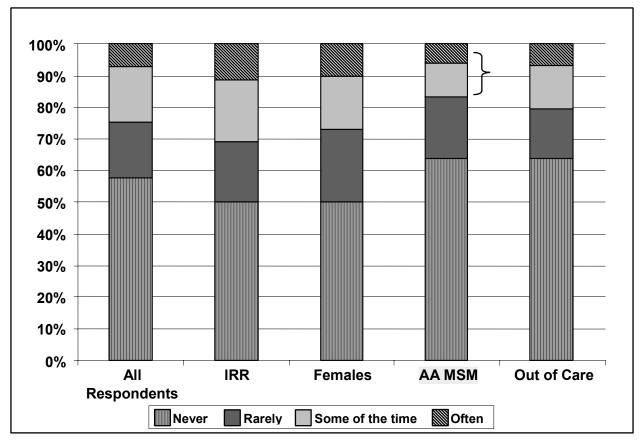
■ Commercial /COBRA

Veteran's Administration

Disability

AA MSM reported the lowest percentage of disabilities among any special study, with less than 18% reporting some or frequent issues as Figure 9-10 illustrates.

Figure 9-10: FREQUENCY OF DISABILITY PROBLEMS BY SPECIAL STUDY GROUP



Comorbidities

Comorbidities are a severe issue for AA MSM, though the areas in which these are higher than all respondents, hypertension and diabetes, may reflect the higher propensity of African Americans vs. PLWH/A. See Figure 9-11.

No other comorbidities are escalated in comparison to all respondents. This ethnic predisposition indicates that PLWH/A who are African American must be carefully monitored for the interaction of high blood pressure and diabetes with antiretroviral medication.

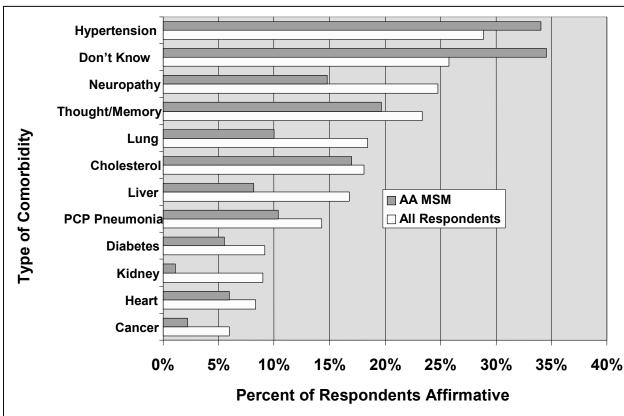
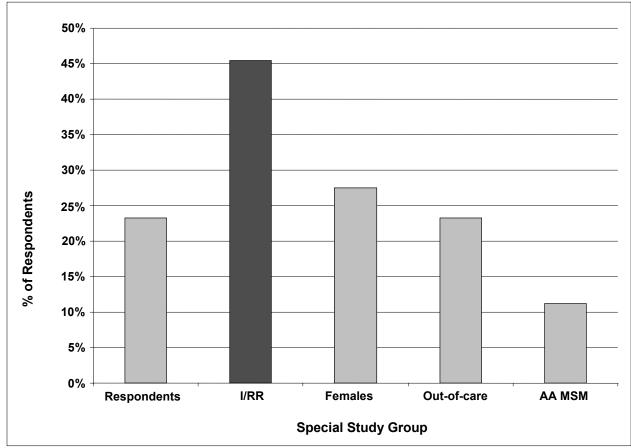


Figure 9-11: COMORBIDITIES – AA MSM VS ALL RESPONDENTS

Substance Use/Abuse

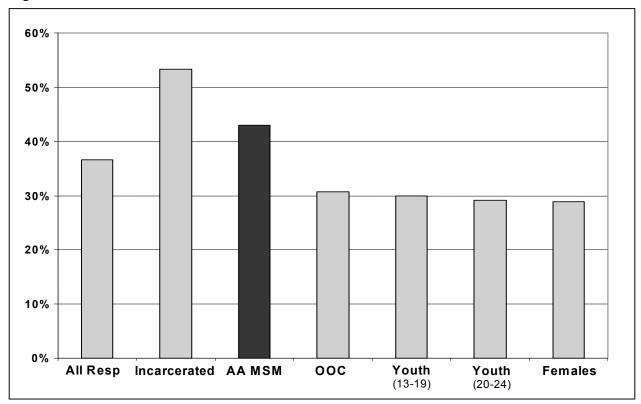
AA MSM were the least likely group to admit injecting substances. 10% report 'ever' injecting substances compared to 23% for all respondents as shown in Figure 9-12.

Figure 9-12: ADMISSION OF 'EVER' INJECTING SUBSTANCES BY SPECIAL STUDY GROUP



42% reported using substances compared to all respondents at 36%. See Figure 9-13.

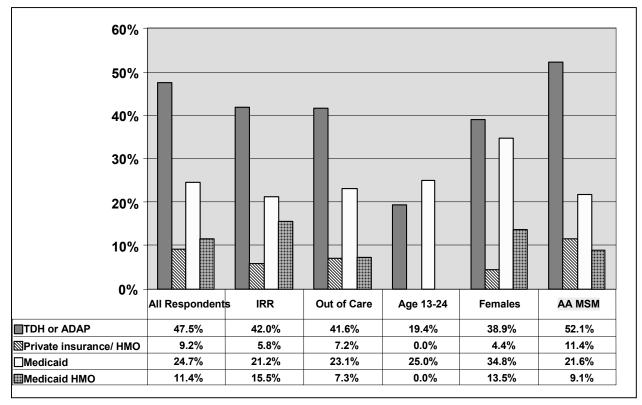
Figure 9-13: SUBSTANCE ABUSE BY SPECIAL STUDY GROUP



Use of Drug Assistance

Drug Assistance funds (TDH or ADAP) were most frequently accessed by AA MSM (52%). These were followed by Medicaid (30.7%) for an 83% cumulative public sector financing. The remainder of AA MSM (11.4%) paid for medications with private insurance or Medicaid HMO funding. AA MSM are the most likely group to have commercial insurance. See Figure 9-14.

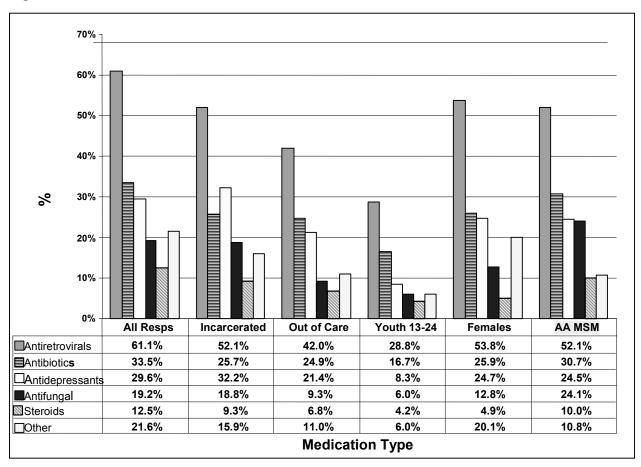




Use of Medication

Although 8% lower than all respondents, AA MSM used antiretroviral drugs at a rate equal to 2 other groups: (Females and Incarcerated). AA MSM had the highest antifungal use and were second to all respondents in use of antibiotics, steroids and antidepressants. See Figure 9-15.

Figure 9-15: USE OF PRESCRIBED MEDICATION BY SPECIAL STUDY GROUP



Homelessness and Housing

ΑII

AA MSM were the most likely of the special study groups to live alone with 48% able to secure individual housing vs. 32% of all respondents. They were also the least likely to have children living with them. See Figure 9-16 and Figure 9-17.

60%
50%
40%
20%
10%

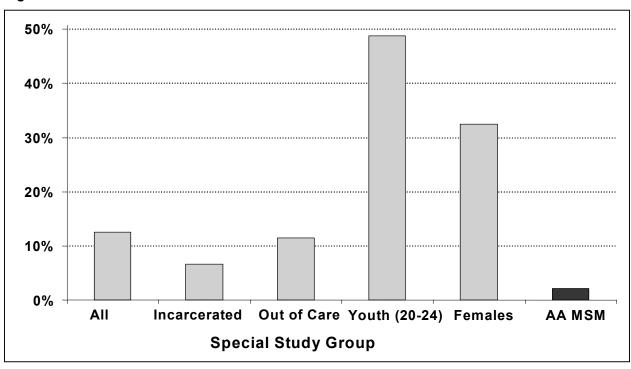
Incarcerated

Special Study Group

Figure 9-16: LIVING ALONE BY SPECIAL STUDY GROUP



Females



OOC

AA MSM

Sexually Transmitted Infections (STIs)

Gonorrhea and syphilis were the sexually transmitted infections with the highest incidence among AA MSM, with rates approaching 40% among AA MSM respondents. These are early indicators of HIV risk, and ongoing comorbidities for AA MSM who are PLWH/A. See Figure 9-18.

Gonorrhea was reported at a 14% higher incidence with a 16% higher rate for syphilis than all respondents.

45% 40% 35% **All Respondents** 30% AA MSM 25% 20% 15% 10% 5% 0% **Hepatitis** Gonorrhea **Syphilis** Genital Chlamydia Herpes Yeast (A, B, or C) Infections (Genital) Warts

Sexually Transmitted Infection

Figure 9-18: REPORTED SEXUALLY TRANSMITTED INFECTIONS- AA MSM VS ALL RESPONDENTS

Use and Barrier Analysis

Need and gap rankings are analyzed to determine unmet need. Use statistics represent the percentage of AA MSM who indicated on the client survey that they have used the services and barriers that they perceived the service as "hard to get." As is seen in the charts, the services with the highest use and perceived barriers are included in support services. See Table 9-4.

Table 9-4: AA MSM - USE AND BARRIERS ANALYSIS

USE				
SERVICE CATEGORY	Use %			
Ambulatory/Outpatient Medical Care	80			
Social Case Management	63			
Nutritional Counseling	63			
Support Services	84			
Dental Care	73			
Substance Abuse Counseling	54			
Drug Reimbursement	57			
Mental Health Services	70			
Hospice*	13			
Home Health Care*	71			
Rehabilitation*	50			

BARRIER				
SERVICE CATEGORY	Barrier %			
Ambulatory/Outpatient Medical Care	17			
Social Case Management	9			
Nutritional Counseling	6			
Support Services	37			
Dental Care	10			
Substance Abuse Counseling	8			
Drug Reimbursement	7			
Mental Health Services	9			
Hospice*	10			
Home Health Care*	13			
Rehabilitation*	11			

^{*}See note on page 176 regarding these service categories.

Needs Analysis

Need statistics represent the percentage of African American MSM who indicated on the client survey that they believed that they currently need the service. It does not differentiate whether or not they believe that the need is being met. See Table 9-5.

Table 9-5: AA MSM - NEED ANALYSIS

NEED				
SERVICE CATEGORY	Need %			
Ambulatory/Outpatient Medical Care	28			
Social Case Management	64			
Nutritional Counseling	47			
Support Services	57			
Dental Care	82			
Substance Abuse Counseling	29			
Drug Reimbursement	47			
Mental Health Services	29			
Hospice*	6			
Home Health Care*	13			
Rehabilitation*	20			

^{*}See note on page 176 regarding these service categories.

Gap Analysis

Perceived service gaps were determined based on a respondent indicating that services were "needed" but "not available" as shown in Table 9-6.

Table 9-6: AA MSM - GAP ANALYSIS

GAP				
SERVICE CATEGORY	Need %			
Ambulatory/Outpatient Medical Care	36			
Social Case Management	3			
Nutritional Counseling	11			
Support Services	41			
Dental Care	4			
Substance Abuse Counseling	5			
Drug Reimbursement	8			
Mental Health Services	12			
Hospice*	3			
Home Health Care*	11			
Rehabilitation*	19			

^{*}See note on page 176 regarding these service categories.

Qualitative Findings - Needs, Gaps, and Barriers:

In the focus groups we asked questions about needs, gaps and/or barriers. In the modified RARE research, we concentrated on risk factors to HIV/AIDS.

Focus Group Findings: Needs - AA MSM

Education:

"Educate the public that HIV is not a death sentence. Help them know it's not fatal. I don't know how to bring that together but"

<u>Awareness/Prevention with Bisexuality:</u>

"Women are a real concern in our area. Many of them are with men who we know are bisexual, they know their lifestyle is shaky but they still sleep with us"

Underserved Areas:

"Yes, the North and South part. Most services are in Montrose."

"Houston has a lot of agencies. If there isn't help there, it's here. I think outside the Beltway has troubles."

Wait for Prescription Drugs at Clinics:

"I'd personally not have too many complaints except when it comes time for receiving my prescription that's my biggest peeve. There are times when you wait exceptionally long and then there are times when you get your prescription within an hour."

Access into System:

"I see, the hardest problem for me was, getting into the system they were pretty sticky about me having a proof of address. Unless I provided proof of address and stuff like that, they wouldn't let me in. I was getting the run-around."

Insurance Verification:

"If you don't have your eligibility card, you don't receive no services. They want proof of income, proof of address, they want your I.D. It was kind of like the situation I was in when I first got out of jail, I needed something but nobody wanted to see me."

"You get the feeling at [provider] that you got to go there. I have a doctor and he told me that one of the medications made me feel sick—the doctor there told me 'tough' if you don't take it, you'll die anyway. That's the doctor's attitude. I wished he would care. When I got out of jail, I didn't have medical insurance, and I was on Social Security but I couldn't get Medicare. When I walked into [Provider], they told me I was in the computer before getting medication. It took months to get into their system so I was denied medications."

Focus Group Findings: Barriers - AA MSM **Qualifying for Transportation:** "Gas card is another issue. The length of time between either using the bus or having a car with a gas card is a problem. Now when you come around, you have to fill out 150 pages and you don't have it anymore—you have to keep qualifying." Discrimination: "I've had it. In an outreach program for a church, I went there one time, me and my wife used to go there to get clothing vouchers. I told them I was HIV, and then they would not help me."

THEMES AND RECOMMENDATIONS:

AFRICAN AMERICAN MSM

Theme 1: AA MSM are better educated more likely to carry employer-sponsored or private insurance or COBRA and have drug assistance from those payers than all respondents or other special study groups.

Recommendation: This socioeconomic group can better access resources yet is slightly less likely to be 'in care' at 77% than all respondents. This may demonstrate cultural beliefs or misperception or unawareness of providers. Respondents reported that providers advised against aggressive primary care despite a tendency for AA MSM to be unaware of their viral load. This suggests that either the providers for AA MSM need to be educated regarding more aggressive primary care or at a minimum, more proactive education of their clients regarding viral load needs to occur.

Theme 2: AA MSM admitted in both focus groups and the RARE street interviews to hustling with both sexes whether they are truly bisexual or not. They openly express concern about transmission to African American Women.

Recommendation: Proactive and open communication and education among the African American community needs to occur about protection (condoms) and/or education of African American women about rejection or refusal techniques.

Theme 3: Comorbidities are of particular concern for AA MSM due to their ethnic propensity to be at higher risk for high blood pressure and diabetes. The interaction of these two conditions to antiretroviral therapy is most concerning.

Recommendation 3: Ensure that providers to AA MSM are aware of the complications and risks associated with antiretroviral medication and conditions to which African Americans are predisposed. Fully alert all providers, including non-ASO's who may be less aware of these complications than AIDS service organizations.

Chapter 10: Special Study Youth Living with HIV/AIDS (Age 13 - 24)

Importance

According to the Center for Disease Control, in the U.S. in 2000, 1,688 young people (ages 13 to 24) were reported with AIDS, increasing the cumulative total to 31,293 cases of AIDS in this age group. Among young men aged 13- to 24-years:

- 49% of all AIDS cases reported were among men who have sex with men (MSM);
- 10% were among injection drug users (IDUs); and
- 9% were among young men infected heterosexually.

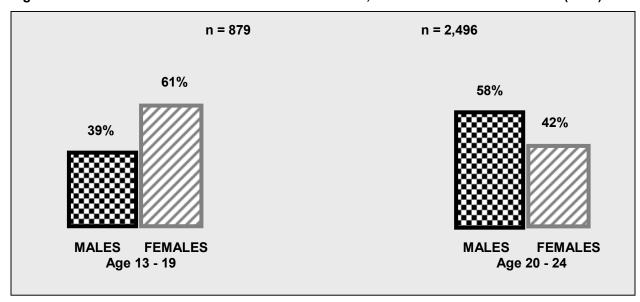
In 2000, among young women the same age:

- 45% of all AIDS cases reported were acquired heterosexually and
- 11% were acquired through injection drug use.

Surveillance data for the period between January 1996 and June 1999 indicate that young people (aged 13 to 24) accounted for a greater proportion of HIV (13%) than AIDS cases (3%). These data show that even though AIDS incidence is declining, *there has not been a comparable decline in the number of newly diagnosed HIV cases among youth.*

Scientists believe that cases of HIV infection diagnosed among 13- to 24-year-olds are indicative of overall trends in HIV incidence because this age group has more recently initiated high-risk behaviors. Females made up nearly half (47%) of HIV cases in this age group - and in young people between the ages of 13 and 19, a much greater proportion of HIV infections was reported among females (61%) than among males (39%). Young African Americans are most heavily affected, accounting for 56% of all HIV cases reported among 13 to 24 year-olds. See Figure 10-1.

Figure 10-1: HIV INFECTIONS: AGE 13 - 19 AND 20 - 24, REPORTED FROM 34 AREAS (2000)



Health care and support services planning for this growing group of young people requires consideration of their particular risks and needs, as noted by Jonathan Ellen, MD, in the May, 2002 issue of the Hopkins HIV Report:

- A large cohort of youth infected with HIV and sustained by HAART, is coming of age and in need of specialized medical care, including counseling and services to address their reproductive health choices.
- Heterosexually acquired HIV among young females is a growing problem, but identifying specific characteristics of those at risk remains a problem.

Epidemiologic/Demographic Profile

The Houston Area Epidemiological Profile produced by the Houston Regional HIV/AIDS Resource Group in April 2002 provides population-based data for living PLWH/A. These can be used to compare special populations (Youth, ages 13 - 24) with the full surveyed population. The weighted surveyed population for the Needs Assessment contained 10 Youth (age 13 - 19) and 14 Youth (age 20 - 24) for a total of 4.3% of the surveyed population. In contrast, the 2002 Epidemiological Profile reported 11.8% of PLWH/A are contained within those age bands in the EMA/HSDA. See Table 10-1.

Table 10-1: TOTAL LIVING ADULT/ADOLESCENT PLWH/A, TDH 2002

AGE	FEMALE	MALE	TOTAL
13 –19	1.6%	0.6%	2.3%
*20 -29	8.9%	16.7%	25.6%
*20 – 24	4.3%	5.2%	9.5%
*25 - 29	4.6%	11.5%	16.1%
30 – 39	8.4%	34.3%	42.7%
40 – 49	4.1%	17.9%	22.0%
50 – 59	1.2%	4.9%	6.1%
60 - 69	0.2%	0.9%	1.1%
70+	0.0%	0.2%	0.3%
TOTAL	24.6%	75.4%	100.0%

^{*} Age group 20 – 29 is a combination of youth age 20 - 24 and adults age 25 - 29.

Although the client survey attracted fewer respondents in those age groups, focus groups were able to add important qualitative inputs to this study. Due to small numbers, we have consolidated these two age bands into "All Youth" ages 13 - 24.

Gender

More females than males participated in the EMA/HSDA groups. This reflected the greater willingness of younger females to speak their mind in helping provide input into resources for HIV/AIDS. Of interest is that the 20 - 24 age band is the only age group in which there is an even male/female ratio at the EMA/HSDA level. See Table 10-2.

Table 10-2: GENDER - YOUTH, AGE 13 - 24

Gender	All Respondents	All Youth	Youth 13 – 19	Youth 20 - 24
Male	70.3%	21.9%	10.0%	30.4%
Female	28.7%	78.1%	90.0%	69.6%
Transgender	1.1%	0.0%	0.0%	0.0%
Total	100.0%	100.0%	100.0%	100.0%
	EMA/HSDA	All Youth	Youth 13 – 19	Youth 20 - 24
	Male	49.3%	27.9%	54.4%
	Female	50.7%	72.1%	45.6%
	Transgender	0.0%	0.0%	0.0%
	Total	100.0%	100.0%	100.0%

Race and Ethnicity

Surveyed Youth were distributed similarly to the full EMA/HSDA along racial and ethnic lines as shown in Table 10-3.

Table 10-3: ETHNICITY - SURVEYED YOUTH

Ethnicity	All Respondents	All Youth	Age 13 – 19	Age 20 – 24	HSDA
Non Hispanic Anglo	31.9%	12.5%	20.0%	7.2%	13.3%
African-American	45.8%	75.0%	80.0%	71.4%	75.3%
Hispanic	21.1%	12.5%	0.0%	21.5%	10.9%
Other	1.3%	0.0%	0.0%	0.0%	0.4%
Total	100.0%	100.0%	100.0%	100.0%	100.0%

HIV Status

HIV status for Youth matched the EMA/HSDA and the full respondent population. Multiple responses involving "HIV negative" plus another response indicating the respondent was actually HIV positive were common on this question, possibly because of confusion between being positive and viral load detection. See Table 10-4.

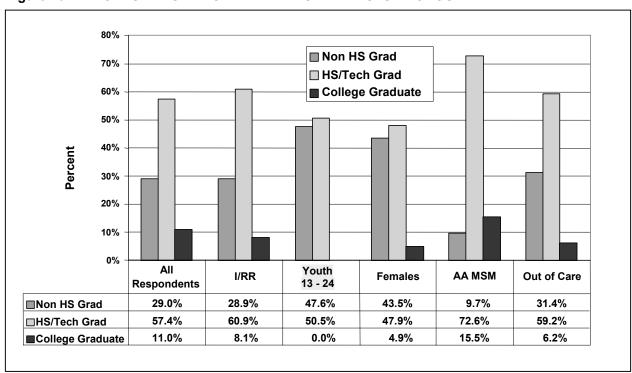
Table 10-4: HIV STATUS - YOUTH

HIV Status	All Respondents	All Youth	Youth 13 - 19	Youth 20 – 24	All Youth (EMA/HSDA)
HIV Negative	4.5%	26.9%	20.0%	31.8%	NA
HIV Positive (No symptoms)	51.4%	56.4%	60.0%	53.9%	61.8%
HIV Positive (Symptoms)	31.2%	12.5%	10.0%	14.3%	01.070
Living with AIDS	30.3%	8.3%	10.0%	7.1%	38.2%
Total*	117%	104%	100.0%	107.1%	100.0%

Educational Level

Youth lack college education and complete high school education. Seventy-five percent of the older age group had graduated from high school, which exceeds any other group except the AA MSM as shown in Figure 10-2.

Figure 10-2: HIGHEST EDUCATION LEVEL BY SPECIAL STUDY GROUP



Sexual Orientation

Most youth participating in the survey were heterosexual. See Figure 10-3.

100% 90% ■ Heterosexual 80% **■** MSM 70% □ Bisexual 60% Percentage 50% 40% 30% 20% 10% 0% ΑII Youth 13-24 Incarcerated **Out of Care Females AA MSM** Respondents ■ Heterosexual 44.6% 37.7% 42.9% 84.6% 86.1% 38.7% 30.7% 34.4% 13.6% 0.6% 74.4% ■ MSM 13.1% 28.2% 16.0% 1.9% 6.3% 25.3% □ Bisexual

Figure 10-3: SEXUAL ORIENTATION BY SPECIAL STUDY GROUP

PROFILE OF SOCIOLOGIC AND HEALTH OBSERVATIONS - YOUTH:

Care Status

The percentage of youth who indicated that they were "out-of-care" due to provider advice was higher than the percentage of any of the other special populations as shown in Table 10-5 and Table 10-6.

Table 10-5: CARE STATUS - ALL YOUTH

Care Status	All Respondents	All Youth
In-care	81%	65%
Out-of-care	12%	26%
Never-in-care	7%	9%
Total	100%	100%

Table 10-6: REASON OUT OF CARE BY SPECIAL STUDY GROUP

Reason Out of Care	All Respondents	000	Incarcerated	Youth	Females	AA MSM
Personal Choice	45.8%	43.0%	41.9%	42.9%	38.3%	38.9%
Provider Advice	32.9%	33.9%	28.0%	57.1%	41.4%	36.7%
Access	21.3%	23.1%	30.1%	0.0%	20.3%	24.4%
Total	100.0%	100.0%	100.0%	100.0%	100.0%	100.0%

Viral Load

Youth were less likely to know their viral load than all respondents and had a profile similar to those "out-of-care" as Figure 10-4 illustrates.

60% ■ Don't Know ■ No Answer 50% % Don't Know 40% 30% 20% 10% 0% ALL OOC IRR YOUTH FEMALE AAMSM **Special Study Group**

Figure 10-4: VIRAL LOAD PROFILE BY SPECIAL STUDY GROUP

Viral load profiles for all Youth showed current levels to be more similar to the highest rather than lowest historical loads, suggesting a less than ideal health and adherence profile for youth PLWH/A. See Figure 10-5.

100% 80% □ Don't Know 60% > 1 MM 500K - 1MM 50K -500K 40% ☐ 5K - 50K < 5K</p> 20% **Undetectable** 0% **Highest** Current Lowest

Figure 10-5: VIRAL LOAD PROFILES - YOUTH

Testing History

The high number of diagnoses of HIV with pregnancy testing reflects a high percentage of female respondents in the Youth group. Perinatal transmission was determined to be the explanation for the high (16.7%) 'not applicable' response registered only by the "out-of-care" group (7.2%). These "out-of-care" respondents were determined to be Youth who had HIV since birth. See Figure 10-6.

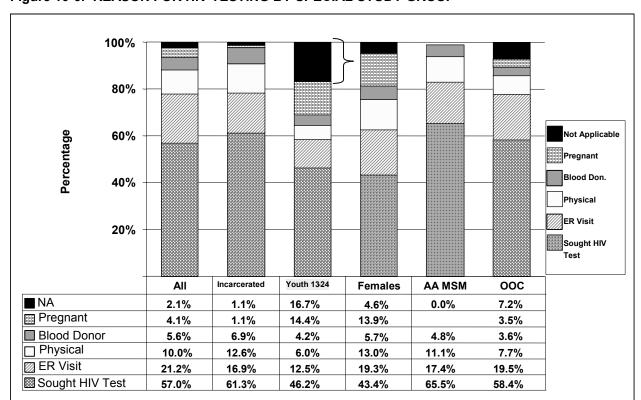


Figure 10-6: REASON FOR HIV TESTING BY SPECIAL STUDY GROUP

Transportation

Youth reported transportation-related problems that were different from the rest of the population with more trouble trying to get to social service and childcare appointments as illustrated in Figure 10-7. This is consistent with feedback from focus groups.

50% 45% All Youth 40% 35% Percent of Respondents 30% 25% 20% 15% 10% 5% 0% **Medical Services Social Services Child Care Basic Services Purpose of Travel**

Figure 10-7: TRANSPORTATION "NOT EASY" BY SERVICE TYPE ALL YOUTH VS ALL RESPONDENTS

Insurance

Youth were more likely than all respondents and most subgroups to be uninsured. See Figure 10-8. This correlates with national studies that find they are 3 to 15% less likely to be insured than any other group.¹

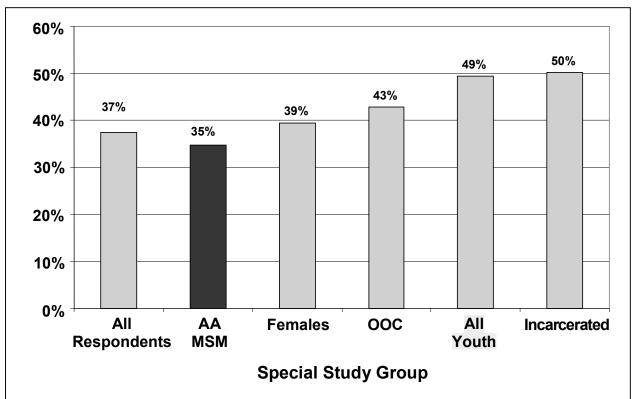


Figure 10-8: PERCENT UNINSURED BY SPECIAL STUDY GROUP

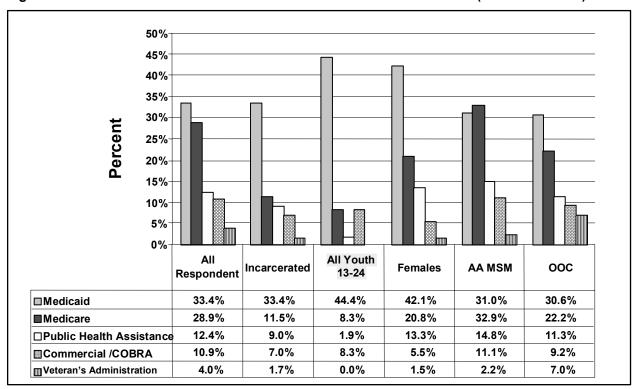
"Despite two consecutive years of declines in the number of uninsured Americans at the end of the 1990s boom, essentially the same percentage of the U.S. population was uninsured in 2000 as was in 1994 - about 17 percent."

Chapter 10: SPECIAL STUDY: YOUTH LIVING WITH HIV/AIDS

¹ Pohl, Mary Beth and Holahan, John. "Changes in Insurance Coverage: 1994-2000 and Beyond." <u>Health Affairs</u>, April 3, 2002.

If insured, they tend to have Medicaid coverage, as Figure 10-9 shows.

Figure 10-9: HEALTH INSURANCE SOURCE BY SPECIAL STUDY GROUP (INSURED ONLY)



Comorbidities

Youth, as expected, had few comorbidities. Hypertension was the only significant comorbidity. This may be more related to the high percentage of African Americans reported in the youth group (75% vs. 45.8% for All Respondents). The incidence of hypertension is twice as great in African Americans as in Caucasians. The small number of respondents and comorbidities reported make analytic conclusions difficult. See Figure 10-10.

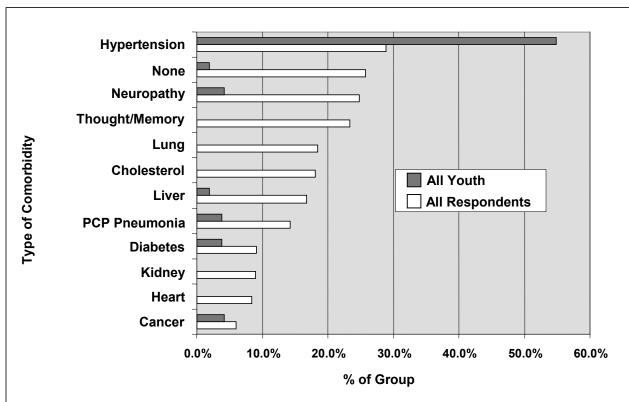
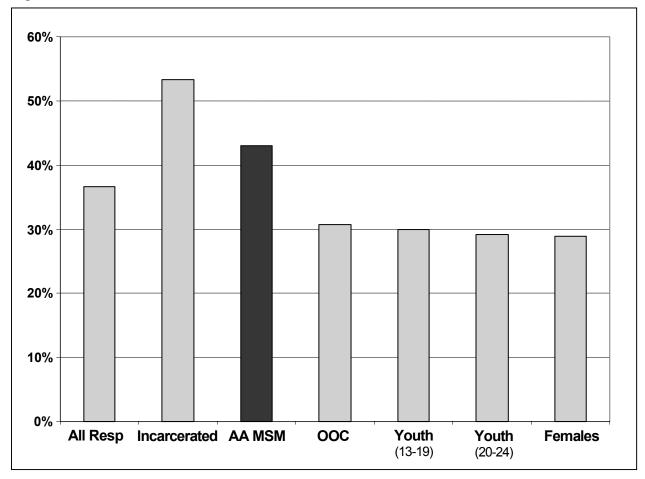


Figure 10-10: COMORBIDITIES: YOUTH VS ALL RESPONDENTS

Substance Use/Abuse

Youth reported no injection abuse and modest substance abuse compared to the full population as illustrated in Figure 10-11.

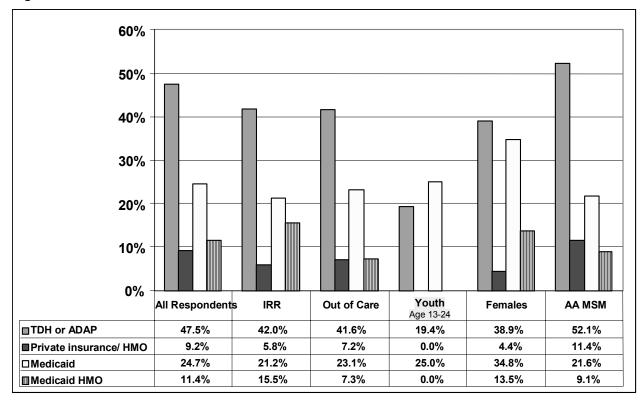
Figure 10-11: SUBSTANCE ABUSE BY SPECIAL STUDY GROUP



Use of Drug Assistance

Although most youth receive Medicaid, drug assistance of any sort was lower among Youth perhaps reflecting low use of medication or lack of awareness of this service (see Figure 10-12 below).

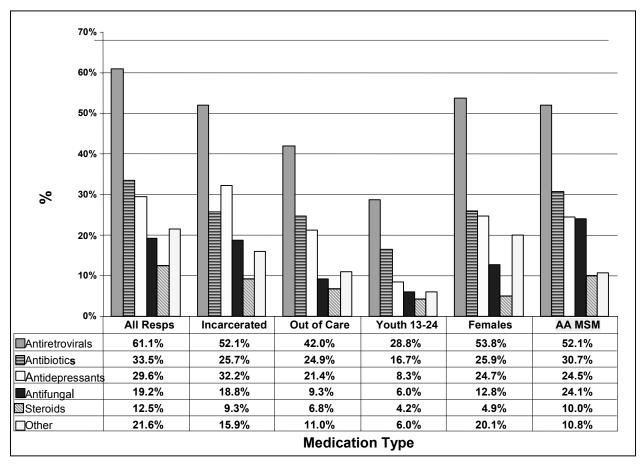
Figure 10-12: DRUG REIMBURSEMENT USE BY SPECIAL STUDY GROUP



Medication Use

Youth had low antiretroviral use rates and low use of medication in general, as illustrated in Figure 10-13.

FIGURE 10-13: USE OF PRESCRIBED MEDICATION BY SPECIAL STUDY GROUP



Homelessness and Housing

Youth were the least likely to live alone, as indicated in Figure 10-14 below.

60% 50% 40% 30% 20% 10% 0% All Females I/RR OOC Youth AA MSM 13 - 24

Figure 10-14: LIVING ALONE BY SPECIAL STUDY GROUP

Youth were also the most likely to live with children, as shown in Figure 10-15. None of the surveyed Youth was homeless.

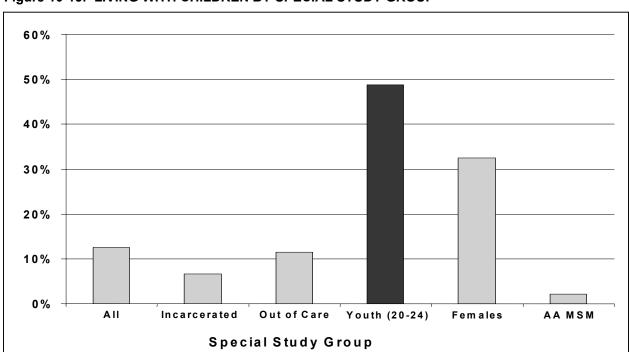


Figure 10-15: LIVING WITH CHILDREN BY SPECIAL STUDY GROUP

Sexually Transmitted Infections (STI)

Youth were the least likely to be infected with any form of hepatitis. See Figure 10-16.

50% 45% 40% 35% 30% Percentage 25% 20% 15% 10% 5% 0% All Out-of-All Incarcerated AA **Females** Respondents Youth care **MSM**

Figure 10-16: HEPATITIS (A, B, or C) BY SPECIAL STUDY GROUP

Youth reported more incidence of chlamydia than any group other than females and less syphilis than any group. See Figure 10-17.

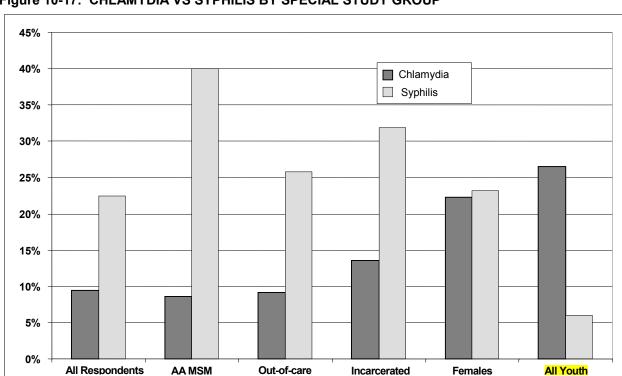


Figure 10-17: CHLAMYDIA VS SYPHILIS BY SPECIAL STUDY GROUP

Chapter 10: SPECIAL STUDY: YOUTH LIVING WITH HIV/AIDS

Use and Barrier Analysis

Need and gap rankings are analyzed to determine unmet need. Use statistics represent the percentage of Youth who indicated on the client survey that they have used the services and barriers that they perceived the service as "hard to get." See Table 10-7.

Table 10-7: YOUTH - USE AND BARRIERS ANALYSIS

SERVICE CATEGORY	Use %
Ambulatory/Outpatient Medical Care	68
Social Case Management	14
Nutritional Counseling	13
Support Services	48
Dental Care	38
Substance Abuse Counseling	7
Drug Reimbursement	49
Mental Health Services	40
Hospice*	0
Home Health Care*	18
Rehabilitation*	0

SERVICE CATEGORY	Barrier %
Ambulatory/Outpatient Medical Care	29
Social Case Management	9
Nutritional Counseling	5
Support Services	19
Dental Care	9
Substance Abuse Counseling	9
Drug Reimbursement	5
Mental Health Services	9
Hospice*	9
Home Health Care*	9
Rehabilitation*	9

^{*}See note on page 176 regarding these service categories.

Needs Analysis

Need statistics represent the percentage of Youth who indicated on the client survey that they currently need the service, but not whether they believe that the need is being met. See Table 10-8.

Table 10-8: YOUTH - NEED ANALYSIS

SERVICE CATEGORY	Need %
Ambulatory/Outpatient Medical Care	40
Social Case Management	26
Nutritional Counseling	10
Support Services	17
Dental Care	38
Substance Abuse Counseling	10
Drug Reimbursement	**0
Mental Health Services	14
Hospice*	***0
Home Health Care*	3
Rehabilitation*	0

^{*}See note on page 176 regarding these service categories.

^{**29%} of youth respondents indicated a need in the individual service, Medications/Therapeutics; however, none reported a need in Drug Reimbursement. This discrepancy is due to the low number of respondents and limitations in the survey.

^{***}Respondents reported a 4.3% need in both residential and home-based hospice (individual services), but none reported a need in the service category Hospice. This discrepancy is also due to the low number of youth respondents and limitations in the survey.

Gap Analysis

Perceived service gaps were determined based on a respondent indicating that services were needed but not available. See Table 10-9.

Table 10-9: YOUTH - GAP ANALYSIS

SERVICE CATEGORY	Need %
Ambulatory/Outpatient Medical Care	15
Social Case Management	2
Nutritional Counseling	0
Support Services	17
Dental Care	7
Substance Abuse Counseling	0
Drug Reimbursement	7
Mental Health Services	0
Hospice*	0
Home Health Care*	0
Rehabilitation*	0

^{*}See note on page 176 regarding these service categories.

Qualitative Findings - Needs, Gaps, and Barriers:

Focus group findings for Youth are consolidated rather than divided into comments relating to needs and those relating to gaps and/or barriers. For informants participating in the modified RARE research, these distinctions were blurred.

Focus Group Findings: - Youth

Q: "What kind of help did you have when they told you that you were positive? Did they give you medical help or counseling help?"

A: "They told me I had to go to [provider] and I go there now."

Q: "And did you go there while you were in lockup?"

A: "Yes, I went there about once a month. My roommate, I talked to her, she told me if I needed any help, I should call or write her. I thought she would take it different - I thought she would want to go to another room. She and I still write."

Q: "That must have felt good, that she gave you a vote of confidence right there in the beginning."

A: "Yes, cause she had a best friend who died of AIDS and I took that pretty hard cause I don't want nothing to happen to my child."

Q: "So how do you think you got infected?"

A: "I'm not too sure but I was in this clinic and got tested and it was negative (some STD thing). I went to [Provider] about 2 months later and I was positive, so I'm not too sure."

Q: "And do you know what kinds of things that you might have done that put you at risk? Have you ever used IV drugs? Do you think you were infected while having sex?"

A: "No, I've never used drugs. It must be through sex."

Q: "Are you taking any birth control?"

A: "Not right now because we're having money problems, and I can't get them right now, but I would."

Q: "And at [provider] you can't get drugs without paying for them?"

A: "Yes - I don't have a eligibility card cause I don't have Medicaid."

Q: "Has anyone talked to you about the HIV drug program?"

A: "No"

Focus Group Findings: - Youth

Q: "Do you have a case manager?"

A: "Yes"

Q: "Has she talked to you about the HIV Drug program?"

A: "No, I haven't seen her in a long time."

Q: "So do you go to the clinic once a month?"

A: "Not now"

Q: "So when was the last time you were there?"

A: "About December" [3 months prior to interview]

Q: "And at that time did you see your case manager? And what types of things did you talk about then?"

A: "I was actually really late for my appointment so she gave me a lunch thing and told me to go home, cause I was really late."

Q: "So she didn't set up a new appointment for you?"

A: "Oh yeah, I have one coming up."

Q: "What's this one coming up?"

A: "It's in March." [4 months from last visit to provider]

Q: "And she knew that you weren't taking meds at that point? And your doctor told you that you ought to be taking them?"

A: "Yes, cause back when I had the money and I tried to get it prescribed, and then when the doctor sent me the prescription, we live too far for me to drop that off and come pick it up. When they finally called, I didn't have the money."

Q: "You mentioned about how far you live—one of the things that we're interested in is transportation. How do you get back and forth for medical care? How far do you live from [provider]? How do you get there and home?"

A: "I live in [neighborhood] and [provider] [is] a long distance ..."

Q: "So how would you normally get there?"

A: "There was a cab program and a cab would bring you there and you give them a voucher, then they take you back home, but it ran out of money."

Focus Group Findings: Youth

Q: "What would have made a difference about what you learned, what you were taught that might have made you feel it was more of a danger."

A: "I would say when I was growing up, I was moved from home to home to home. I figure if I was in with my mom, I was with her for 3 months, and then she got locked up. In those 3 months, I had a great time—she would lock me out of my room if I didn't do what was right, but she let us do whatever we wanted as long as we told her where we were. Whenever she went to work she would make sure no boys were at the house, make sure we were ok. I think if I had stayed with her, I wouldn't have a child right now, I'd be in school."

Q: "Anything you think schools could do or agencies? You were probably 13-15 when you left school? What could they do to help kids from being infected?"

A: "In schools they need to talk about STD's and HIV and the harder parts of what could happen with sex vs. condoms and periods. We heard about it when we were in 6th grade, Junior High and that's too late."

RARE FINDINGS: YOUTH

Outreach

"I'm not sure what affiliation they're from, but some people come in on the weekends, on Fridays, Saturdays and sometimes Sunday too. They pass out condoms and take little surveys and that stuff, 'cause I've done it before. Some take them, some don't. I think that's real good...I see the majority of folks in my circle, my friends or associates practice safe sex. I see another group, like kids, who are whores or prostitution, chicks for money; I know the majority of them don't use condoms. And it's available for them but they don't use condoms and I think that's sad."

THEMES AND RECOMMENDATIONS:

YOUTH

Theme 1: Youth consistently demonstrated a desire for more education, information at an earlier age. This extends to risk factors such as unprotected sex and drug use. Early grade school seems premature, but specific comments about sex education not starting until the 6th grade as far too late show the need to start these efforts early.

Recommendation: Continue to provide prevention education at increasingly earlier ages in school systems, churches and day care. Extend patient education programs targeted to young mothers and female teens.

Theme 2: Youth are among the most likely to be uninsured. Many lose coverage when they turn 18 years old.

Recommendation: Further target those PLWH/A Youth who are turning 18 to ensure continuity of care and funding.

Theme 3: Youth are vulnerable to being unconnected to any care system due to their lack of means to pay for care, lack of awareness to find out what services are offered, belief that they are not at high risk and their probability of being uninsured.

These vulnerability factors are stressed when many young women have children at an early (under 20 years) age. Lack of employment or under-employment further stresses their situation.

Recommendation: Coordinate AIDS prevention efforts with other social service agencies (schools, after-school programs, youth development programs) that cater to youth. Develop risk profiles to have for agencies to use in assessing and referring those youth most vulnerable to risk of developing HIV.

Consider a peer outreach program to inform and educate Youth regarding risk factors and areas for testing/treatment.

Theme 4: 16.7% of Youth stated that they were born HIV positive and of the "out-of-care" youth, 7.2% also stated that they were HIV positive at birth. This may indicate either that they received early aggressive treatment and appropriate medical advice to not receive primary care in the past 6 months or a fatalistic attitude towards the disease.

Recommendation: Continue to assess any difference in the care needs of perinatally infected youth.

Theme 5: Surveillance data suggest that the rate of new infection among youth is increasing and that as many as 25% - 30% of those infected may not know their HIV status.

Recommendation: Expand outreach, testing and early intervention programs to youth. Explore the opportunities for assistance in these efforts from the NIH-funded Adolescent Trial Network, which was created to "develop effective methods of enhanced case findings for Youth living with HIV/AIDS, and to develop and test prevention efforts for the most vulnerable youth." 1

¹ [Ellen, JM, Adolescents and HIV. May, 2002. The Hopkins HIV Report.

Chapter 11 Special Study: Women Living with HIV/AIDS

Importance

Between 1992 and 1999, a growing proportion of persons living with AIDS were women, reflecting the ongoing shift in populations affected by the epidemic. In 1992, women accounted for 14% of adults/adolescents living with AIDS - by 1999, that proportion had grown to 20%.

Since 1985, the proportion of all AIDS cases reported among adult and adolescent women has more than tripled, from 7% in 1985 to 25% in 1999. The epidemic has increased most dramatically among women of color. African American and Hispanic women together represent less than one-fourth of all U.S. women, yet they account for more than three-fourths (78%) of AIDS cases reported to date among women in our country. In 2000 alone, African American and Hispanic women represented a greater proportion (80%) of cases reported in women. See Figure 11-1.

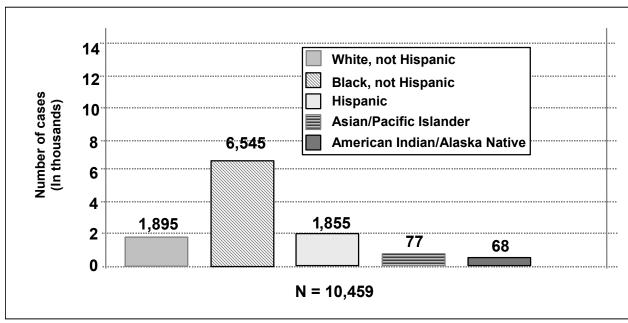


Figure 11-1: AIDS CASES IN ADULT/ADOLESCENT WOMEN BY RACE/ETHNICITY, 2000

Source: HIV/AIDS Surveillance in Women, Centers for Disease Control and Prevention, 2001

While HIV/AIDS-related deaths among women continued to decrease in 1999, largely as a result of recent advances in HIV treatment, HIV/AIDS was the 5th leading cause of death for U.S. women aged 25 - 44. Among African American women in this same age group, HIV/AIDS was the third leading cause of death in 1999.

In 2000, 38% of women reported with AIDS were infected through heterosexual exposure to HIV; injection drug use accounted for 25% of cases. In addition to the direct risks associated with drug injection (sharing needles), drug use also is fueling the heterosexual spread of the epidemic. A significant proportion of women infected heterosexually were infected through sex with an injection drug user. See Figure 11-2.

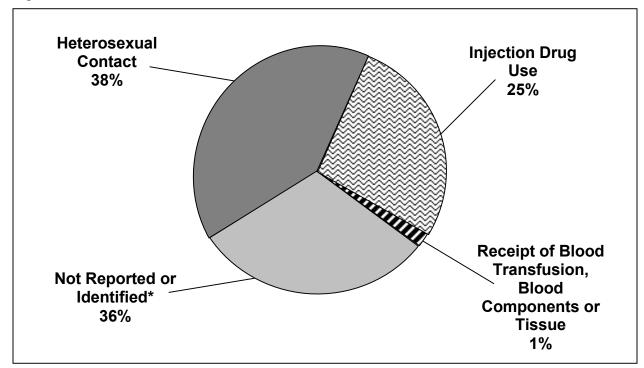


Figure 11-2: AIDS CASES AMONG WOMEN BY RISK EXPOSURE, 2000

Epidemiologic/Demographic Profile

The Houston Area 2002 Epidemiological Profile produced by the Houston Regional HIV/AIDS Resource Group in April 2002 provides the full set of population based data for living, reported PLWH/A. The Epidemiological Profile begins on page 1.

^{*}Most will be reclassified as heterosexual or IDU after follow-up investigations are completed.

Race and Ethnicity

Surveyed females contained twice as many Hispanic (20.9% survey vs. 10.9% EMA/HSDA) and a slightly smaller proportion of African American women (62.5% survey vs. 75.3% EMA/HSDA) than the EMA/HSDA count as shown in Table 11-1.

Table 11-1: ETHNICITY - FEMALES

Ethnicity	All Respondents	Females	All PLWH/A (EMA/HSDA)
Non Hispanic Anglo	31.9%	14.6%	13.3%
African-American	45.8%	62.5%	75.3%
Hispanic	21.1%	20.9%	10.9%
Other	1.3%	1.9%	0.4%
Total	100.0%	100.0%	100.0%

HIV Status

Surveyed females included a smaller percentage of females Living with AIDS (23.0% vs. 54.6%) HIV positive females responding to the client survey were equivalent to the proportion of females in the EMA/HSDA as shown in Table 11-2.

Table 11-2: HIV STATUS - FEMALES

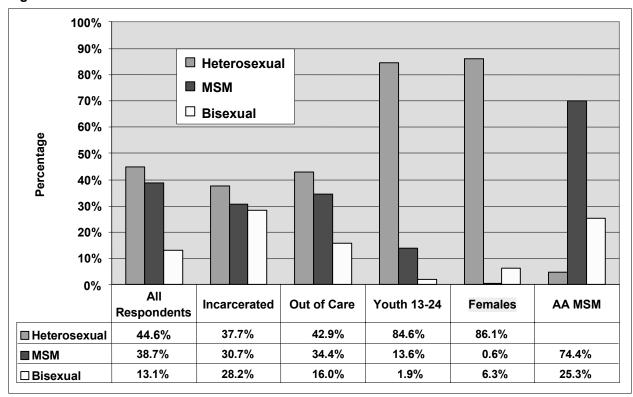
HIV Status	All Respondents	Females	EMA/HSDA
HIV Negative	NA	NA	NA
HIV Positive (No Symptoms)	51.5%	56.2%	45.4%
HIV Positive (Symptoms)	31.4%	25.5%	45.470
Living With AIDS	30.4%	23.0%	54.6%
Total*	113%	105%	100.0%

^{*}Note: Totals of surveyed individuals include "double responses" by some individuals

Sexual Orientation

Females who participated in the survey were predominantly heterosexual. The bisexual percentage of 6.3% was below that of the full surveyed population (13.1%) as illustrated in Figure 11-3.

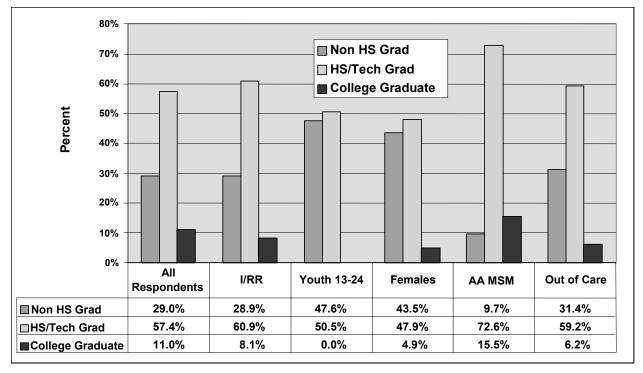
Figure 11-3: SEXUAL ORIENTATION BY SPECIAL STUDY GROUP



Educational Level

Females were less educated than the general respondent population with higher percentages of non-high school graduates and lower percentages of college educated PLWH/A as indicated in Figure 11-4 below.

Figure 11-4: EDUCATION LEVEL BY SPECIAL STUDY GROUP



PROFILE OF SOCIOLOGIC AND HEALTH OBSERVATIONS - FEMALES:

Care Status

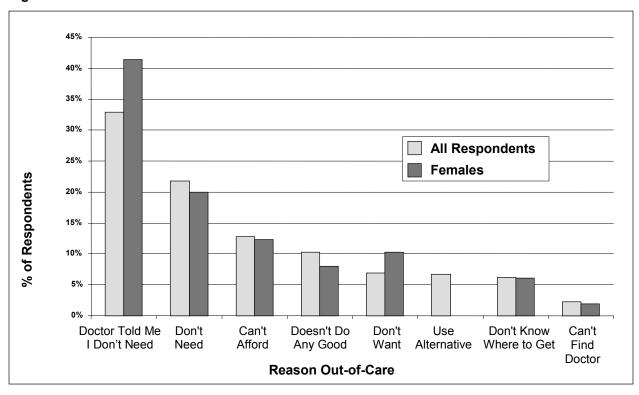
Female PLWH/A were similarly distributed by care status category when compared to the full surveyed population as shown in Table 11-3.

Table 11-3: CARE STATUS - FEMALES VS ALL RESPONDENTS

Care Status	All Respondents	Females
In care	81%	80%
Out-of-care	12%	15%
Never-in-care	7%	5%
Total	100%	100%

Reasons to be out-of-care were similar to the population although females were 10% more likely to report that providers advised them to be out-of-care than the general population, as illustrated in Figure 11-5.

Figure 11-5: REASONS OUT OF CARE - FEMALES VS ALL RESPONDENTS



When compared to all respondents, females were less likely to report a personal choice reason (36% vs. 46%) and more likely to report a provider supported decision to be out-of-care (41% vs. 33%).

Viral Load

Females were less likely to know their viral load than all respondents or other special study groups, as Figure 11-6 indicates.

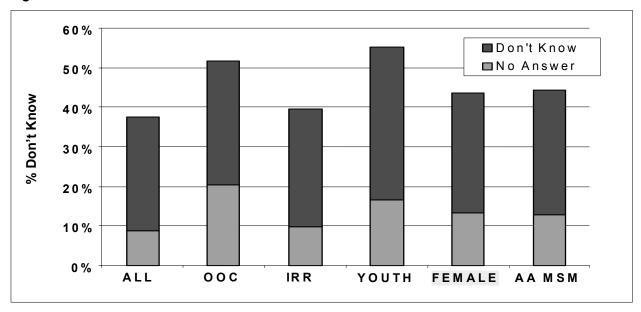


Figure 11-6: VIRAL LOAD KNOWLEDGE BY SPECIAL STUDY GROUP

Viral load profiles for all females showed current loads to be more similar to their highest than lowest historical loads suggesting a less than ideal health and adherence profile for female PLWH/A. See Figure 11-7.

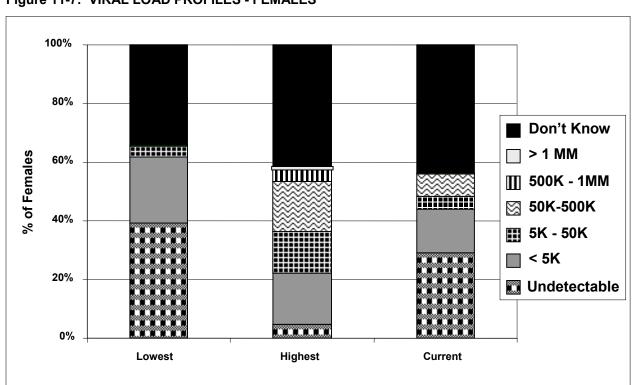


Figure 11-7: VIRAL LOAD PROFILES - FEMALES

Testing History

Females differed from the survey population in testing history. A large percentage were diagnosed as HIV positive when they were being tested for pregnancy or had physical examinations (see Figure 11-8). This represents a unique opportunity and should be used as a tool to bring women into care and to improve fetal and neonatal disease outcomes. Three (3) recommendations result from these findings: (1) communicate with the agencies conducting pregnancy testing about developing protocols for care, (2) aggressively refer or treat these women and (3) ensure that sensitive handling of females occurs when being informed of their diagnosis.

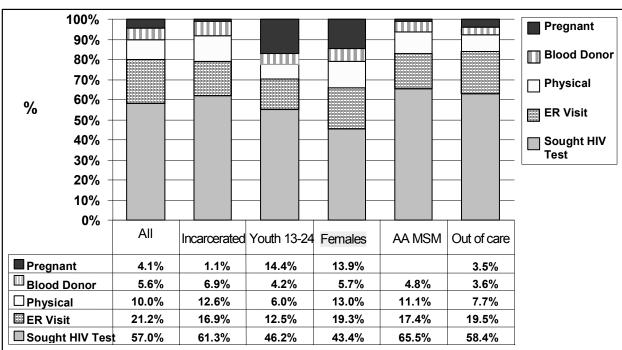
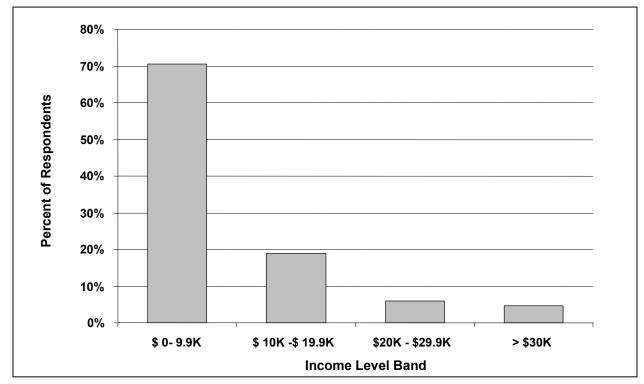


Figure 11-8: REASON FOR HIV TESTING BY SPECIAL STUDY GROUP

Income

While income levels for females did not differ from the population as a whole, the entire population is an impoverished one as Figure 11-9 illustrates.

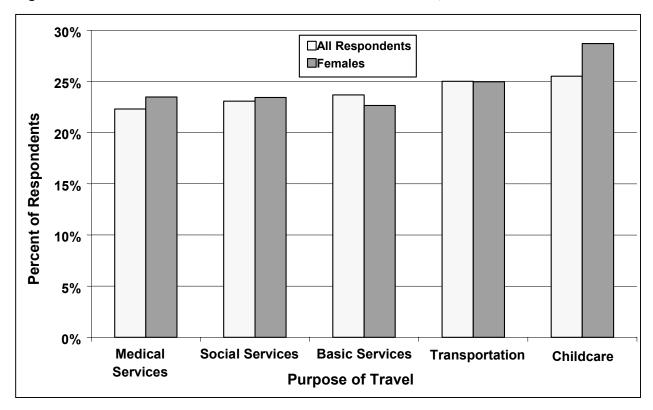
Figure 11-9: INCOME LEVEL - ALL RESPONDENTS



Transportation

Females reported similar transportation problems as the rest of the population. 20% - 25% believed that transportation was 'not easy' when trying to make medical and social service appointments, as indicated below in Figure 11-10.

Figure 11-10: TRANSPORTATION "NOT EASY" BY SERVICE TYPE, ALL RESPONDENTS



Insurance

Although women were close to the survey population as a whole in their rate of being uninsured (39%), that rate is still high when compared to the national average of 17% (see Figure 11-11). Inquiries should be made to assure that women living with HIV/AIDS are aware of the full spectrum of services that they can receive free in addition to their ability to be insured by public sector offerings such as Medicaid. This is vitally important given their role as caregivers to children.

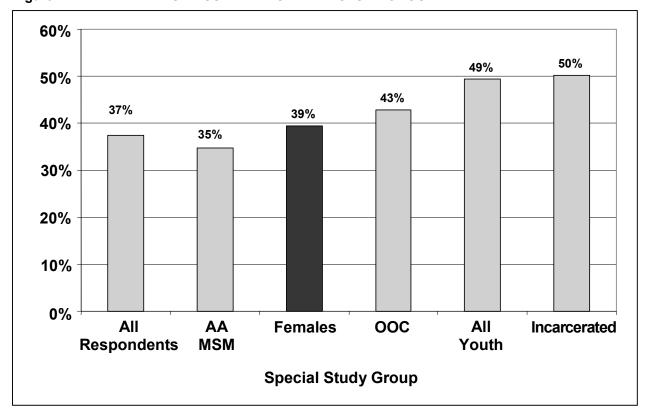


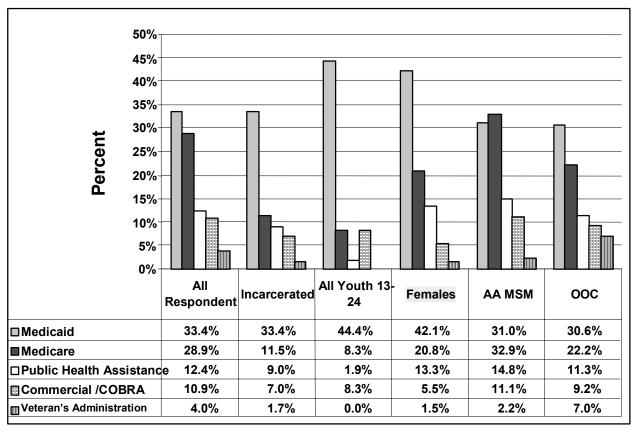
Figure 11-11: PERCENT UNINSURED BY SPECIAL STUDY GROUP

"Despite two consecutive years of declines in the number of uninsured Americans at the end of the 1990s boom, essentially the same percentage of the U.S. population was uninsured in 2000 as was in 1994 - about 17 percent."

¹ Pohl, Mary Beth and Holahan, John. "Changes in Insurance Coverage: 1994-2000" and Beyond." <u>Health Affairs</u>, April 3, 2002

Women who were insured predominantly reported Medicaid coverage at rates much higher than the All Respondents as illustrated in Figure 11-12.

Figure 11-12: HEALTH INSURANCE SOURCE BY SPECIAL STUDY GROUP (INSURED ONLY)

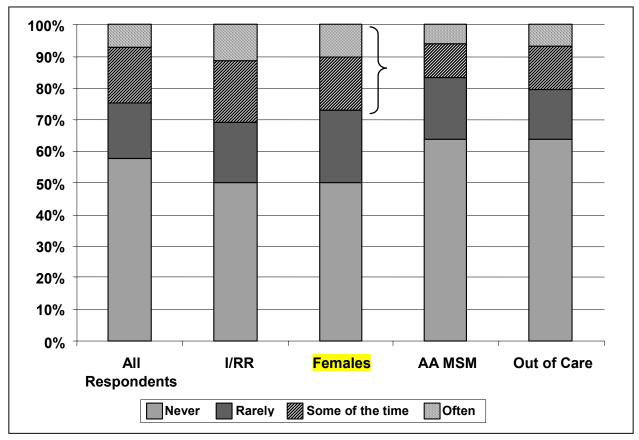


Those with insurance were very satisfied with their coverage.

Disability

While females reported disability with the same frequency as other respondents, they reported more functional impairment as a result. See Figure 11-13.

Figure 11-13: FREQUENCY DISABILITY IS A PROBLEM BY SPECIAL STUDY GROUP (INSURED ONLY)



Comorbidities

Women reported similar comorbidities to the population with the exception of a slightly higher rate of reporting heart disease (11% vs. 7%), diabetes (13 % vs. 8%) and pneumocystis carinii pneumonia (16 vs. 14%) as shown in Figure 11-14.



