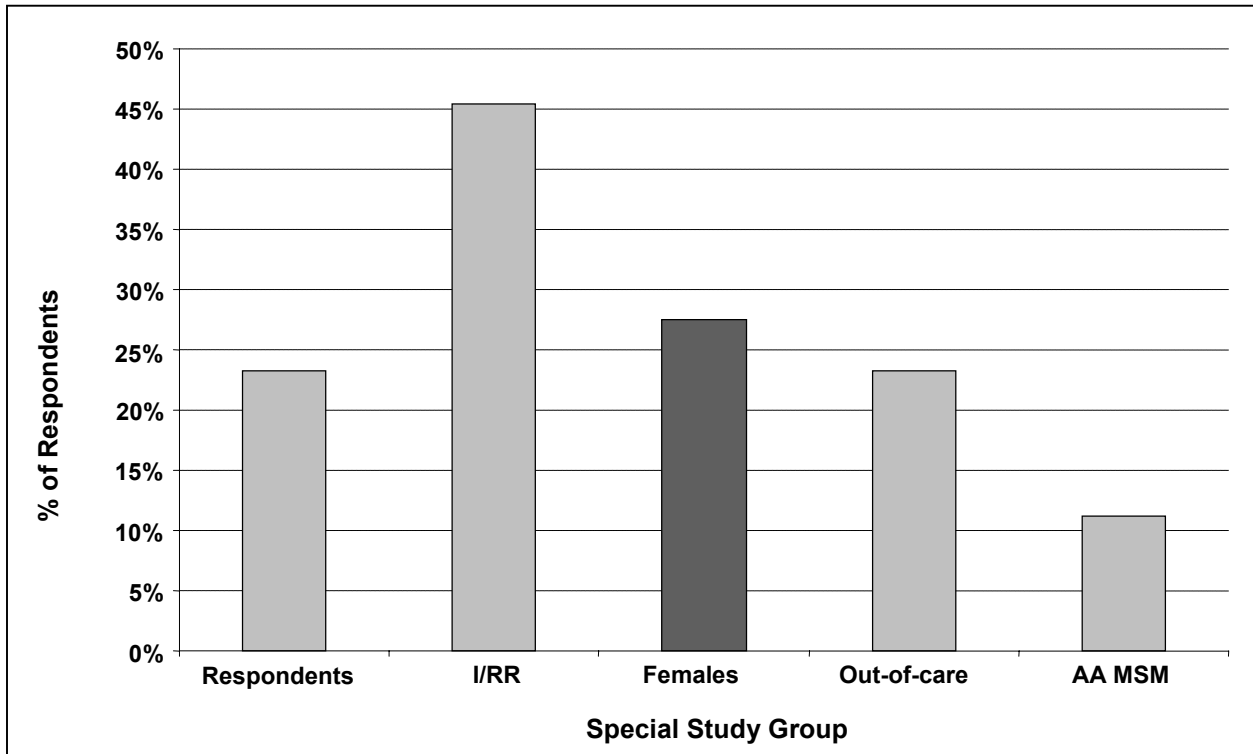

Substance Use/Abuse

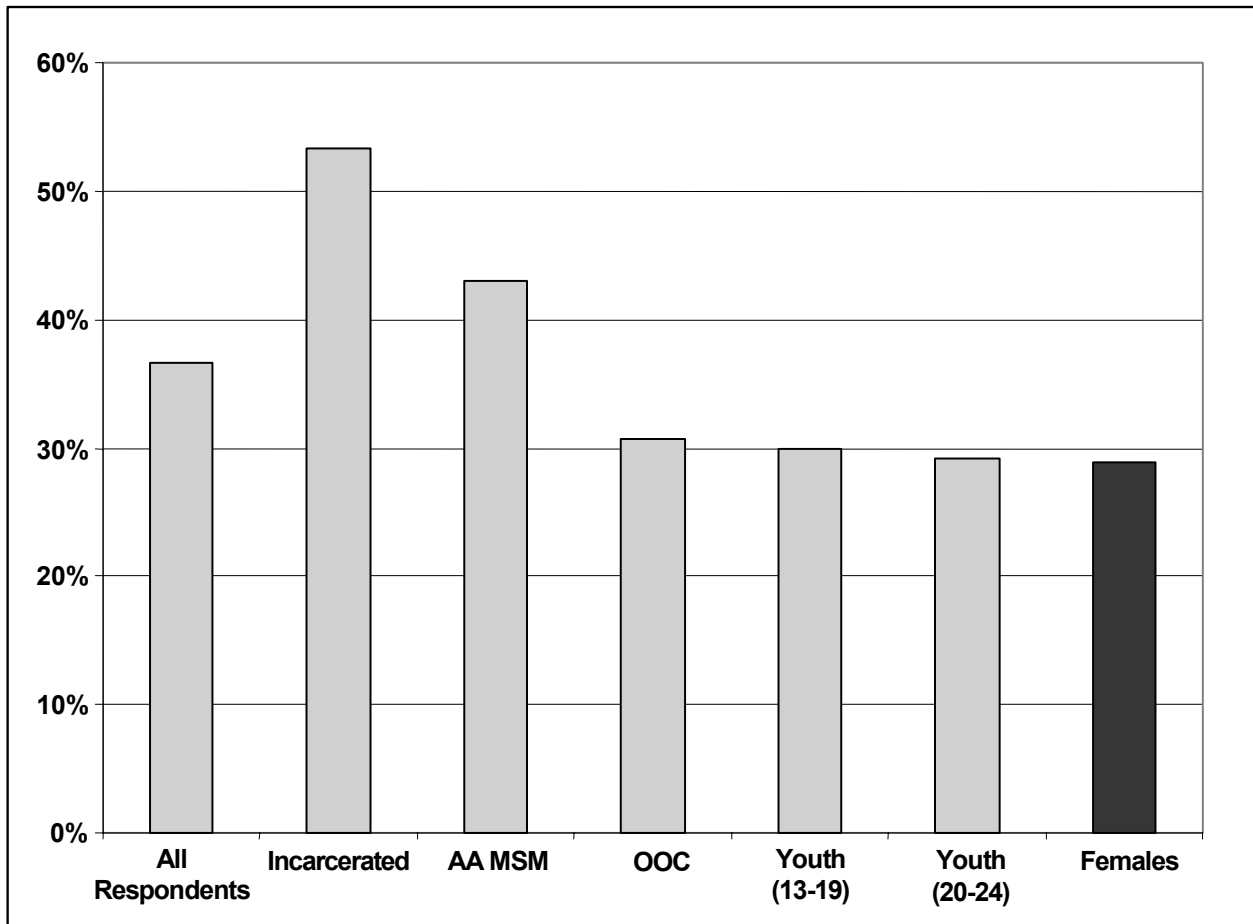
Women were more likely to inject drugs than All Respondents, surpassed only by the Incarcerated/Recently Released as shown below in Figure 11-15.

Figure 11-15: ADMISSION OF 'EVER' INJECTING SUBSTANCES BY SPECIAL STUDY GROUP



Their percentage of substance use overall, however, was lower suggesting that IV drug abuse is a more pressing problem for women. See Figure 11-16.

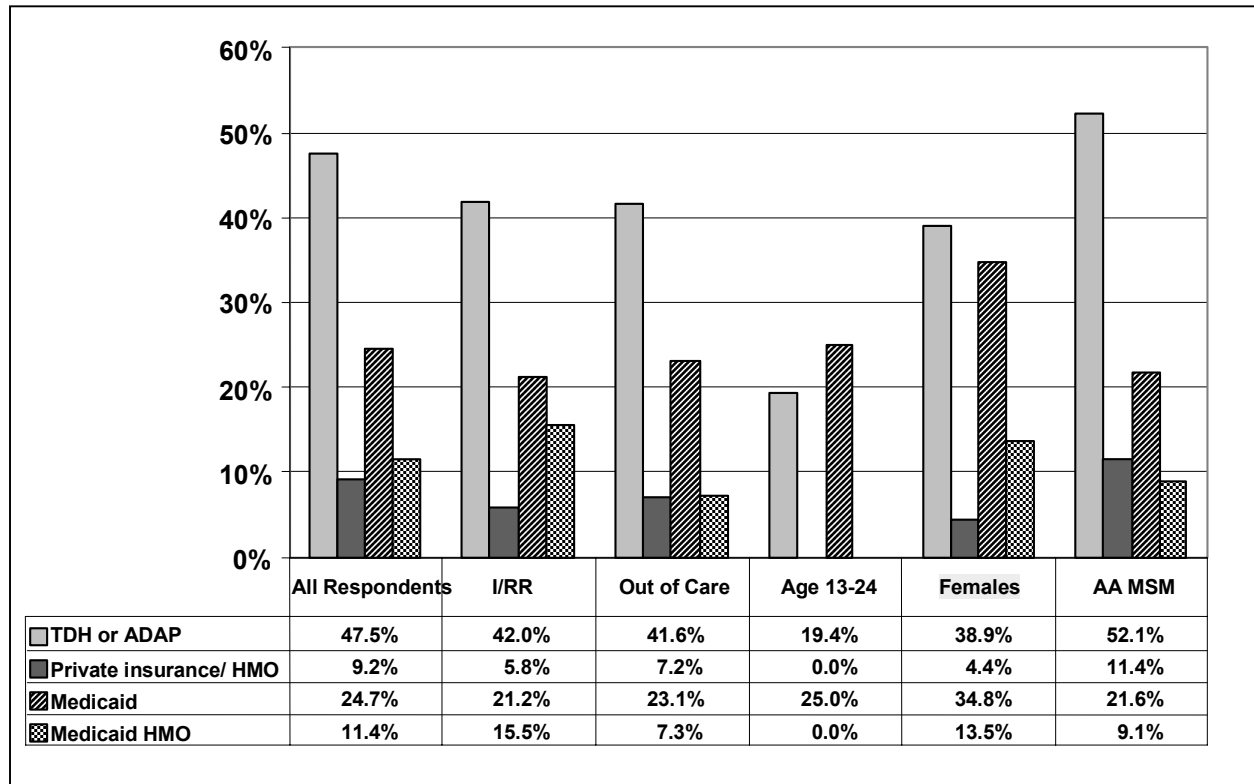
Figure 11-16: SUBSTANCE USE BY SPECIAL STUDY GROUP



Use of Drug Assistance

Women used ADAP (AIDS Drug Assistance Program) less than the rest of the population (see Figure 11-17). Their increased Medicaid drug coverage rates may explain this or it may be due to lack of awareness of this benefit. Further exploration is required to determine the reduced use of drug reimbursement by this subset.

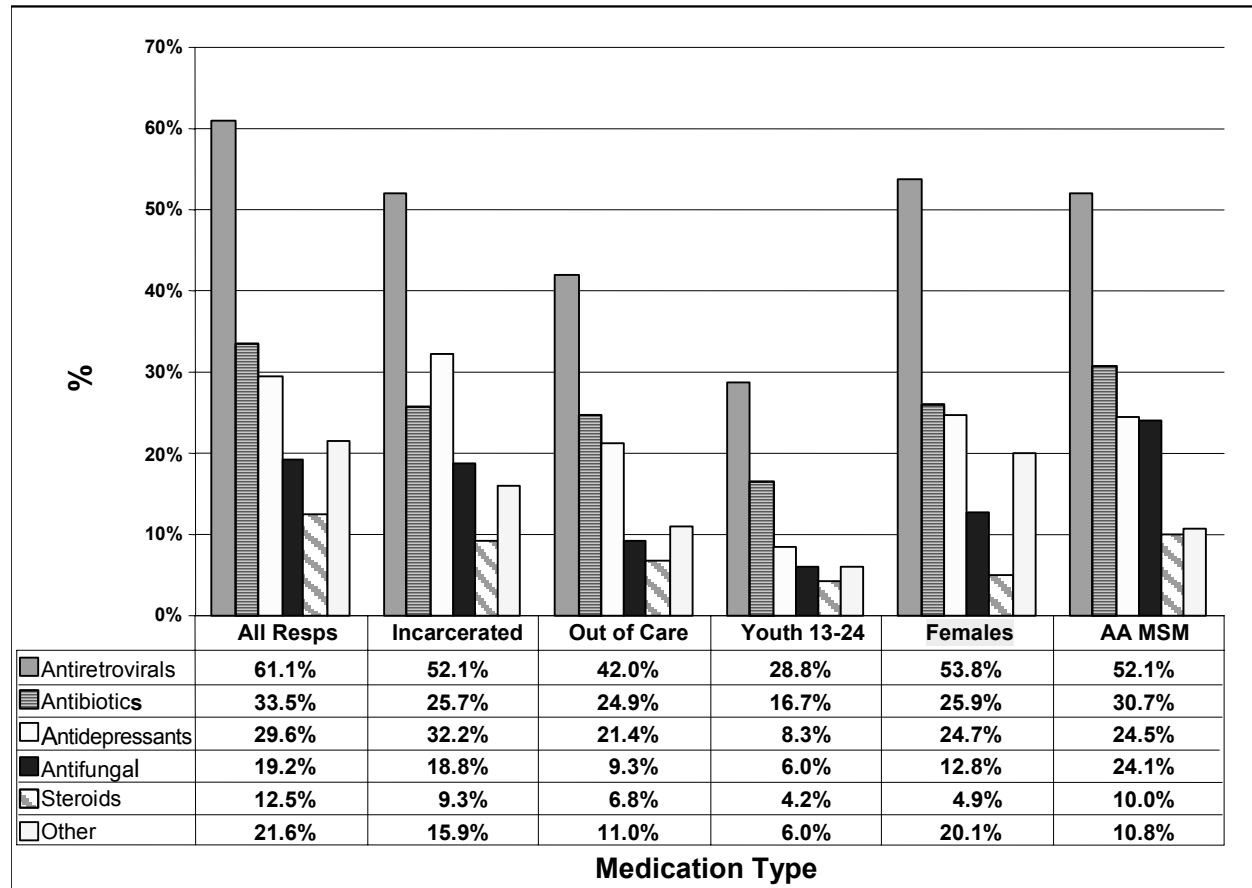
Figure 11-17: DRUG REIMBURSEMENT USE BY SPECIAL STUDY GROUP



Use of Medication

Females use of prescription medications is comparable to the other special study groups, including antiretrovirals as illustrated in Figure 11-18.

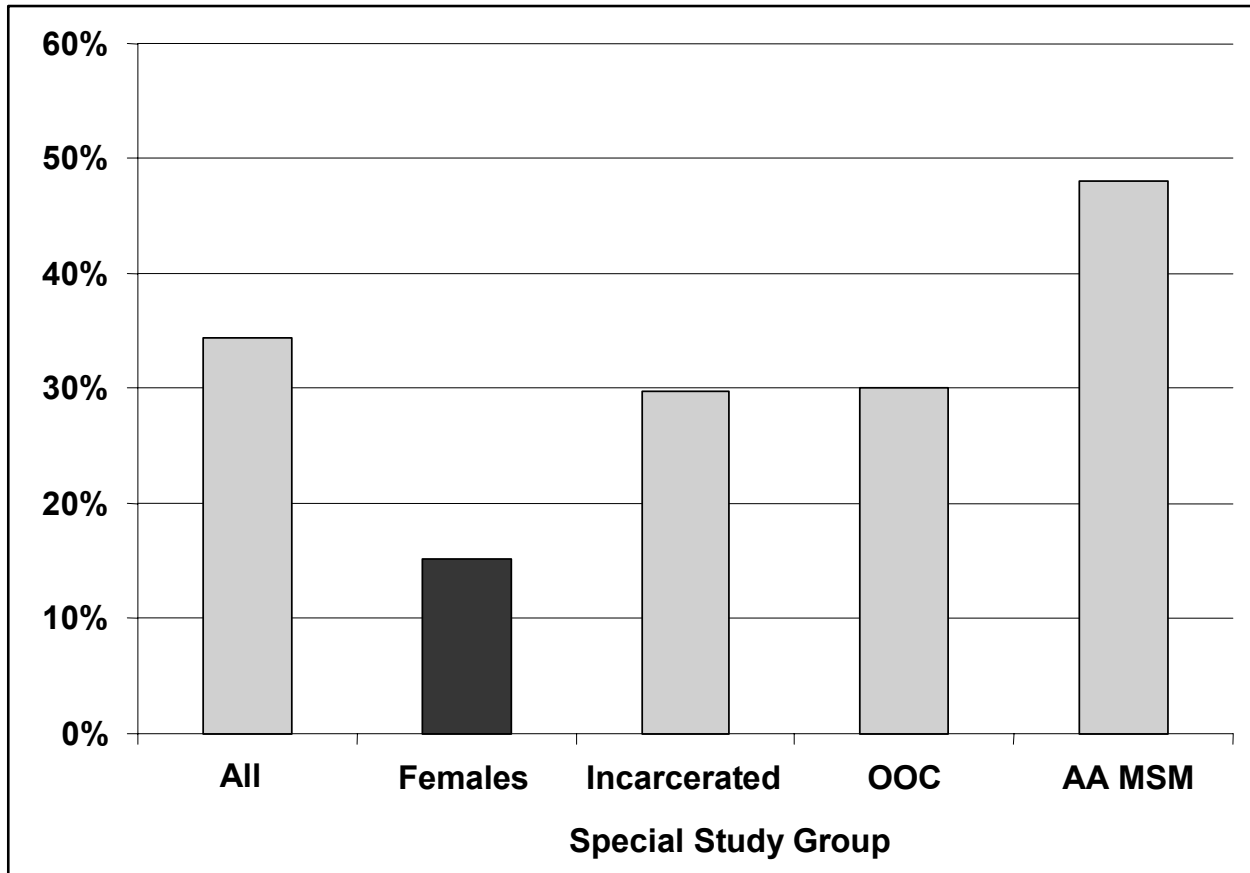
Figure 11-18: USE OF PRESCRIBED MEDICATION BY SPECIAL STUDY GROUP



Homelessness and Housing

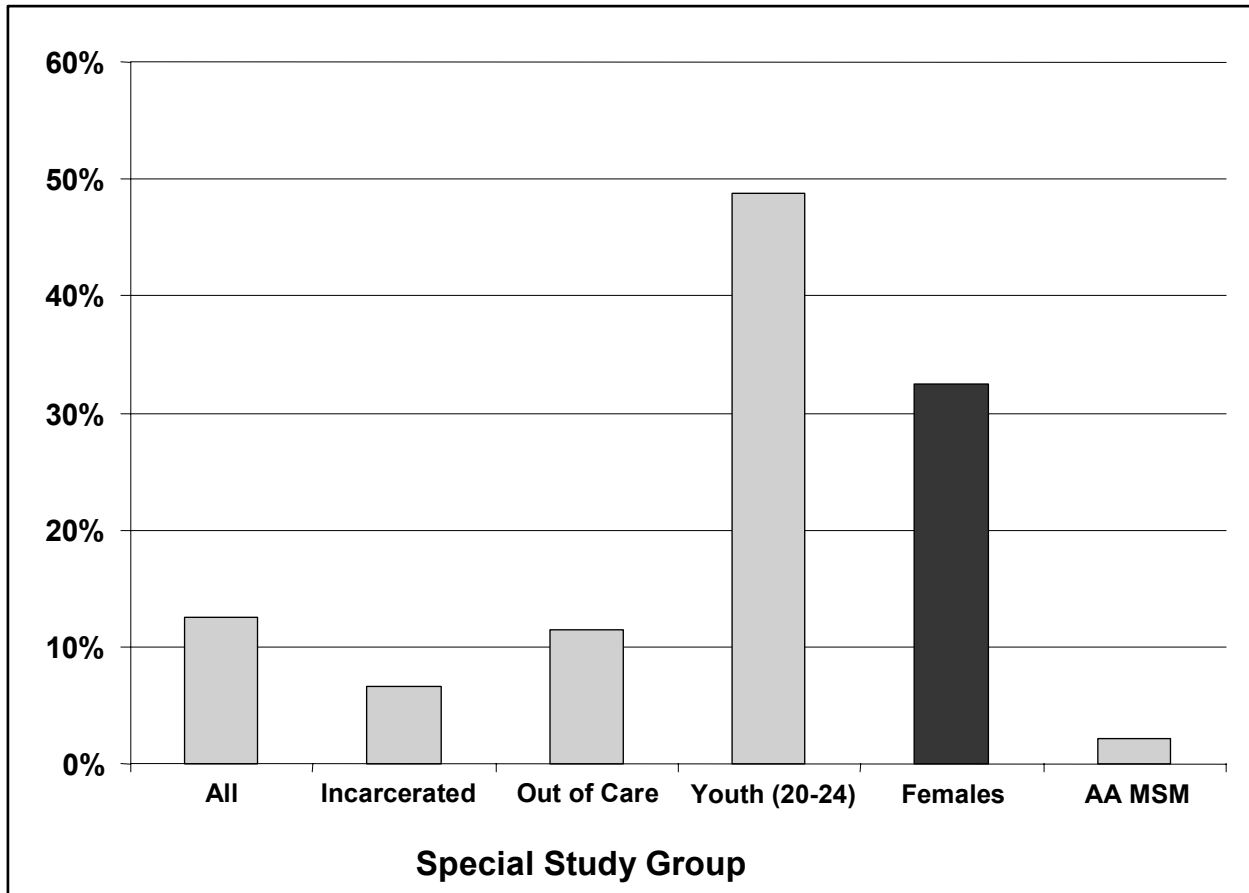
Women were less likely than other special study groups to live alone, as shown below in Figure 11-19.

Figure 11-19: LIVING ALONE BY SPECIAL STUDY GROUP



Women were likely to live with children, as illustrated in Figure 11-20. None of the surveyed women was homeless.

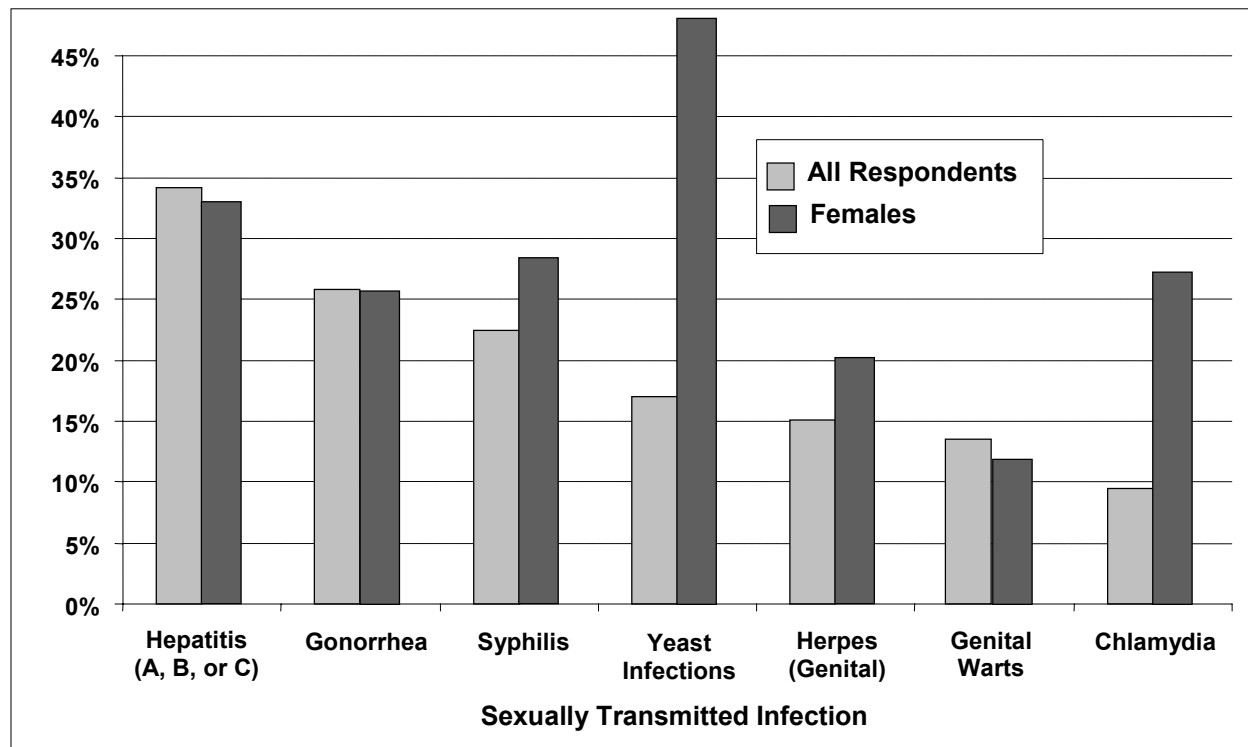
Figure 11-20: LIVING WITH CHILDREN BY SPECIAL STUDY GROUP



Sexually Transmitted Infections (STI)

Women reported more yeast infections and chlamydia and less hepatitis than the overall response group, as shown in Figure 11-21.

Figure 11-21: REPORTED SEXUALLY TRANSMITTED INFECTIONS– FEMALES VS ALL RESPONDENTS



Use and Barrier Analysis

Need and gap rankings are analyzed to determine unmet need. Use statistics represent the percentage of women who indicated on the client survey that they have used the service and they perceived the service as “hard to get.” As is seen in Table 11-4, the services with the highest use and perceived barriers are included in support services.

Table 11-4: FEMALES - USE AND BARRIERS ANALYSIS

USE ANALYSIS		BARRIER ANALYSIS	
SERVICE CATEGORY	Use %	SERVICE CATEGORY	Barrier %
Ambulatory/Outpatient Medical Care	81	Ambulatory/Outpatient Medical Care	23
Social Case Management	66	Social Case Management	11
Nutritional Counseling	43	Nutritional Counseling	6
Support Services	82	Support Services	38
Dental Care	64	Dental Care	9
Substance Abuse Counseling	39	Substance Abuse Counseling	4
Drug Reimbursement	62	Drug Reimbursement	7
Mental Health Services	57	Mental Health Services	9
Hospice*	10	Hospice*	8
Home Health Care*	31	Home Health Care*	7
Rehabilitation*	35	Rehabilitation*	8

**NOTE: Interpretation of data for Hospice, Home Health Care and Adult Day Care is limited by 2 factors: 1- the population surveyed was primarily ambulatory and relatively healthy; 2- the questions on the survey were inadequate to accurately assess the need for these services.*

Rehabilitation, Research and Long-Term Care were terms that survey respondents may have found confusing, which may have influenced their response. During the validation process, several told facilitators that they interpreted rehabilitation to refer to such services as substance abuse treatment or post-incarceration services, such as employment training.

Need Analysis

Need statistics represent the percentage of women 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 11-5.

Table 11-5: FEMALES - NEED ANALYSIS

NEED ANALYSIS	
SERVICE CATEGORY	Need %
Ambulatory/Outpatient Medical Care	37
Social Case Management	54
Nutritional Counseling	42
Support Services	50
Dental Care	71
Substance Abuse Counseling	7
Drug Reimbursement	40
Mental Health Services	27
Hospice*	2
Home Health Care*	16
Rehabilitation*	12

*See note on page 284 regarding these service categories.

Gap Analysis

Perceived service gaps were determined based on a respondent indicating that services were “needed” but “not available”. See Table 11-6.

Table 11-6: FEMALES - GAP ANALYSIS

GAP ANALYSIS	
SERVICE CATEGORY	Need %
Ambulatory/Outpatient Medical Care	28
Social Case Management	3
Nutritional Counseling	6
Support Services	40
Dental Care	4
Substance Abuse Counseling	1
Drug Reimbursement	5
Mental Health Services	7
Hospice*	1
Home Health Care*	8
Rehabilitation*	8

*See note on page 284 regarding these service categories.

Qualitative Findings – Needs, Gaps, and Barriers:

Focus group findings were divided into comments relating to needs and those relating to gaps and/or barriers. For RARE, any comments were accepted in an effort to probe high-risk behaviors of hard to access street informants.

Focus Group Findings: Needs - Females

At the time of diagnosis, 4 of the 6 women in this focus group were not directly told they were HIV positive, were moved into another room once they were told with a dramatic difference in how they were initially treated, or the treatment changed as the provider realized they had been diagnosed HIV positive. Behaviors included:

- Transfer to an office with providers, with caregivers whispering about them, glancing at them
- Some still not directly told their diagnosis even when they had left the physician office or clinic
- The perception as ‘infected’ impacting their care
- Discussion of how the feeling of isolation that occurred when they found out they were HIV positive negatively contributed to their realization of the disease and initial handling of their care. (Many became depressed, got drunk, avoided aggressive or any treatment at first while trying to individually cope with the disease)

“Everybody that had been so nice changed—talked from the curtain. Acted as if I had the plague.” (Difference in behavior from when she first arrived to her diagnosis)

“I went over my diagnosis and was depressed all over again and even worse, felt guilt when I found out my daughter and grand-baby were HIV positive.”

“It is such a sad experience—I came from Mexico and lost my son and husband to AIDS.”

“Other children are hyperactive, but my son (even though I haven’t told him) seems to know I have HIV. He makes me take my medicine, is very protective of me and guards others from me when I don’t feel well.”

“I became very suicidal (when I found out that I was HIV positive), I thought of death, but [provider], she wouldn’t ‘have it’”.

Focus Group Findings: Needs – Females

Specific Housing Concerns:

[Female participant] is an African American, single mother of a 22 year old daughter who lives with her daughter, stepfather and her mother. ...She is scheduled for release from incarceration... the family is aware of her serostatus and she has been “*thrown out on the streets with my daughter*” more than once since her diagnosis.

Q: What are your most important needs related to your HIV care?

A: “*Housing: The most important thing to me is getting money to get my own place for me and my daughter.*”

“*I’d like to get my own apartment, cause we’re in this little room and we have so much stuff.*”

Need for Communication/Information:

“*I want to help other people with this. We all need to talk... in our neighborhoods.*”

“*We need to help the kids. I used to have good self-esteem, now it’s low. I’m scared to get out of here. When I get my first piece of money, I’m panicky. What I am going to do about housing for me and my kids?*”

“*We need more information passed out here for people who don’t have this and people who do. They go through your stuff and steal your medicines if you have them. I tell them they’re for AIDS and they say, “no way you have it.” We need pamphlets or something, so they know. Then they can find out if they have it. They can get tested to see.*”

“Please rank the three (3) most important services that help you with your HIV/AIDS:”

<u>Participant</u>	<u>#1</u>	<u>#2</u>	<u>#3</u>
1	Primary medical	Housing	Transportation
2	Life Insurance	Case Management	Housing
3	Primary medical	Case Management	Childcare
4	Primary medical	Housing	Financial help
5	Primary medical	Housing	Employment help
6	Primary medical	Case Management	Nutrition

Focus Group Findings: Barriers - Females

Please rank the three (3) most important things you do to succeed with having HIV/AIDS.”

<u>Participant</u>	<u>#1</u>	<u>#2</u>	<u>#3</u>
1	Medications	Nutrition	Rest
2	Start treatment	Counseling	
3	Medications	Physician research	12 Steps
4	Education	Medication	Reduce stress
5	Get to MD on time	Transportation	
6	Medications	Case Management	Nutrition

“Please tell us the three (3) barriers to accessing services”

<u>Participant</u>	<u>#1</u>	<u>#2</u>	<u>#3</u>
1	Transportation	Housing	Bureaucracy
2	Life Insurance	Language	Housing
3	Attitudes	Bureaucracy	Child Care
4	Attitudes	Housing	Financial help
5	Money	Housing	Employment help
6	Psychological help	Finances	Nutrition

“Living right there where you picked us up, these women are just having sex, having babies, ain’t nobody thinking about a condom. And the reason that’s happening is that it has not sunk in that you don’t have to be gay to get this. That’s why women are showing up with HIV, and they think, I’m a woman, I’m doing this with a man.”

Focus Group Findings: Barriers – Females

“And that’s another issue, people are just not addressing the fact that there’s this whole bisexual going on—there’s a lot of bisexuality going on. It should not be focused on homosexuality or heterosexual but on sex period. Cause what they’re doing as husbands and wives, they’re doing other things, it doesn’t mean they have to be gay - it’s about sex period...”

“Bisexuality is becoming more of a trend in rural areas than homosexuality. Because bisexuality is more acceptable.”

“For women, it’s more acceptable - “We have one gay bar that has taken off - it’s predominantly women who go there. I think 34% of our clients are gay, almost 50% if you include the bisexuals—50% of my 158 clients.”

RARE Findings: Females Gaps and Barriers

(Responses from or about Females made in RARE Interviews)

Q. What are the different types of risks that people are engaging in? Like sex for sex, sex for money, sex for drugs.”

A. *“Yeah, prostitution for money or drugs. A lot of women prostitute to take care of their kids, they don’t have an education and they don’t think they have any other way to make money to pay for bills and stuff.”*

Q. Do you know if these sex workers use condoms or if they don’t, why or why not?

A. *“Some of them use condoms, but for the most part, people just have sex. It’s not planned out, it’s not like going on a date or anything. They just don’t use them... I am most concerned about the young women who seem unaware of the risks they face in turning around tricks quickly.”*

THEMES AND RECOMMENDATIONS

FEMALES

Theme 1: A high percentage of women (56.6%) were diagnosed as HIV positive incident to other testing (did not seek out direct test to confirm HIV). Women were the special study group least likely to be diagnosed following a visit for HIV testing. Pregnancy testing is a unique means of detection with 13.9% determining their HIV status at this point.

Recommendations:

- Communicate with the agencies conducting pregnancy testing about developing protocols for care since this is a frequent locus for HIV diagnosis
- Aggressively refer or treat these women
- Ensure that females are informed of their diagnosis in a way that is sensitive and respectful.

Theme 2: Females were less likely to use ADAP or other drug reimbursement benefits despite their high use of antiretroviral therapy (expensive medications with co-payment currently averaging \$105).

Recommendation: Review females' awareness of drug reimbursement benefits, particularly ADAP.

Theme 3: Females represented a higher "out-of-care" population than the population (15% vs. 12%) with 41% of the 15% "out-of-care" reporting that they did not seek primary care within the past 6 months due to physician advice.

Recommendation: Further explore the report that providers advise females against actively accessing primary care services. A high percentage of "out-of-care" was reported yet current viral load most resembles highest viral load.

Chapter 12

**Special Study:
Incarcerated/Recently
Released Individuals
Living with HIV**

Importance

Factors associated with HIV/AIDS risk - illicit drug use and high-risk sexual behaviors - overlap with the issues surrounding incarceration. The incidence of AIDS in prisons has been estimated to be 6 to 14 times higher than the incidence in the general population, with prevalence cited at 199 per 100,000, six times the national rate of 31 per 100,000.¹

Many inmates are not tested for HIV and/or not diagnosed with AIDS, particularly in county jails. Incarcerated individuals face additional health threats, including exposure to tuberculosis, limited access to treatment for HIV-related medical conditions, and difficulty maintaining the timing and food restrictions necessary for proper adherence to drug therapies.

Disclosure of HIV status can result in severe stigma and repercussions from both facility staff and other inmates, a fact that further limits an infected inmates' access to proper medical care.

Incarcerated individuals who are not HIV infected are at high risk to become so. Risk behaviors including unprotected anal intercourse, injection drug use and the frequent official position of not supplying condoms or needle cleaning equipment exacerbate all risk factors.

High HIV seropositivity is associated with incarcerated populations due to the above stated factors. Studies indicate that entrants to federal and state prisons have HIV seroprevalence rates that range from 2.1% to 7.6% for men and 2.7% to 14.7% for women. This compares to 'normal' seroprevalences of first-time blood donors of .04% for men and .02% for women.

HIV transmission that occurs within prisons is also magnified due to the overriding proportion of inmates with prior drug use histories. A report by the National Institute on Drug Abuse indicated that approximately 83% of injection drug users (IDUs) have been in jail at some point. The risks are greatest in prison with large inmate populations or for those incarcerated who serve long terms.

Recently, the emergence of multi-drug resistant tuberculosis as an opportunistic infection of PLWH/A's has emphasized the need for not only primary but secondary HIV-prevention services in prisons.

Release back into the community is very complicated for the incarcerated who rank 'staying clean' above caring for their HIV infection. They have limited knowledge of all resources, let alone those specific to HIV/AIDS. Many suffer from the deficit of any formal mechanism to provide prisoners with information or connect them with resources upon release.

Often, these individuals have no place to go as their remaining families have absorbed their children and may ostracize them. They frequently return to high-risk behaviors which may further spread the virus into the community. If they are unaware of their

¹ Fleming, Patricia and Dean-Gaitor, Hazel. *AIDS*, December 3, 1999: 13: 29-2435, 2475-2476)

infection or are unwilling to discuss the risk behaviors that occurred while they were in jail, they can infect spouses and other sexual partners upon release.

The community has undertaken discharge planning efforts to improve the health status of those released from incarceration. However, transition is complicated since many individuals do not disclose their serostatus while incarcerated and remain unknown unless they are taking HIV medications, housed in a special medical unit or are in the care of an HIV counselor.

Brief Epidemiologic/Demographic Profile

In 2001, in Texas, there were 2,388 incarcerated PLWH/A (1.6% of total incarcerated in Texas) of which 859 had AIDS (36% of PLWH/A that are incarcerated), with an average incarcerated population of 144,900.

114 Incarcerated/Recently Released (I/RR) individuals were surveyed in the Houston Area EMA/HSDA Client Needs Assessment Survey. This constitutes 17% of the survey base. Since the I/RR group includes individuals currently incarcerated as well as those released within two years, no exact peer epidemiologic comparison exists.

Specific surveillance and estimate data on the EMA/HSDA incarcerated population was not available in the 2002 HSDA Epidemiologic Profile. EMA/HSDA Incarcerated/Recently Released (I/RR) respondents are therefore compared to statewide demographic composition of incarcerated PLWH/A and to individuals incarcerated within Harris County when such data is available. In addition, the standard comparison was conducted to the full population of survey respondents from the EMA/HSDA and to other high risk/special study groups.

Table 12-1: GENDER – INCARCERATED/RECENTLY RELEASED

Gender	All Respondents	I/RR	Harris County Incarcerated	TX Incarcerated PLWH/A
Male	70.3%	72.7%	72.5%	90.8%
Female	28.7%	26.2%	27.5%	9.2%
Transgender	1.1%	1.1%	0.0%	0.0%
Total	100.0%	100.0%	100.0%	100.0%

Table 12-2: RACE – INCARCERATED/RECENTLY RELEASED

Race	All Respondents	I/RR	Harris County Incarcerated
African-American	52.7%	60.0%	38.1%
White	43.7%	33.0%	56.7%
Other	3.6%	7.0%	5.2%
Total	100.0%	100.0%	100.0%

Table 12-3: ETHNICITY – INCARCERATED/RECENTLY RELEASED

Race	All Respondents	I/RR	Harris County Incarcerated
Hispanic	22.4%	23.0%	29.9%
Non Hispanic	76.1%	74.6%	70.1%
Not Applicable	1.5%	2.4%	NA
Total	100.0%	100.0%	100.0%

Table 12-4: HIV STATUS – INCARCERATED/RECENTLY RELEASED

HIV Status	All Respondents	I/RR	TX Incarcerated PLWH/A
HIV Negative	NA	NA	NA
HIV Positive (No symptoms)	51.5%	49.5%	55.7%
HIV Positive (Symptoms)	31.4%	37.3%	8.3%
Living with AIDS	30.4%	32.0%	36.0%
Total*	113.0%	119.0%	100.0%

Note: Totals of surveyed individuals include “double responses” by some individuals so totals may add to more than 100%..

Table 12-5: HIV SERVICES – INCARCERATED/RECENTLY RELEASED

	All Respondents	I/RR
HIV Positive (Receiving services)	86.6%	82.9%
HIV Positive (No services)	8.9%	12.3%
Caregiver	12.8%	6.2%
Total	108.3%	101.5%

Note: Totals of surveyed individuals include “double responses” by some individuals so totals may add to more than 100%..

Figure 12-1: SEXUAL ORIENTATION BY SPECIAL STUDY GROUP

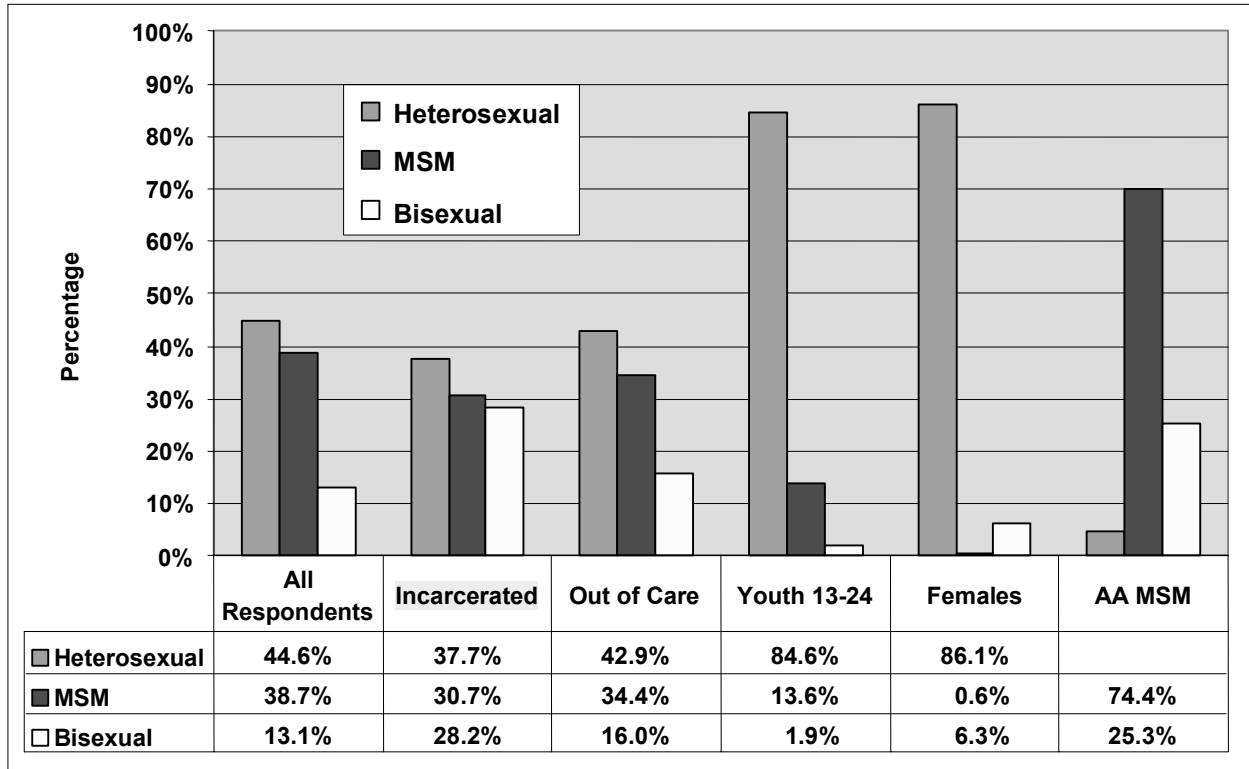


Figure 12-2: HIGHEST EDUCATION LEVEL BY SPECIAL STUDY GROUP

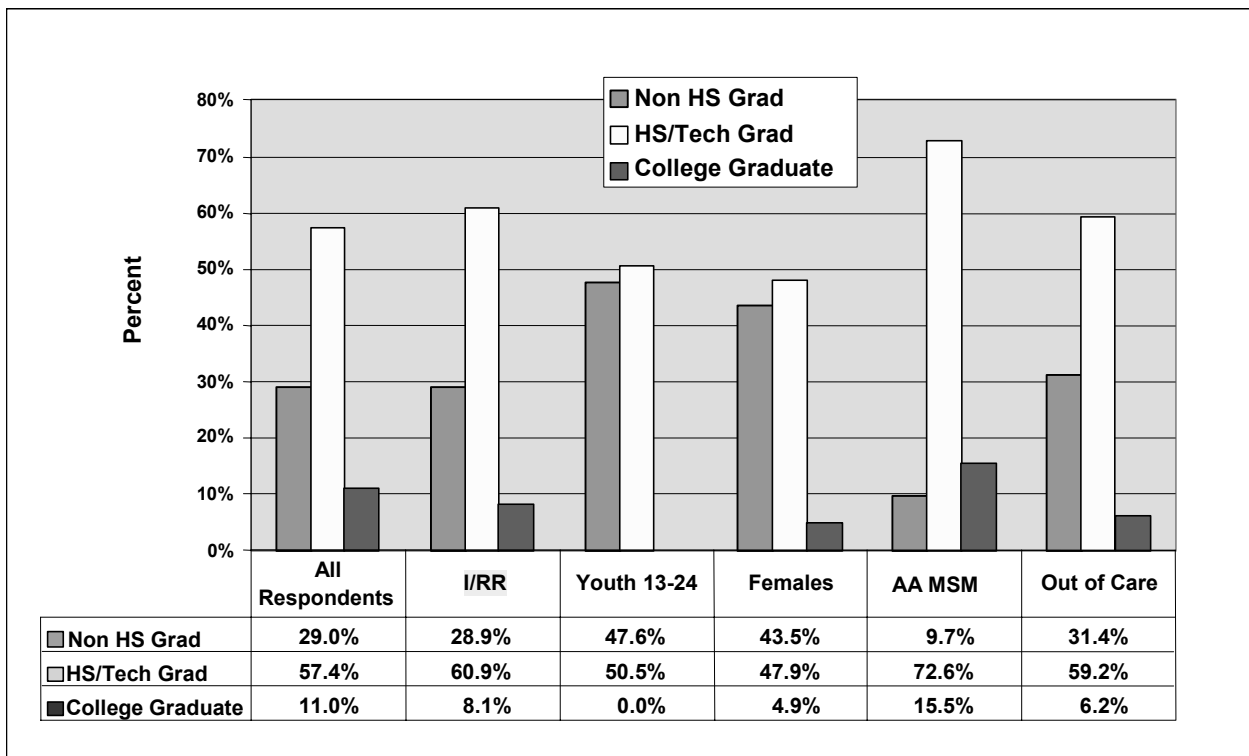
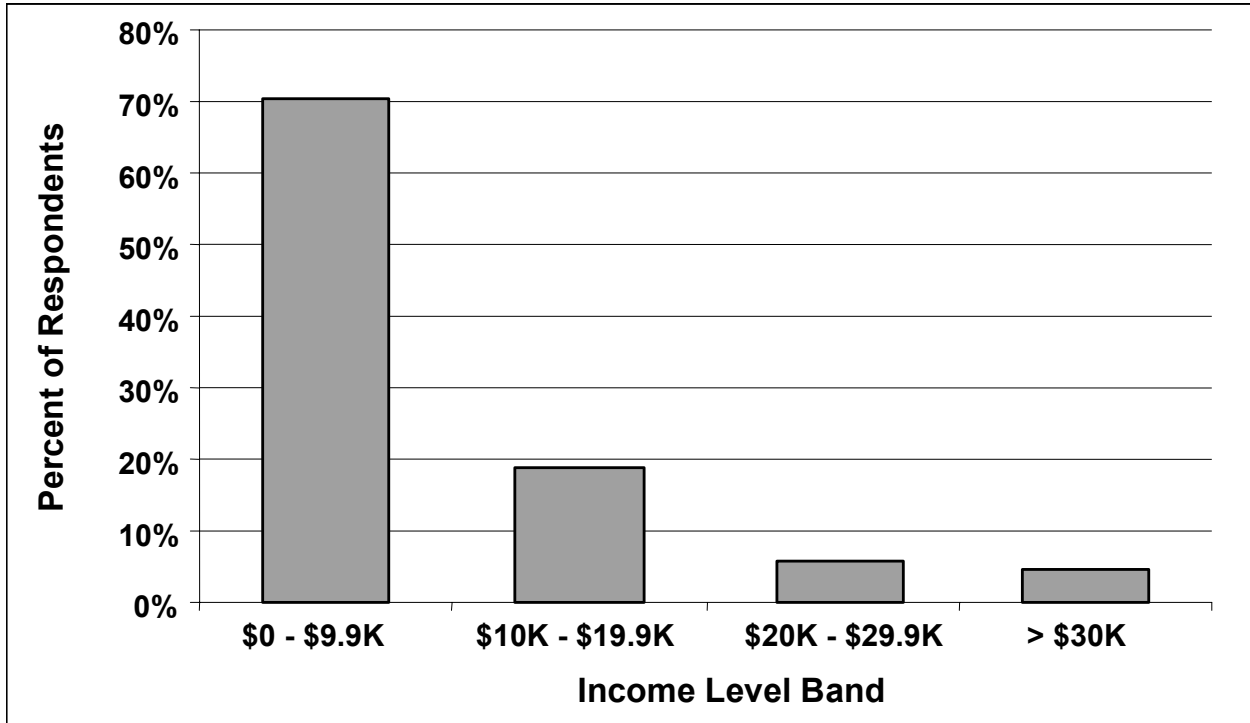


Figure 12-3: INCOME LEVEL – ALL RESPONDENTS



PROFILE OF SOCIOLOGIC AND HEALTH OBSERVATIONS – I/RR:

Table 12-6: CARE STATUS – INCARCERATED/RECENTLY RELEASED

Care Status	All Respondents	I/RR
In-Care	81%	69%
Out-of-care	12%	19%
Never-in-care	7%	12%
Total	100.0%	100.0%

Figure 12-4: PERCENT UNINSURED BY SPECIAL STUDY GROUP

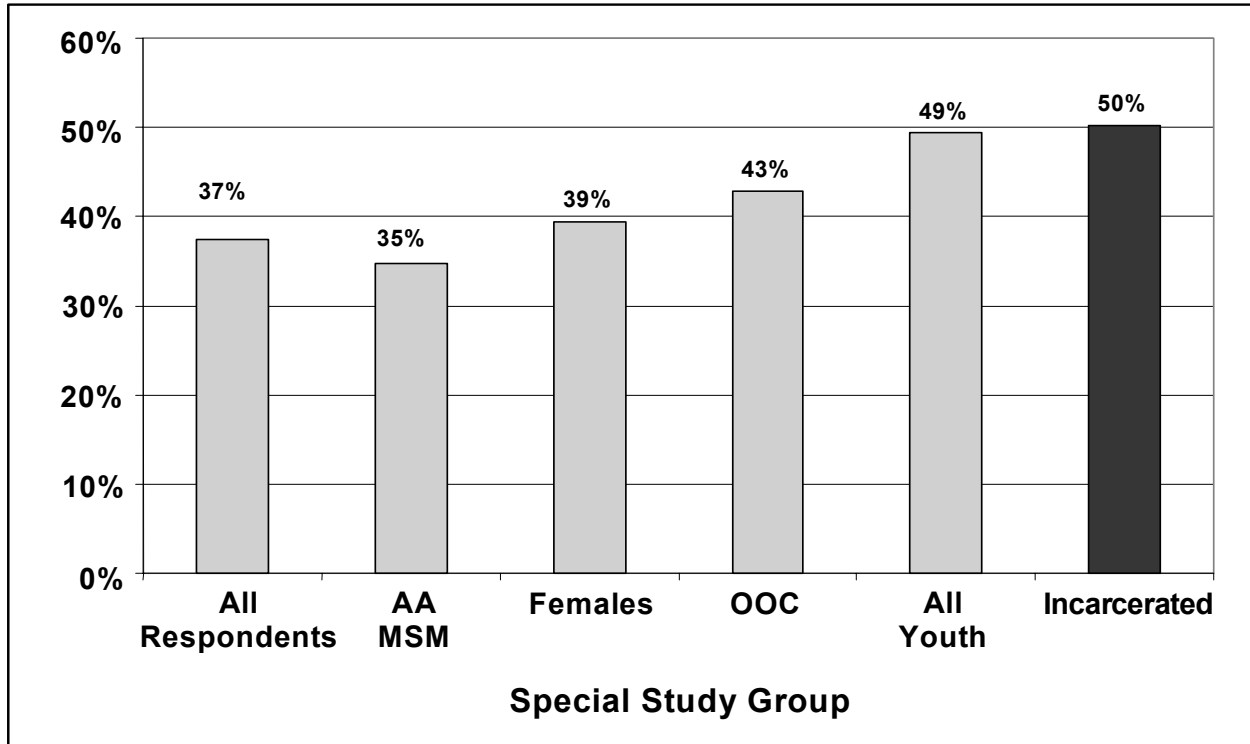


Figure 12-5: FREQUENCY OF DISABILITY PROBLEMS BY SPECIAL STUDY GROUP

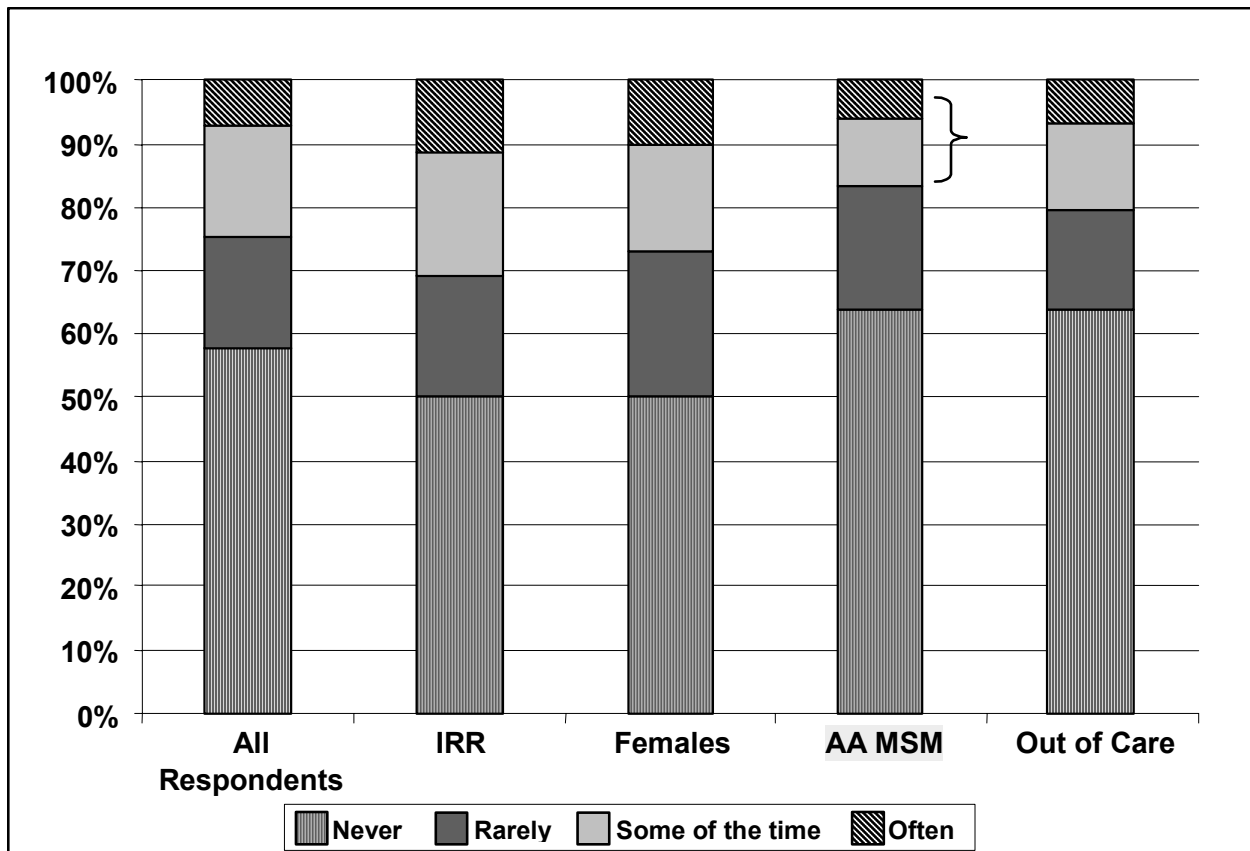


Figure 12-6: SUBSTANCE USE BY SPECIAL STUDY GROUP

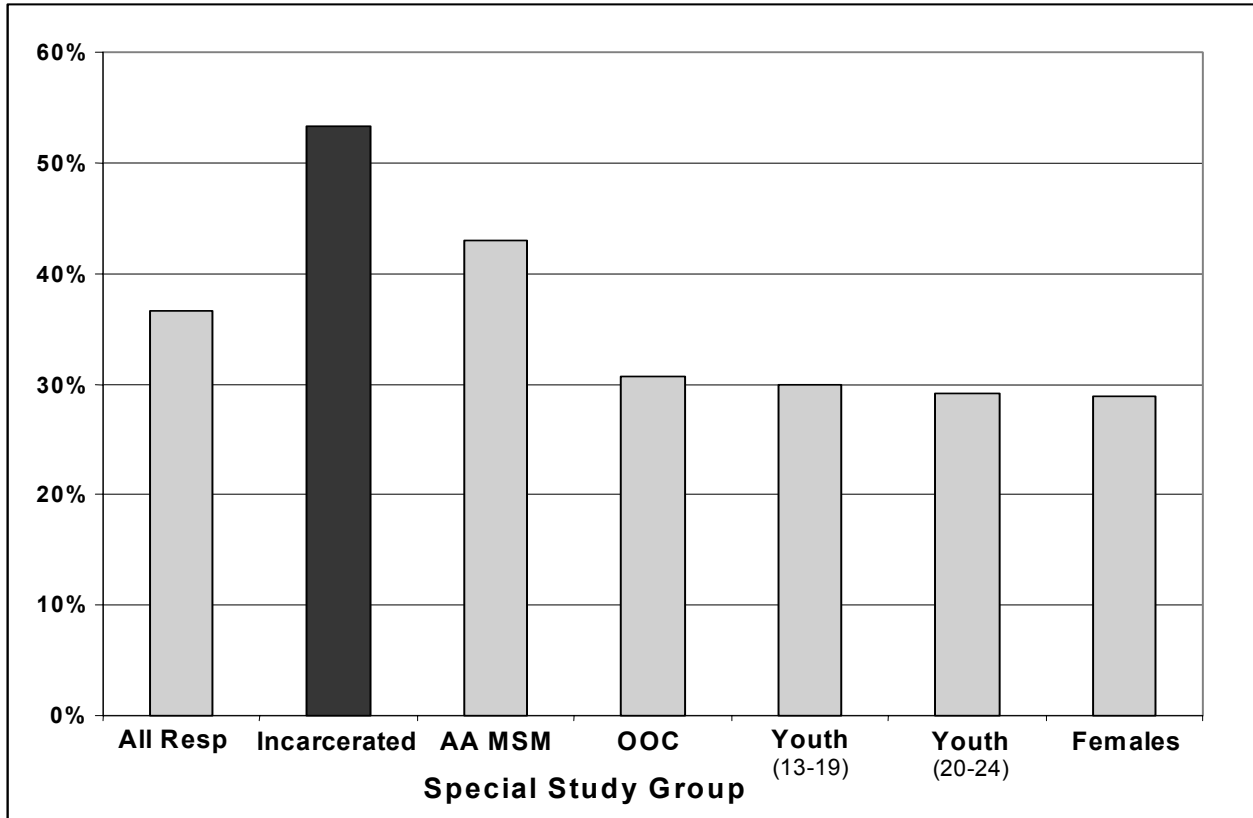
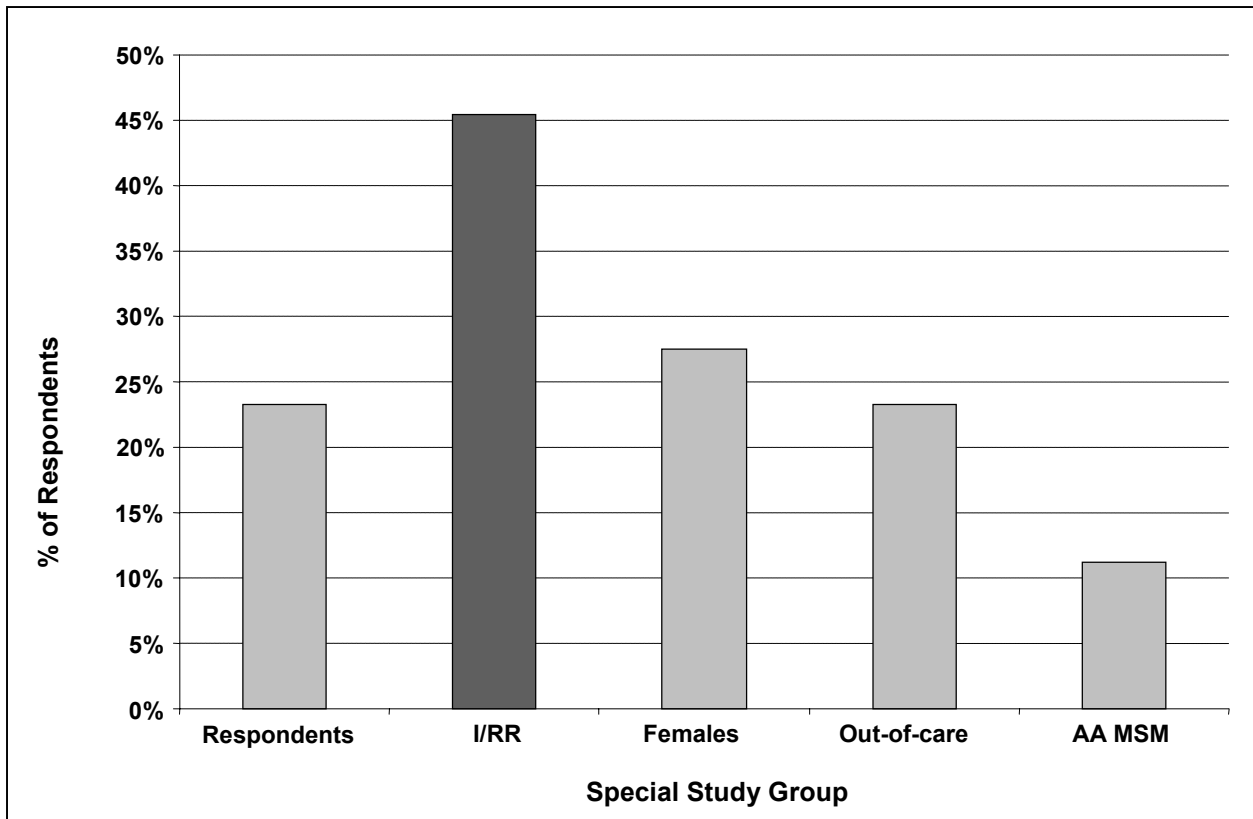


Figure 12-7: PERCENT INJECTING SUBSTANCES BY SPECIAL STUDY GROUP



SUMMARY OF EPIDEMIOLOGY/DEMOGRAPHICS AND HEALTH OBSERVATIONS: INCARCERATED/RECENTLY RELEASED (I/RR)

The I/RR population matches to the full surveyed EMA/HSDA population and to all individuals incarcerated in Harris County by gender, HIV status, and HIV service status.

It includes more females than the Texas PLWH/A incarcerated population because an effort was made in the survey process to represent the community. Most recently released individuals surveyed and willing to participate were female.

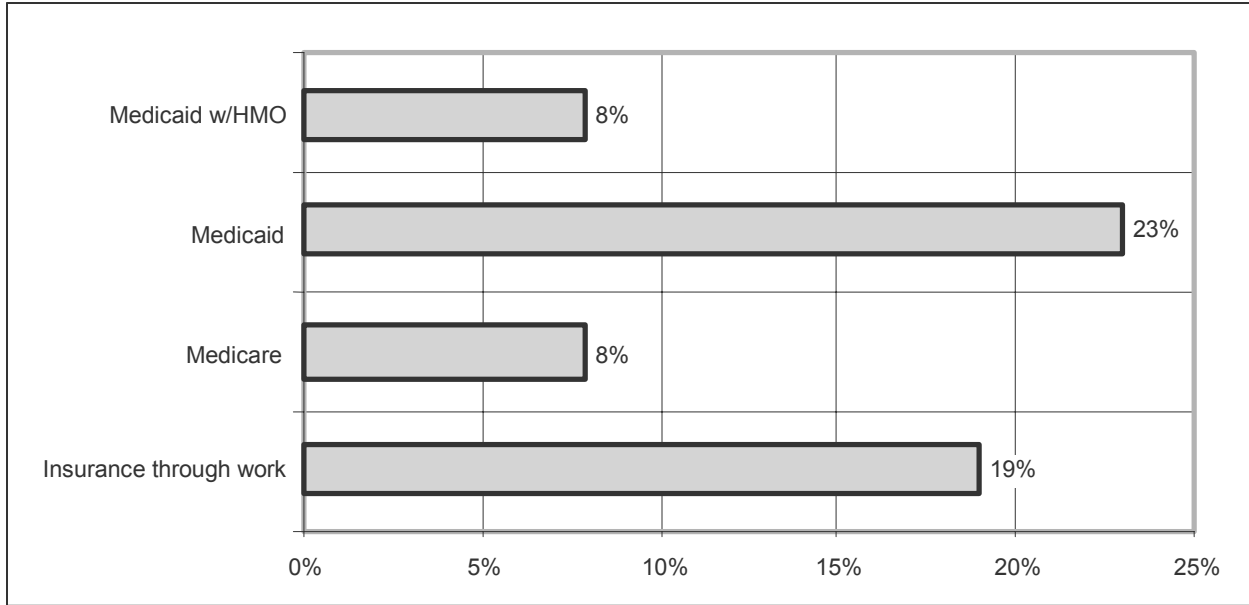
There is a greater African American racial composition, similar ethnic composition, and higher out-of-care percentage when compared to the full population of PLWH/A surveyed and to all individuals incarcerated in Harris County. Sexual orientation was comparable to the full population. Educational levels for I/RR were similar to all respondents with slightly lower income levels.

From a needs and gap analysis perspective, sociologic or health status factors rather than epidemiology differentiate this group. For instance, I/RR were far more likely not to have health insurance coverage, to have a substance abuse and injection history, to have a disability and be functionally impaired from that disability.

Insurance status was calculated for each of the special study groups. Using those methods, the aggregate for the incarcerated and recently released, showed 50% as uninsured. Separating these 2 groups and specifying the coverage that they do have is more revealing.

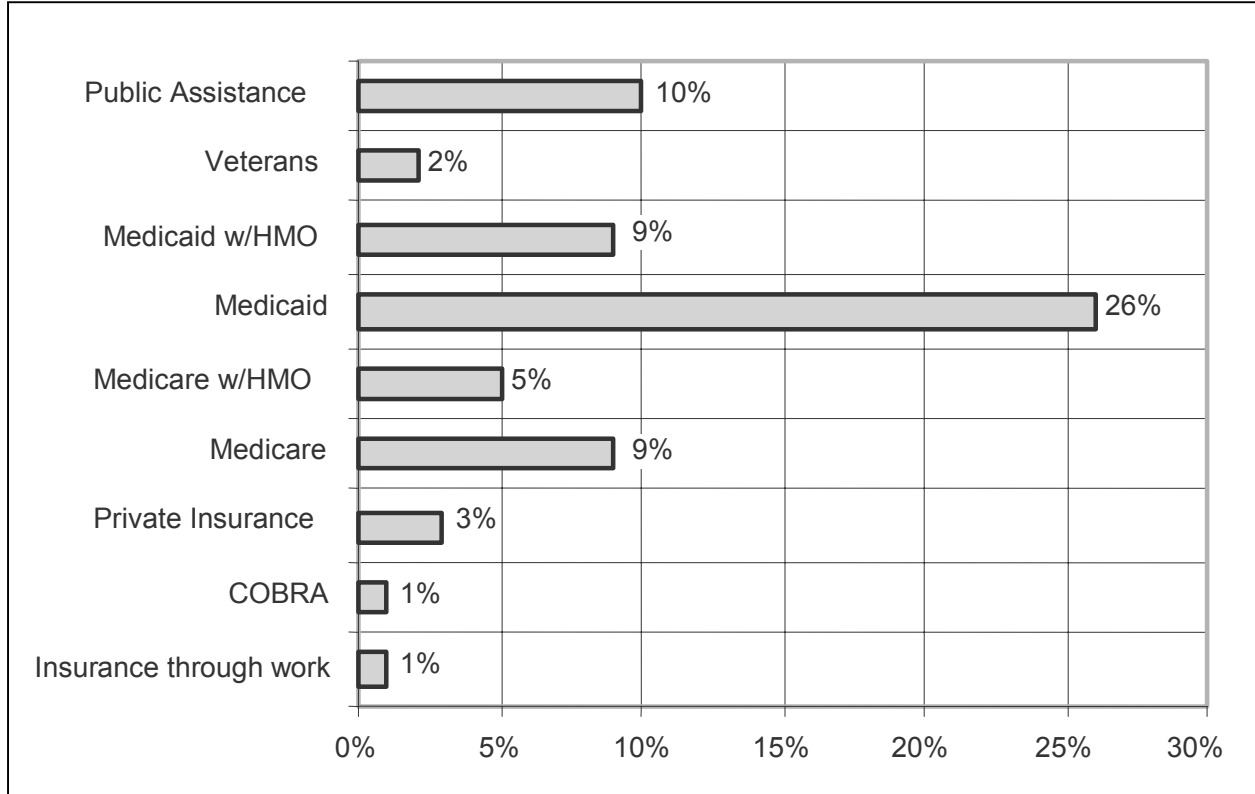
Although they are technically “in-care” and the costs of care do not accrue to them, the incarcerated report several sources of insurance. Because of a limitation of the client survey, it cannot be determined whether incarcerated respondents were specifying the coverage held by their families, themselves prior to incarceration or their expectation of coverage once released. Figure 12-8 illustrates the responses of the currently incarcerated.

Figure 12-8: INSURANCE AMONG INCARCERATED



Those recently released from incarceration reported most frequently that they have accessed Medicaid coverage (26%), followed by public assistance (10%), as seen in the Figure 12-9.

Figure 12-9: INSURANCE AMONG RECENTLY RELEASED



Use and Barrier Analysis

These reference individuals who are currently incarcerated or recently released from incarceration (I/RR). Need and gap rankings are analyzed to determine unmet need. Use statistics represent the percentage of those who indicated on the client survey that they have used the service and the service was perceived as “hard to get.” See Table 12-7.

Table 12-7: INCARCERATED/RECENTLY RELEASED - USE AND BARRIER ANALYSIS

USE		BARRIER	
SERVICE CATEGORY	Use %	SERVICE CATEGORY	Barrier %
Ambulatory/Outpatient Medical Care	79	Ambulatory/Outpatient Medical Care	20
Social Case Management	63	Social Case Management	7
Nutritional Counseling	57	Nutritional Counseling	6
Support Services	81	Support Services	41
Dental Care	59	Dental Care	6
Substance Abuse Counseling	66	Substance Abuse Counseling	8
Drug Reimbursement	54	Drug Reimbursement	5
Mental Health Services	64	Mental Health Services	9
Hospice*	7	Hospice*	8
Home Health Care*	19	Home Health Care*	8
Rehabilitation*	40	Rehabilitation*	13

Need and Gap Analysis

Need statistics represent the percentage of the I/RR respondents 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. Perceived service gaps were determined based on a respondent indicating that services were “needed” but “not available”. See Table 12-8.

Table 12-8: INCARCERATED/RECENTLY RELEASED - NEED AND GAP ANALYSIS

NEED		GAP	
SERVICE CATEGORY	Need %	SERVICE CATEGORY	Gap %
Ambulatory/Outpatient Medical Care	30	Ambulatory/Outpatient Medical Care	39
Social Case Management	63	Social Case Management	2
Nutritional Counseling	41	Nutritional Counseling	4
Support Services	67	Support Services	53
Dental Care	67	Dental Care	3
Substance Abuse Counseling	32	Substance Abuse Counseling	2
Drug Reimbursement	50	Drug Reimbursement	8
Mental Health Services	35	Mental Health Services	8
Hospice*	2	Hospice*	6
Home Health Care*	15	Home Health Care*	10
Rehabilitation*	19	Rehabilitation*	12

*NOTE: Interpretation of data for Hospice, Home Health Care and Adult Day Care is limited by 2 factors: 1- the population surveyed was primarily ambulatory and relatively healthy; 2- the questions on the survey were inadequate to accurately assess the need for these services.

Rehabilitation was a term that survey respondents may have found confusing, which may have influenced their response. During the validation process, several told facilitators that they interpreted rehabilitation to refer to such services as substance abuse treatment or post-incarceration services, such as employment training.

Qualitative Findings – Needs, Gaps, and Barriers:

Focus group findings were appropriate for division 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: I/RR Needs

Q: “What are your most important needs related to your HIV care?”

A: *“Medication, good doctors, planning for when I am released from here”*

Q: “Other needs?”

A: *“We need more free clinics and outpatient care”*

African-American female, 39 years old. Recently diagnosed with cervical cancer, however, she reports that she has neither sought, nor received medical care related to HIV other than right after her diagnosis in prison. She reported that she did not intend to seek treatment for cervical cancer.

“I don’t worry about it. I have to see what will happen with the cancer. I’m not worried about it. I’m not gonna tell anyone about this”.

“[Substance abuse counseling and...] support is important, too. I was a drug user and that’s how I found out I was HIV. I got really sick and then I got diagnosed.

“Yes, there’s also a big need for [substance abuse services] for people getting out of prison. You have a lot of straight men coming out of the joint and they’re insecure about having the virus - they don’t want to be associated with something they aren’t - that’s my own problem. 85% of the people in the penitentiary have drug or alcohol problems.”

[Participant] is a 34 year old single mother of six.... She reports that she is not currently taking HIV-related medications and is unaware of either her current CD4 count or viral load, although she is under medical care.

Q: “What are your most important needs related to your HIV care?”

A: *“Employment: I need a job to provide for my kids and to get a sane life. HIV education” I need more information about this.”*

Focus Group Findings: I/RR Needs

[Participant] is an African-American, single mother of a 22 year old daughter... lives with her daughter, stepfather and her mother. ...scheduled for release... family is aware of her serostatus and has been “*thrown out on the streets with my daughter*” more than once since her diagnosis.

Q: “What are your most important needs related to your HIV care?”

A: “*Housing: The most important thing to me is getting money to get my own place for me and my daughter.*”

Q: “What resources do you have to assist you?”

A: “*I want to help other people with this. We all need to talk... in our neighborhoods. We need to help the kids. I used to have good self-esteem, now it’s low. I’m scared to get out of here. When I get my first piece of money, I’m panicky. What I am going to do about housing for me and my kids?*”

Q: “What else would you like us to know?”

A: “*We need more information passed out here for people who don’t have this and people who do. They go through your stuff and steal your medicines if you have them. I tell them there for AIDS and they say, “no way you have it.” We need pamphlets or something, so they know. Then they can find out if they have it. They can get tested to see.*”

Focus Group Findings: I/RR Gaps and Barriers

(Comments/responses from I/RR made in focus groups)

“I have a case manager from [provider]. They are good to me, they help me.”

“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 [needed to be] in the computer before getting medication. It took months to get into their system so I was denied medications.”

Q: “Did you get your meds when you were in jail?” “When you left jail did they give you a certain amount?”

A: “*Yes. A three day supply*”

Q: “They didn’t give you any kind of hookup where you get them after 3 days?”

A: “*No. This is what they tell you when you get out of jail. If you’re getting HIV medicine in jail, they tell you to go to [provider]?”*

Q: “Then [provider] tells you you’re not eligible?”

A: “*No, because you don’t have a permanent address. You need to be in the system so they’re sure you’re not homeless. You have to be staying in a shelter or have a permanent address.*”

Modified RARE Research Findings: I/RR Needs, Gaps, and Barriers

(Comments/responses from or about I/RR made in RARE Interviews.
Please see full Modified RARE Report for additional comments and context)

...While the intersects among all four populations exacerbate HIV risk, the pervasive co-factors of barriers to services, history of incarceration, co-morbidities, and inconsistent use of condoms further impede prevention and treatment efforts...

"I've been out [of jail] for a month and a half now. I've turned tricks since then. I haven't IV banged or anything like that. My tricks are low risk, it depends, I do it for money, for food... I always categorize my behaviors as low risk."

Q: "What are your most important needs related to your HIV care?"

A: "I need transportation. I need an eligibility card (insurance card). Housing"

Q. "...are most of the sex workers and drug users homeless?"

A. "About 75 percent of them are out here on the streets."

Q. ..."Most of the people who sell sex, are they ex-cons or have they been in jail?"

A. "Quite a few – some incarcerated, some not. Some just homeless, like me?"

[This respondent indicated he was homeless, formerly incarcerated for substance abuse, and a current substance abuser.]

Q. "What kind of barriers would keep you from going to a treatment center"?

A. "Transportation #1."

Modified RARE Research Findings: I/RR Needs, Gaps, and Barriers

Q. “OK, alright. For that year or two, where were you located?”

A. *“Gatesville—in jail.”*

Q. “When you were incarcerated, did they provide any type of substance abuse awareness?”

A. *“Yes. I didn’t have the training, but they have some programs.”*

Q. “How long were you in prison?”

A. *“Three years....”*

Q. ‘...and then you came back to earn extra money.’

A. *“Yeah, basically it’s just the thing about getting a job you know... “[currently hustling)“*

Q. “On the street here, do you see a number of the prostitutes, have they been in prison?”

A. *“Oh yes, 90 percent have been in prison”*

Texas Council on Offenders with Mental Impairments

The Council is the umbrella structure for providing support and services to incarcerated individuals with special needs. As the name implies it is limited to incarcerated individuals with mental health needs and although its mission is stated more broadly, it includes very few health impairments such as HIV:

...to provide a formal structure for criminal justice, health and human service, and other affected organizations to communicate and coordinate on policy, legislative, and programmatic issues affecting offenders with special needs. Special needs include offenders with serious mental illnesses, mental retardation, terminal or serious medical conditions, physical disabilities and those who are elderly.

HEALTH CARE RELATED PROGRAMS FOR INCARCERATED PLWH/A:

Health Services Liaison

This department coordinates the transfer of offenders who require reassignment for medical purposes. The Health Services Liaison is also responsible for conducting medical screenings of offenders who are entering facilities or programs where specific medical criteria must be met.

TDCJ Preventive Medicine Department

The Department of Preventive Medicine is responsible for monitoring and reporting on the incidence of offender infectious diseases such as HIV, tuberculosis, sexually transmitted diseases, hepatitis and other communicable diseases. The department provides training and consulting services to facility health services staff. Preventive Medicine also coordinates and formulates policy for all TDCJ employee health care programs. This department provides technical assistance to the TDCJ Risk Management in matters of employee Worker's Compensation.

Syphilis / Sexually Transmitted Infections (STI)

The Texas Department of Criminal Justice has reported treatment of STIs to the Texas Department of Health since 1956 when they first required it. In 1988 the Texas Department of Criminal Justice began their own monitoring system and created a database for the accumulation of information and tracking of offenders who are treated for syphilis.

The Texas Department of Criminal Justice will identify, test, and manage all offenders with suspected or confirmed syphilis with a uniform testing and management program. Once an offender has tested positive the physician at the facility where the offender is assigned will determine, through a history of the offender, whether or not treatment is required.

Department of Professional Standards

The Department of Professional Standards is responsible for investigating all medical related offender grievances at the last step of the grievance process. Complaints concerning medical services are investigated by the department's Patient Liaison Program.

The Health Services Quality Improvement Program is monitored and coordinated by Professional Standards staff. The Operational Review process requires that each facility be audited every two years to ensure compliance with policies, procedures, and standards. This is also a responsibility of the Department of Professional Standards.

Programs include those focused on:

- Continuity of care
- Special parole and release programs
- Community based programs:
 - Intensive case management
 - Rehabilitation
 - Crisis services
 - Mental health services

THEMES AND RECOMMENDATIONS:

INCARCERATED/RECENTLY RELEASED

This special study group represented the highest risk factors:

- 50% uninsured (highest)
- Over 50% disabled
- 53% self-reported substance abuse, 45% injected drugs 'ever'
- 19% Out-of-care

This was the only group who did not place their HIV/AIDS diagnosis as their most pressing concern. They unanimously stated that staying free of drugs was their #1 mission. Their children tend to live with relatives, with their key concerns being finding housing, employment and basic resources to stay 'clean' of drugs.

Theme 1: The Incarcerated/Recently Released notably ranked substance abuse and mental health services higher than the other special study groups. According to experience reported by providers of substance abuse services, very few individuals receive any substance abuse treatment while incarcerated.

Recommendation: Work to develop more transition programs including those inside prisons to ease the transition of the high (53% self-reported) rate of substance abuse. The Texas Department of Criminal Justice (TDCJ) has established a program of halfway houses for individuals who are identified or who request transition opportunities that incorporate substance abuse treatment.

Theme 2: In prison, transitional HIV medication adherence is a significant issue with recently released often reporting being issued a very limited supply of drugs. Lack of permanent address is a confounding obstacle to being 'in-care' and continuing adherence to a strict medication regimen.

Recommendation: Develop a comprehensive transitional program that allows clinics to 'adopt' recently released, with prior resources provided including a permanent address if none is otherwise available, ongoing medication regimen and basic resources (nutrition and basic medical care).

Theme 3: Transportation is frequently mentioned as a limitation to accessing other needed services. In addition, many individuals, upon release, do not have a valid identification, such as a driver's license, which is also a barrier to accessing transportation and other services.

Recommendation: Incorporate transportation as a resource provided before release.

Theme 4: High disability and low employment rates make this group vulnerable to remain “out-of-care” (19% vs 12% for all respondents). Among those recently released from prison, there is a high rate of uninsured.

Recommendation: Within the comprehensive transition program, incorporate job retraining, insurance eligibility and other efforts to economically support the recently released. These efforts need to be anticipated well before release (up to 1 year prior).

Theme 5: A substantial percent of I/RR individuals are in care and express concerns about medication availability and service coordination. A smaller, but important, subset of I/RR appears disinterested in care. Several focus group interviews with I/RR revealed that this disinterested population exists and may be difficult to reach. This is true despite the presence of comorbidities disproportionate to the full population (neuropathy, thought/memory disorders, liver disease, pulmonary disease)

Recommendation: More comprehensive screening on intake and release of these individuals from incarceration, both for HIV and comorbidities (See Table 12-9). From these efforts, a more thorough assessment of treatment needs can be determined.

Table 12-9: COMORBIDITIES – INCARCERATED VS ALL RESPONDENTS

Type of Comorbidity	All Respondents	Incarcerated
Hypertension	29%	30%
Neuropathy	25%	33%
Thought/Memory	23%	34%
Lung	18%	22%
Cholesterol	18%	22%
Liver	17%	21%
PCP Pneumonia	14%	17%
Diabetes	9%	8%
Kidney	9%	5%
Heart	8%	10%
Cancer	6%	7%
Don't Know/None	26%	26%

Theme 6: Releasees with felony drug offenses are not eligible for food stamps leaving them vulnerable and straining food banks.

Recommendation: Work with providers to insure access to service.

Chapter 13
Special Study:
Out-of-Care Individuals
Living with HIV

Importance

As Ryan White programs mature and evolve, they are transitioning from providing services to those who request them to moving out into the community in search of HIV positive people who need their services and are not receiving them.

Reasons frequently offered for non-receipt of services by PLWH/A despite the free or subsidized nature of this care include:

- Lack of access to services
- Lack of knowledge of services
- Advised against services by provider
- Personal choice
- Religious beliefs
- Believe they don't need them
- Deep distrust of any 'system'

There is a belief from studies conducted in 1999 by the Columbia University School of Public Health and Seattle that fewer people stay outside the system of care once they know their status¹.

Background

The “never-in-care” is the most resistant population, and tends to be those who are not connected to any service delivery system. This group is frequently homeless, have high rates of substance abuse, engage in high-risk sexual behaviors and often suffer from serious mental health issues.

“Out-of-care” constitutes the proportion of the population that the Health Resources and Services Administration (HRSA) define as not currently receiving HIV-related medical care. This technical formula is failure to access primary care within the past six (6) months.

These individuals could be aware of their HIV status, have no regular medical source of care for HIV, and/or do not access case management services. They could also be receiving sporadic or urgent care or be under treatment for mental health and/or substance abuse issues. They may also use medical care when faced with acute emergencies but not for HIV. In 1999, the combination of these two populations was estimated at 20.5% nationally by the CDC.

Research from Boston University indicates that many people who test HIV-positive delay medical treatment for more than a year after learning their results. The study, published in the Archives of Internal Medicine, surveyed 189 patients testing positive from Boston Medical Center and Rhode Island Hospital. According to the data, 39% of the patients waited over a year to seek primary care, over 30% delayed two years, and almost 20% waited more than five years. Patients with a history of drug abuse or poor social support were more likely to

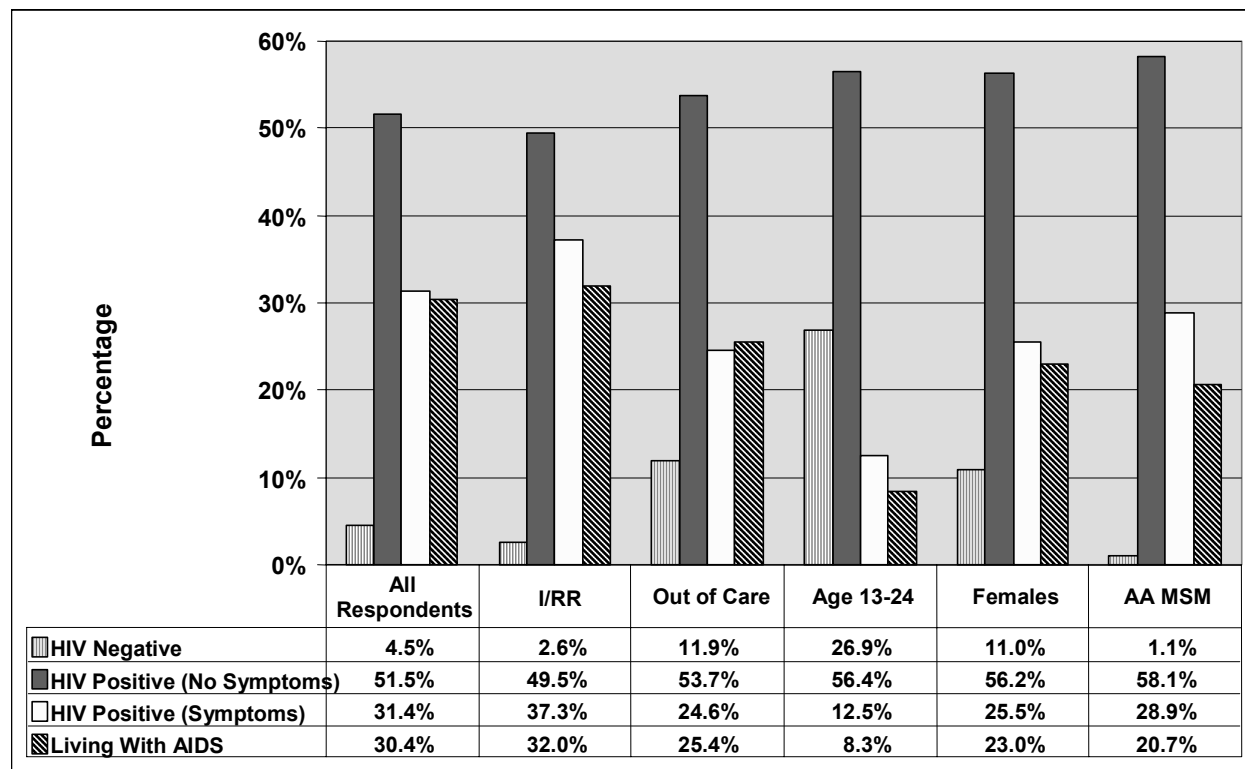
¹ Columbia University School of Public Health, 1999. “The Unconnected”: Service Needs of HIV –Positive Person Outside or Marginal to the Service Delivery System.

postpone medical treatment. The lead researcher recommended that people be linked with primary care services immediately following a positive test for HIV.¹

Harris County Experience

In the client survey, individuals were defined as “in-care” if they received primary medical care within six months prior to the survey and “out-of-care” (OOC) if they had not. Individuals also could indicate that they were “never-in-care”. Although the majority (81%) of surveyed individuals received medical care within the prior 6 months, nearly 20% had not. See Figure 13-1.

Figure 13-1: SELF REPORTED HIV STATUS FOR ALL RESPONDENTS AND SPECIAL STUDY GROUPS



NOTE: Clients could select more than one response (for example: HIV positive with symptoms and Living with AIDS) so percentages add to more than 100%.

As a group, individuals who have not had care in the past 6 months reported an unfavorable current viral load profile. This suggests that the self-choice for remaining out-of-care may not always be clinically well informed.

Surprisingly, 40% of those out-of-care (compared with over 60% in the general population) listed antiretroviral use. Since these individuals are by definition not receiving regular medical care, it is not clear how they obtain or retain prescriptions and how they are monitored if they do take antiretrovirals.

¹ **Archives of Internal Medicine**, "HIV-Positive Put Off Care, Study Finds" April 16,1998)

Geographic Variance

Out-of-care percentages were higher for PLWH/A outside the Beltway versus inside the ten county EMA/HSDA, as illustrated in Figure 13-2 and Figure 13-3.

Figure 13-2: MAP OF 10 COUNTY EMA/HSDA

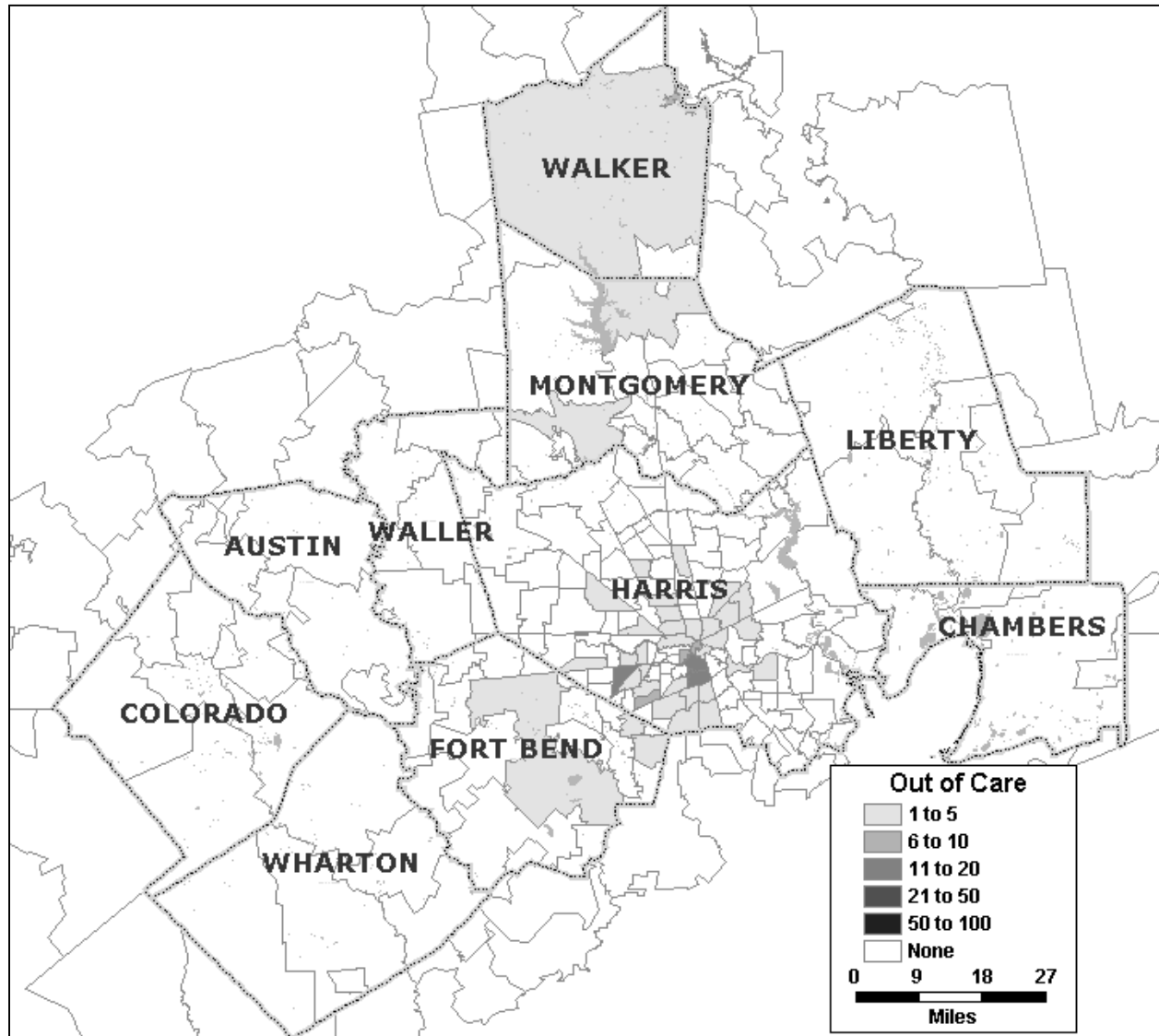
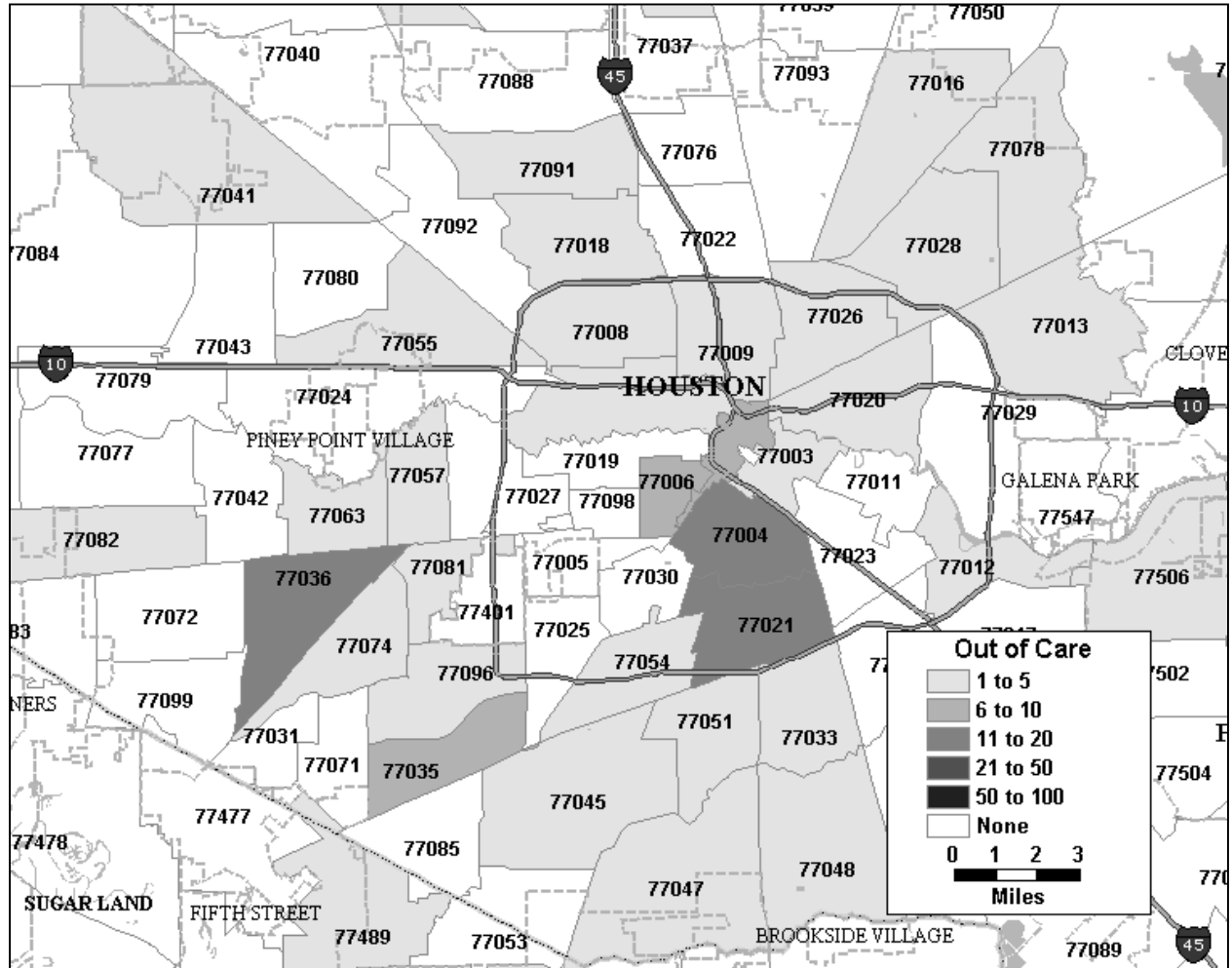
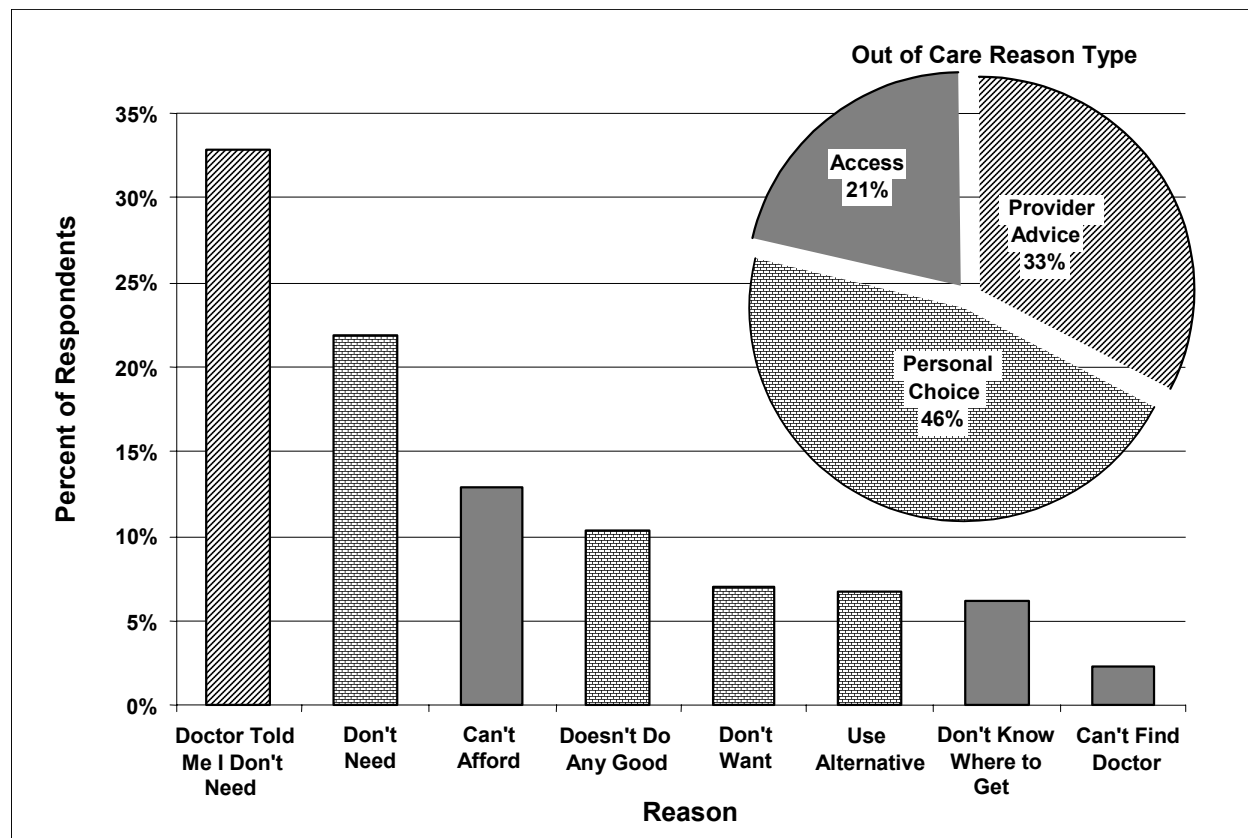


Figure 13-3: OUT-OF-CARE – OUTER LOOP



The reasons offered for out-of-care were either provider advice that they not be in care or misperception of the doctor's instructions. Some may have low viral loads that do not require aggressive antiretroviral therapy, but still meet the need for primary care, see Figure 13-4. (HRSA defined 'in-care' as accessing primary care within the past 6 months)

Figure 13-4: REASON OUT-OF-CARE – ALL RESPONDENTS



Four special study groups were identified as requiring further analysis due to their high-risk nature. These are:

- African American MSM (AA MSM)
- Youth 13 - 24 (Youth)
- Incarcerated and Recently Released individuals (Incarcerated)
- Females (Women of Child Bearing Age, 15 - 45)

Table 13-1: CARE STATUS – ALL RESPONDENTS

Care Status	All Respondents	AA MSM	Females	I/RR	Youth
In-Care	81%	77%	80%	69%	65%
Out-of-care	12%	13%	15%	19%	26%
Never-in-care	7%	10%	5%	12%	9%
Total	100%	100%	100%	100%	100%

Table 13-1 shows that the highest “out-of-care” group is youth, with 35% either “out-of-care” or “never-in-care”. Incarcerated/Recently Released follow with 19% “out-of-care” which when combined with the highest “never-in-care” rating, equal 31% either out or “never-in-care”.

Females are the most compliant, with an “in-care” proportion that matches the general client respondent percentage, and the lowest (20%) combined “out-of-care” and “never-in-care” sum, only 1% higher than that of all client respondents. AA MSM are close to the female experience, with 23% in the “out-of-care” and “never-in-care” categories.

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.

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

PLWH/A aged 13 - 24 were slightly more likely to be “out-of-care” when compared to the full surveyed population. Youth had the highest percentage of “out-of-care” due to provider advice among subgroups studied (see table below). The Needs Assessment associates this with generally lower viral loads on a full population basis. However Youth viral loads may represent an exception, as shown in Table 13-2.

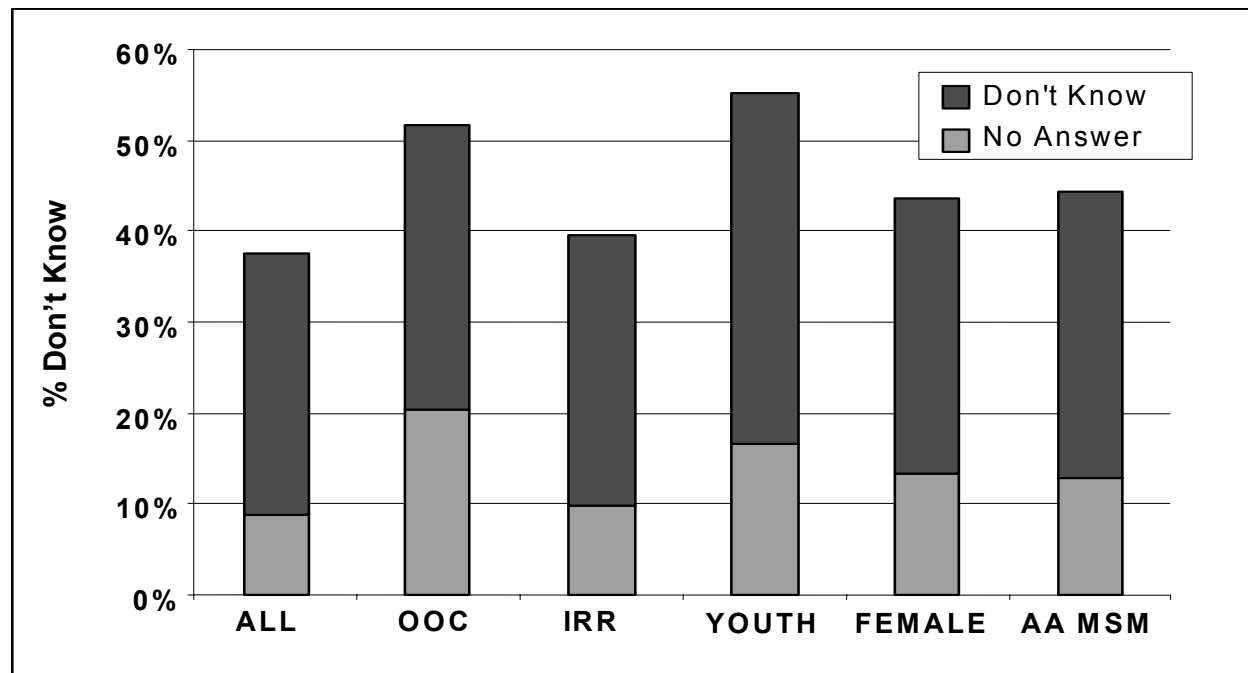
Table 13-2: OUT-OF-CARE REASONS BY SPECIAL STUDY GROUP

Reason Out of Care	All Respondents	OOC	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%

**NOTE: Shading indicates differences from full population*

Youth were much less likely to know their viral load than all respondents and had a profile similar to the “out-of-care” (which they partially comprise) as illustrated in Figure 13-5.

Figure 13-5: VIRAL LOAD KNOWLEDGE BY SPECIAL STUDY GROUP



Conclusions

The “never-in-care” are a difficult group who tend to be very similar in socioeconomic and epidemiologic profiles. They have beliefs, practices and traits very different from the “in-care” and “out-of-care” and are:

- More likely to report that they don’t know where to access services
- More likely to state that they can’t afford care
- More likely to profess that they don’t need medical care (of any kind, not just for HIV or substance abuse/mental health)
- Have little trust in any authority figure, let alone doctors or the medical profession
- Are concerned, if not paranoid, about confidentiality

They also are not readily accessible by traditional outreach efforts, even street outreach. These programs tend to stress one-on-one interaction, and these are highly threatening to the “never-in-care”.

Better mediums would be use of radio, bus billboards or other public medium for communication of services.

Many “never-in-care” are homeless, have criminal records, and these records are most often associated with substance abuse and/or mental health conditions.

RECOMMENDATIONS

- Discuss policy of the planning bodies regarding desired and achievable numbers of “out-of-care” and “never-in-care” to phase in to the service delivery system.
- Further study of the “out-of-care” (12% of client survey respondents) would help determine which are appropriately not accessing ambulatory primary care services and which should, but are not, due to lack of access, awareness and desire.

Reasons regarding access and awareness are surmountable with information and outreach; lack of desire is a personal choice.

- Ensure that further outreach to the higher percentage of “out-of-care” will not deteriorate current service to the majority (81% of client survey respondents) of “in-care”.
- Conduct a similar policy decision regarding the resistant “never-in-care” (7%).
- Focused efforts can be made with the two highest subgroups, youth and the incarcerated/recently released.
- Use public media to reach the “never-in-care” with further RARE or street outreach efforts aimed at probing the hard-to-reach, unconnected PLWH/A.
- Conduct testing where permitted so that knowledge of serostatus can convert to action with information provided about free services, locations, etc.

Chapter 14

Recommendations

RECOMMENDATIONS

General:

- Recognize the changing face of the HIV epidemic in the Houston EMA/HSDA and ensure representation, in Needs Assessment and other community research, by females (increased from 17% female in the 1999 Needs Assessment to 25% female) and bisexuals (13% gender identification with higher fraction in severe needs population – “not-in-care”, incarcerated and African American and Anglo MSM groups).
- Aggressively educate the community about the need to receive primary medical care.
- Specific attention should be paid to the incarcerated (access) and youth/females (provider related) populations.
- The importance of client’s knowledge of viral load as essential to modern antiretroviral therapy should be stressed to all providers and clients.
- The crucial role of non-ASO’s as ‘portals’ or ‘points of entry’ into the HIV/AIDS system cannot be over-stressed with nearly half the respondents to both qualitative and quantitative surveys reporting their diagnosis when accessing services for reasons other than specific HIV testing. Continued efforts at networking, education and quick referrals are essential.
- Continue to work, network and outreach to general providers, especially those who are likely to test potential HIV positive individuals as they enter the system. (Nearly half determined they were HIV positive unrelated to HIV testing).
- Educate the general community about HIV/AIDS, especially the poorest levels of society.
- Include in planning efforts, programs that address the needs of those dually diagnosed with HIV and substance abuse.
- Comorbidities were rife throughout the population. Substance abuse, psychiatric disorders and sexually transmitted diseases were expected, but considerable medical comorbidities related or incident to antiretroviral therapy were also listed, key among them hypertension, cardiac issues, and diabetes.
- Of concern were the reported psychiatric conditions versus what emerged in qualitative research. Paranoid schizophrenia and bipolar disorders were frequently cited on the quantitative client survey and in focus groups. With little probing, however, situational depression or chronic depression emerged as a much more pervasive issue.
- It would be worthwhile to survey for situational or chronic depression at a later date.
- Ensure that depression is listed on any checklist for new client evaluation

Service-Specific:

- Ambulatory/Outpatient Medical Care was ranked high as a service gap with 32% of respondents reporting an issue with use. Some concern was expressed specifically towards non-ASO (AIDS Service Organization) ambulatory services or the lack of coordination between insurance and ambulatory access.
- Continue to expand information systems, such as CPCDMS, to ensure system-wide knowledge of client access into the ambulatory system. This is particularly vital as AIDS converts to a chronic disease with ambulatory access the mainstay of treatment.
- Another service ranking high as a gap was medical case management, particularly as an individual service. Three (3) issues were reported as themes requiring greater attention. These were:
 - Coordination of health care services, particularly inter-agency
 - Coordination of health care and support services
 - Accessibility and continuity of care with case managers

The issue of accessibility and continuity of care with case managers was intriguing, as even long-term survivors had a disparaging notion of discontinuing regular contact with case managers, even if they reported increasing lack of knowledge among newer and younger case managers. Many of the long-term survivors (even in focus groups other than long-term survivors - the disabled), reported that they could negotiate the system better than any case manager that they had ever been assigned with the exception of their first case manager upon entry into the system.

- Dependence on social case management seems integrated with services that require case manager referral—specifically cited were transportation and housing.
- Efforts to psychologically disconnect social case management from dependence and praise those clients, especially long-term survivors, who achieve independence from the system, should be recognized, praised and initiated upon entry to the system as the goal of effective case management. This would also ease burdens on an already strained system.
- Increase coordination among agencies to reduce duplication of services and enhance clients ability to navigate through the care system.
- Coordination of health and support services would be fostered by the same information system discussed in the first service-specific recommendation.
- Dental care ranked as a high service category need with over 50% of respondents listing this service and individual service codes matching this ranking. There was a perception of a gap with this service, related to:
 - Location of services
 - Block scheduling
 - Lack of timely access – interrelated issue with transportation resulting in 35 - 40% of respondents citing delayed or rescheduled service

-
- Dental providers might consider a study to further probe these concerns and to develop additional options to service delivery that address these perceived gaps.
 - A specific recommendation offered by focus group participants was the possible expansion of services in both the North and South rural areas and in Northwest Houston.
 - Mental Health Services are a significant area for interaction with the HIV service delivery system. Those clients who have been homeless in the past two (2) years ranked these services as essential (71%).
 - Appreciate the critical nature of mental health services along the spectrum (psychological/psychiatric counseling, mental health, emergency psychiatric services). This is a widely used service (57% used this service) with a high satisfaction rating as a service category (68%), and individual service ranking (7th as priority).
 - Research the incidence of depression, especially as clients are first diagnosed or enter the system. Many focus group attendees relayed extreme feelings of rage, depression and lingering sadness not only upon learning they were HIV positive, but as they attempted to master system access. Many of the women in these groups were unaware of the importance of treating their depression and the impact that it could have on treatment compliance or progression.
 - Include community mental health centers in planning, since they are mandated to serve those with severe mental illness, defined as major depression, schizophrenia and bipolar disorder as well as the developmentally delayed.
 - Disabilities were commonly reported (38%), especially by the incarcerated/recently released and females. 25% of survey respondents stated that disabilities have been a problem at some time in their disease, with 14% needing a housing modification to address their non-HIV/AIDS disability.

Other Service Needs:

- Housing was an overriding need and barrier throughout all populations. 19% reported being homeless or living in a homeless shelter in the past year. Many live with family or friends, with 25% in supervised or group homes. Many PLWH/A are aware that this is a citywide issue with affordable housing for people on fixed incomes, since many of them live with their parent(s) who are in that category.
- Correlated to adequate housing is the rate of recidivism. Many clients yearn for independent housing in a 'safe' neighborhood in which drug dealing, sex work or other risk factors that could weaken their resolve to continue to recover are not present.
- Continue to collaborate with housing related services such as HOPWA.
- Transportation equaled housing in its listing as a pervasive need complicating adherence to treatment regimens, ability to independently function and even concerns with distance to services for medically disabled. METRO Lift and the funded shuttle system were roundly criticized, with 35-40% of PLWH/A citing transportation as a factor in missed appointments.

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- Rural residents also expressed concerns about transportation with excessive transport times (multiple hours) frequently incurred to access services within the Beltway. Finally, the influence of drivers was cited in a few focus groups as a critical resource for the spectrum of services (medical and social) available to those new to the care system.
 - Continue to work with transportation providers to develop accessible mass transit.
 - Maintain one system for transportation - shuttle or taxi with vouchers. Considerable confusion still exists with clients about which system is in place and their qualifications to access that system.
 - Work with planning bodies to maintain funding to not further stress an already overloaded system.
 - Educate shuttle drivers in the resources available to clients, with specific training on spotting those new to care. Provision of brochures, informational materials and other assistance for those entering the system on the shuttles will allow these drivers to further support knowledge of the system. Several focus group participants specifically mentioned their support as vital for them understanding better where to go and what range of services could be accessed.

Economic:

Attempt to more effectively transition adolescents, especially young mothers who are HIV positive, from Medicaid to other forms of insurance. In the young mothers (age 15 – 24) focus group, all six participants expressed confusion and anxiety about their insurance status upon turning 18 years old.

Information:

- Increase public awareness and education through more community-wide media campaigns.
- Most respondents in focus groups and some client surveys (25%) specifically compared the information transmission in Houston to other urban areas regarding HIV/AIDS prevention and/or treatment. The Internet is growing as a source of knowledge, but public relations, advertising and public announcements were viewed as underutilized sources of public information.