2007 Women of Color and Transgender Women Needs Assessment

Follow-up to the 2005 SF EMA Comprehensive Needs Assessment

July 2007



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Executive Summary

n 2005 the San Francisco HIV Health Services Planning Council (CARE Council) conducted the 2005 Comprehensive HIV/AIDS Health Services Needs Assessment (2005 Needs Assessment) in order to identify the needs of people living with HIV/AIDS in the San Francisco Eligible Metropolitan Area (SF EMA). The Needs Assessment primarily focused on the underserved populations and populations with the most severe need for HIV/AIDS-related health and social services. The CARE Council contracted with Harder+Company Community Research (Harder+Company), a consulting firm in San Francisco, to conduct the Needs Assessment. This report is a follow-up to that study focusing on women of color and transgender women of any race or ethnicity in the SF EMA. The purpose of this follow-up study was to conduct further examination of the health and social service needs of this population of persons living with HIV/AIDS (PLWHA) by collecting both qualitative and quantitative data and to make recommendations based on these findings.

Methods

This Needs Assessment study focusing on women of color and transgender women was conducted in two parts: in-depth interviews with 35 women and five focus groups with diverse groups of women. For the interviews, 35 women were interviewed by telephone using a survey instrument that contained a mix of closed- and open-ended questions covering demographics, housing, caregiving, health status, domestic violence and substance use. Five focus groups were organized and conducted in San Francisco and Redwood City. A series of open-ended questions were developed around the themes of healthcare,

domestic violence, stigma and general needs around HIV services in the SF EMA. It is important to note that for both the interviews and focus groups, recruitment was intentionally targeted at HIV positive women of color and transgender women. Therefore, findings are not generalizable to all HIV positive women in the SF EMA.

Background

Prior to conducting the in-depth interviews and focus groups for this study, Harder+Company re-examined the data from the 2005 Needs Assessment by selecting out the data collected from women (including transgender women) and comparing it to the data from the rest of the population. The findings showed that there were differences between women and the rest of the Needs Assessment population – particularly with substance use and health care – suggesting that women may have different needs.

In addition to the data from the 2005 Needs Assessment, informal findings from the Community Forum held in March of 2007 with HIV positive women from the San Francisco community contributed to the follow-up study process. Specifically, women discussed the abuse and domestic violence that they have experienced and the stigma attached to being female and HIV positive. These two topics were not examined in the 2005 Needs Assessment and have been included and explored in this follow-up study in relation to how they affected accessing and using health and social services.

Client Interviews

The following are highlights from the qualitative and quantitative findings from the 35 women who participated in the client interviews.

Participant Characteristics

Of the 35 women interviewed, 63 percent identified as female and 37 percent identified as male-to-female (MTF) transgender. The largest proportion of this sample, 40 percent, identified as African American. This was followed by 20 percent who were of mixed race; eleven percent identified as Latino; nine percent each identified as Asian, White or "Other"; and three percent identified as Native American.

The average age of the women in this study was 45 years old. The youngest participant was 33 years old and the oldest was 63 years old. The majority of the interview participants (63 percent) reported that they were heterosexual, followed by bisexual at 17 percent and lesbian and "Other" each at 9 percent.

The majority of the women (63 percent) had a high school education or less. Over a quarter (29 percent) reported that they had some college or a two-year college degree. Nearly all of the women interviewed (91 percent) were at or below 150 percent of the poverty level.

Housing

Study participants were asked about their current housing situation. The majority of women interviewed reported having housing – only nine percent reported being homeless.

When asked about barriers and challenges related to finding housing as an HIV positive woman, interviewees identified several ways that housing could better meet their current needs. Many felt that there should be more housing specifically for women, particularly in regards to access, safety, and cultural sensitivity. There appeared to be a perception among the interview participants that

there is more housing available for HIV positive men than women.

Health Status

Assessment showed that women, in general, had different health seeking and health access behaviors from the rest of the HIV positive population in the SF EMA. Of particular concern, the 2005 Needs Assessment showed that women and transgender women ranked healthcare utilization and needs considerably lower than the rest of the population of PLWHA (see *Figure 2*).

This follow-up Needs Assessment found that overall, the large majority (94 percent) of the women had health coverage. Most reported that they had Medi-Cal (88 percent), 18 percent reported using Medicare, three percent each had a county-funded plan (San Mateo County) or chose private pay, and 12 percent reported that they had some other type of health coverage.

About half (51 percent) stated that they receive their care from a community clinic such as Clínica Esperanza or Edison Clinic in San Mateo. Forty-three percent reported receiving care at SF General's Ward 86. Another nine percent stated that they go to UCSF to receive medical attention, and three percent selected "Other."

HIV TRANSMISSION Interview participants were asked to identify the most likely way they were infected with HIV. The majority, almost three-quarters (74 percent), said they were infected by having sex with a man. This was followed by sharing needles at 14 percent. Other ways women reported being infected included having sex with a woman, having sex with a transgender individual, "Other," and "Don't know."

The majority of the participants, 63 percent, reported being HIV positive with disabling symptoms. Over half (57 percent) of participants have been living with HIV for more than ten years. Nearly half (46 percent) have been diagnosed with AIDS; of those, three percent were diagnosed with

AIDS at the same time they were diagnosed with HIV.

HEALTH SEEKING BEHAVIOR Almost a quarter (23 percent) of the interview participants stated that there was a period of time when they went for more than one year without visiting a doctor or visiting a clinic. Importantly, all stated that they returned to and continue to receive HIV care.

When asked when their last health care visit occurred, almost all (94 percent) stated that it was less than six months ago. The majority, 83 percent, also reported that they currently see a medical doctor on a regular, ongoing basis.

In order to get a better idea about their regular health seeking behavior, participants were asked if they had missed any medical appointments in the last year. Two-thirds (66 percent) responded that they had missed an appointment. Of this percentage, the largest proportion (43 percent) stated that they missed their appointment because they were too sick to go, including several who also reported missing appointments due to drugs or alcohol. The next most common reason for missing medical appointments was forgetting or having a scheduling conflict (30 percent). Only one person stated transportation as a reason for missing appointments.

Interviewees were asked to describe the primary health care challenges, barriers or needs they face as HIV positive women. Similar to their comments about housing, the women voiced a perception that there were more services for HIV positive men, and stated that they would like more services geared towards understanding women and the transgender community.

OVERALL HEALTH On a five-point scale rating their current health status from poor to excellent, the majority of the women rated their health from fair to good. Over half of the women (51 percent) reported that their health was "fair" and 29 percent rated their health as "good."

SEVERE NEED Based on the June 2004 CARE Council definition of "severe need" and the data that was collected from the interviews with women, just over half (51 percent) were considered to be in the severe need category. Among those in the severe need category, 44 percent were African American/Black; 22 percent were of mixed race; 11 percent were White; 11 percent Hispanic/Latino; 6 percent Asian/Pacific Islander; and another 6 percent chose "Other". Within the subgroup of African American/Black women, the majority (57 percent) were considered severe need. This trend was also true for White and mixed race women where the majority, 67 percent, in both race categories was considered severe need. Likewise, within transgender women, the majority (62 percent) were found to be severe need based on the definition.

Domestic Violence and Abuse

All participants - regardless of if they had experienced any abuse or domestic violence – were asked if they had ever had a discussion about physical or emotional abuse or domestic violence with a health or counseling professional. The majority, 85 percent, indicated that they had had such a discussion. Among those women, 71 percent reported that they discussed abuse or domestic violence with a social worker or case manager, and just over half (51 percent) reported that they had a discussion with a medical doctor. Another 37 percent reported that they had a discussion with a peer advocate; 31 percent with a health educator, counselor or treatment counselor; and 26 percent with a health professional other than a medical doctor.

Over half of the women (57 percent) reported that they have experienced emotional or physical abuse or domestic violence. Ninety percent reported that they were able to find some kind of support for the abuse they had experienced. When asked if experiencing abuse or domestic violence prevented them from seeking care or services for HIV, only 14 percent reported that it did.

Transgender women expressed more concern about experiencing abuse and domestic violence than non-transgender women. The data supports this. Among those who identified as female, 46 percent responded that they had experienced abuse. In contrast, among transgender women, over three-quarters (77 percent) stated that they experienced abuse.

Substance Use

In this follow-up study, interview participants were asked if they had needed substance use counseling or treatment since being infected with HIV. The majority (57 percent) indicated that they did. Among those who needed services, 85 percent reported that they received services.

When asked what substance use support services they depended on the most, many of the participants described the treatment and support services they receive at specific organizations such as Lyon Martin Women's Health Services, Walden House, Ferguson Place and STOP. Many also mentioned the importance of group therapy and meetings such as AA, NA, and support groups at the organizations listed earlier.

Women were asked to identify the biggest challenge or barrier they had faced related to receiving substance use services. Although most reported that they were satisfied with the type of services that they can receive in the SF EMA, many women reported that being in treatment alongside men was a barrier for them. This was a common theme for many other services as well. Many of the women expressed that they would prefer services geared toward women only or transgender women only. Related to this, women also expressed some vulnerability related to being around men in regards to substance use and treatment for substance use.

Regarding substance use, interview participants were asked if they had ever used illicit substances and if they currently use those same substances. Among drugs that women had ever used, the majority (69 percent) reported using

crack/cocaine. This was followed by marijuana at 57 percent, crystal meth at 34 percent, heroin at 31 percent and speedball at 26 percent. Other drugs were used to lesser extent. In total, about one third (34 percent) of the participating women reported that they are current substance users. Among those women who are currently using drugs, marijuana, crack/cocaine, crystal meth and prescription drugs used recreationally are the drugs of choice.

Focus Groups

Five focus groups were conducted in the SF EMA for this follow-up study. The focus groups targeted the following groups of women in order to elicit in-depth information: African American/Black women, Spanish speaking Latina women (one group in San Francisco and one group in Redwood City), Transgender women, and an open focus group which was open to any women of color or transgender women.

The following key themes emerged across all five focus groups:

Health care

- Participants identified primary care and mental health services as their principal health needs.
- Overall, participants were very satisfied with their primary care.
- Barriers to health care included transportation, long waiting lists for dental and vision services and discrimination from certain non-HIV focused providers.
- Many women expressed a desire for support groups for HIV positive women.
- Several participants noted a need for more mental health services and other services in Spanish and Asian languages.

Abuse and Domestic Violence

- Many participants had personally experienced domestic violence, physical abuse or emotional abuse.
- Experiencing abuse discouraged several participants from disclosing their HIV status to others.
- Most have been able to find support.
- Participants expressed a need for more domestic violence services for transgender women.

Stigma

- Most participants identified HIV-related stigma and fear of discrimination as major concerns.
- Many participants had experienced discrimination and/or rejection first hand.
- As a result of the above, many participants reported no longer disclosing their HIV status beyond their primary service providers.
- Several women in different focus groups expressed stigma-related difficulties in receiving emergency services.
- Participants agreed that the insensitivity of providers and the stigma that still exists could lead them to put off much needed care.

Recommendations

The following recommendations are based on the key findings and discuss possible actions and projects that may be considered for HIV positive women of color and transgender women.

 Increase both cultural and linguistic competency regarding HIV positive women of color among service providers.

- Conduct outreach and training on HIV/AIDS standards of practice and cultural competency to emergency service providers.
- Consider setting aside housing and developing or raising awareness of other services, such as treatment for substance use, for women only (separate from men).
- Increase efforts towards maintaining affordable clean and sober housing for HIV positive women to support their recovery.
- Increase awareness of abuse and domestic violence services, especially for transgender women.
- Plan and conduct outreach efforts specifically targeting HIV positive women in the SF EMA about available health and social services.
- Encourage service providers and organizations to organize support groups for HIV positive women of color.

Introduction

In 2005 the San Francisco HIV Health Services Planning Council (CARE Council) conducted the 2005 Comprehensive HIV/AIDS Health Services Needs Assessment (2005 Needs Assessment) in order to identify the needs of people living with HIV/AIDS in the San Francisco Eligible Metropolitan Area (SF EMA). The Needs Assessment primarily focused on the underserved populations and populations with the most severe need for HIV/AIDS-related health and social services. The CARE Council contracted with Harder+Company Community Research (Harder+Company), a consulting firm in San Francisco, to conduct the Needs Assessment. This report is a follow-up to that study focusing on women of color and transgender women of any race or ethnicity in the SF EMA. The purpose of this follow-up study was to conduct further examination of the health and social service needs of this population of persons living with HIV/AIDS (PLWHA) by collecting both qualitative and quantitative data and to make recommendations based on these findings.

Methods

This Needs Assessment study focusing on women of color and transgender women was conducted in two parts: in-depth interviews with 35 women and five focus groups with diverse groups of women.

Client Interviews

In-depth telephone interviews were conducted with 35 women of color and transgender women of any race or ethnicity. Based on key findings and recommendations from the 2005 Needs Assessment, an interview instrument was developed. The instrument contained a mix of closed- and open-ended questions covering demographics, housing, caregiving, health status, domestic violence and substance use. The instrument was reviewed, discussed and finalized with the Needs Assessment Work Group of the CARE Council.

Once the interview instrument was finalized, interviewees were recruited through flyers placed throughout the SF EMA, in-person recruiting at agencies where the target audience might be, as well as through word of mouth. Potential interviewees were asked to call a toll-free telephone number and were screened for eligibility. If the caller was eligible, the interview either took place immediately or was scheduled for a more convenient time for the participant. All interviews were conducted by phone, and participants received a \$25 Safeway gift card.

Closed-ended or quantitative survey items were entered into SPSS (Statistical Package for the Social Sciences) statistical database software. The data were cleaned and analyzed using standard statistical procedures. Statistical techniques were utilized to effectively identify current status, needs and barriers or challenges for this target population.

Open-ended or qualitative survey items were organized into an Excel spreadsheet and content analysis methods were used to examine the data. This method allowed direct participant statements that either supported or contradicted the qualitative findings to be highlighted in order to provide a more in-depth examination of client needs and gaps in services.

Focus Groups

Five focus groups were organized and conducted for this Needs Assessment. Similar to the interviews, the focus group protocol was developed based on key findings and recommendations from the 2005 Needs Assessment. Additionally, the topics of abuse/domestic violence and stigma were explored. A series of openended questions were developed around the themes of health care, domestic violence, stigma and general needs around HIV services in the SF EMA. The focus group protocol was reviewed, discussed and finalized with the Needs Assessment Work Group of the CARE Council.

Focus group participants were recruited through flyers placed in locations that the target audiences may be. Additionally, partner agencies were notified of focus group recruitment efforts. All focus group participants were given \$20 in cash. The focus groups findings were analyzed using a content analysis approach. Key themes and trends were identified, explored and presented.

It is important to note that for both the interviews and the focus groups, recruitment was intentionally targeted at HIV positive women of color and transgender women. Therefore, findings are not generalizable to all HIV positive women in the SF EMA. Findings are intended to provide more insight into issues regarding how HIV services are reaching women of color and transgender women based on the recommendations from the 2005 Needs Assessment.

Background

Prior to conducting the in-depth interviews and focus groups for this follow-up study, Harder+Company reexamined the data from the 2005 Needs Assessment by selecting out the data collected from women (including transgender women) and comparing it to the data from the rest of the population. The findings showed that there were differences between women and the rest of the Needs Assessment population – particularly with substance use and health care – suggesting that women may have different needs.

For substance use, for example, women were using "harder" substances at a higher rate than the rest of the population (see *Figure 1*): crack/cocaine, heroin, speedball, recreational use of prescription drugs and "other street drugs." The data also showed that women were sharing needles at a higher rate than the rest of the population of PLWHA in the 2005 Needs Assessment. When examining the service rankings from the 2005 Needs Assessment, the utilization and need of substance use services ranked higher for women overall, compared to the rest of the population.

Figure 1. 2005 Needs Assessment: Substance Use (ever used)

	Women	Transgender	Combined	Total
Alcohol	75.7%	65.8%	73.2%	76.6%
Crack/cocaine	67.5%	60.5%	65.8%	52.9%
Marijuana or hash	61.7%	55.3%	60.1%	64.9%
Heroin	39.5%	23.1%	35.3%	29.3%
Crystal meth or methamphetamines	33.0%	30.8%	32.5%	41.0%
Speedball	25.2%	15.4%	22.7%	20.1%
Prescription drugs for recreational use	19.1%	10.8%	17.1%	17.3%
Ecstasy (X)	16.5%	15.4%	16.2%	22.6%
Poppers	16.5%	12.8%	15.6%	29.8%
GHB (Gamma Hydroxybutyrate)	13.0%	15.4%	13.6%	15.7%
Special K (Ketamine)	13.9%	12.8%	13.6%	16.5%
Using erectile enhancement drugs in combination with recreational drugs	13.0%	12.8%	13.0%	16.8%
Other street drugs	10.6%	15.4%	11.7%	3.6%

Another interesting finding from the 2005 Needs Assessment showed that for health care, when the service rankings were examined, women ranked health care considerably lower than the rest of the population (see *Figure 2*). For service utilization, health care was ranked fifth compared to second for the overall population; and for service needs, health care was ranked sixth compared to second for the overall population. It was not clear from the data why health care was ranked lower – whether it was an issue of priority, access or other barriers.

Figure 2. 2005 Needs Assessment: Client Service Rankings

Rank	Women and Transgender Service Utilization	Women and Transgender Service Needs	Total Client Population Service Utilization	Total Client Population Service Needs
1	Food	Food	Food	Food
2	Case Management	Housing	Health Care	Health Care
3	Housing	Transportation	Case Management	Housing
4	Transportation	Case Management	Housing	Case Management
5	Health Care	Client Advocacy	Transportation	Transportation
6	Client Advocacy	Health Care	Mental Health	Client Advocacy
7	Substance Use	Substance Use	Client Advocacy	Mental Health
8	Mental Health	Mental Health	Substance Use	Substance Use
9	Day/Respite Care	Day/Respite Care	Day/Respite Care	Day/Respite Care

In addition to the data from the 2005 Needs Assessment, informal findings from the Community Forum held in March of 2007 with HIV positive women from the San Francisco community contributed to the follow-up study process. Specifically, women discussed the abuse and domestic violence that they have experienced and the stigma attached to being female and HIV positive. These two topics were not examined in the 2005 Needs Assessment and have been included and explored in this follow-up study in relation to how they affected accessing and using health and social services. Questions related to abuse and domestic violence were included in both the interviews and focus groups. The topic of stigma was addressed in the focus groups.

Client Interviews

This section of the report provides the quantitative and qualitative findings from the 35 women who participated in the client interviews for this follow-up Needs Assessment study. In some cases the total number may equal less than 35 because of missing data (i.e., the interviewee chose not to answer the questions, or the response provided was not among the selections on the survey). Also, in some cases the percentage total may equal more than 100 percent due to rounding.

Participant Characteristics

Thirty-five HIV positive women of diverse backgrounds from the San Francisco Eligible Metropolitan Area (SF EMA) were interviewed for this special follow-up Needs Assessment focusing on women of color and transgender women of any race or ethnicity. Of the 35 women interviewed, 63 percent identified as female and 37 percent identified as male-to-female (MTF) transgender. The largest proportion of this sample, 40 percent, identified as African American. This was followed by 20 percent who were of mixed race; eleven percent identified as Latino; nine percent each identified as Asian, White or "Other"; and three percent identified as Native American (see *Figure 3*). Eight people said that they spoke a language other than English as their primary language. Of those, three reported speaking Spanish and the rest reported speaking an Asian language (Lao, Tagalog, Thai or Vietnamese).

Figure 3. Reported race/ethnicity of interview participants (N=35)

Race/Ethnicity	% (n)
African American	40.0% (14)
Mixed Race	20.0% (7)
Hispanic/Latino	11.4% (4)
Asian/Pacific Islander	8.6% (3)
White	8.6% (3)
Native American	2.9% (1)
Other	8.6% (3)
TOTAL	100.0% (35)

The average age of the women in this study was 45 years old. The youngest participant was 33 years old and the oldest was 63 years old. The majority of the interview participants (63 percent) reported that they were heterosexual, followed by bisexual at 17 percent and lesbian and "Other" each at 9 percent (see *Figure 4*).

Figure 4. Reported sexual orientation of interview participants (N=35)

Sexual Orientation	% (n)
Heterosexual	62.9% (22)
Bisexual	17.1% (6)
Lesbian	8.6% (3)
Other	8.6% (3)
Missing/declined	2.9% (1)
TOTAL	100.0% (35)

The majority of the women (63 percent) had a high school education or less. Over a quarter (29 percent) reported that they had some college or a two-year college degree. Nearly all of the women interviewed (91 percent) were at or below 150 percent of the poverty level (see *Figure 5*).

Figure 5. Estimated yearly income of participants (N=35)

Income ranges based on 2005 FPL	% (n)
0 - \$9,570	31.4% (11)
\$9,571 - \$14,355	60.0% (21)
\$14,356 - \$19,140	2.9% (1)
\$19,141 - \$28,710	
\$28,711 - \$36,280	2.9% (1)
Greater than \$36,280	
Missing/declined	2.9% (1)
TOTAL	100.0% (35)

Caregiving

Often women are considered caregivers for dependent children or adults, such as elderly parents or disabled family members, a role that may be an additional burden to HIV positive women's ability to meet their own health needs. For this reason, interviewees were asked if they were currently caring for any children or adults (see *Figure 6*). Eleven percent reported that they were caring for a child under the age of 18 and six percent reported that they were caring for an adult. Of those, three-quarters reported that they have someone to care

for their dependents while they are receiving treatment for their HIV/AIDS. This is similar to what was found in the 2005 Needs Assessment.

Figure 6. Women who reported having dependent children or adults (N=35)

Caregivers	% (n)
Women who are caregivers of children	11.4% (4)
Women who are caregivers of adults	5.7% (2)

Housing

Study participants were asked about their current housing situation. The majority of women interviewed reported having housing – only nine percent reported being homeless (see *Figure 7*). Over one quarter (29 percent) of the interviewees reported that they rent an apartment or house, and another 29 percent reported residing in an SRO or hotel. The rest reported that they live in a treatment facility, supportive housing, transitional housing, are living/crashing with someone, living with their parents, or own an apartment/house.

Type of Housing	% (n)
Rent apartment/house	28.6% (10)
SRO with tenancy/hotel	28.6% (10)
Homeless shelter	8.6% (3)
Living/crashing with someone – no rent	8.6% (3)
Halfway house/transitional housing	5.7% (2)
Treatment facility	5.7% (2)
Supportive housing	5.7% (2)
Own apartment/house	5.7% (2)
Live with parents	2.9% (1)
TOTAL	100.0% (35)

When asked about barriers and challenges related to finding housing as an HIV positive woman, interviewees identified several ways that housing could better meet their current needs. Many felt that there should be more housing specifically for women, particularly in regards to access, safety, and cultural sensitivity. There appeared to be a perception among the interview participants that there is more housing available for HIV positive men than women. Women described this as follows:

There should be more housing for women – it's always housing for males. And males always get more incentives... Females get nothing for HIV, here in SF the males get everything.

With a lot of women... they want you to go to a shelter first, and there are women who are not comfortable being in a shelter because of their experiences. They should have more shelters specifically for HIV positive women because many women aren't as open about their status and don't want to go to shelters with their HIV meds.

Sometimes it's hard to place a woman in housing - it seems like they'd rather place men. There are more HIV men who come out. There are not enough HIV ladies who are Native American who are talking about it because we hide in our corners because we're ashamed. It affects the housing services because Native American women don't want to go into HIV housing because they don't want their family members to know.

[There are] lots of women from Asian communities who don't want to speak the language and don't feel confident to go out [to find housing].

They should know about when you move in, men try to get at you, get dirty at you, they have no respect. I was brought up in an age where you treat people the way you want to be treated.

My problem when I had an SRO [was] there were a lot of male predators because I was a single female. That was very intimidating and uncomfortable. There [should be] more security for women. Put females in one living situation where you don't have all the males and other genders that are very intimidating and violent.

Transgender women also felt that they had encountered discrimination when trying to find housing:

My gender – I feel that everyone discriminates against me. I had gotten an apartment from this one lady, and I went back to go look at it again the second time, and the next day she called me and told me that she didn't want to give it to me.

It seems like there's been some prejudice because I'm transgender. I've been working with the Community Housing Partnership and they keep putting me off, and I've done everything they wanted me to do. I know there's been openings.

Discrimination. I've experienced not getting housing because I'm transgender. I've experienced it here [San Mateo] in a hotel overnight.

Interview participants, particularly those who said they were in recovery, expressed concern about living in a clean and sober environment:

...they need to put [housing] where it's safe and there ain't that many drug addicts smoking crack in the hallway, and where it's clean.

The biggest challenge for me is to find anything that's clean and sober and not have addicts running in and out. It's hard to stay clean. Shelters are not clean and sober.

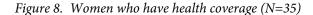
To be able to get housing in an environment free of drugs. I live in the Tenderloin and unfortunately there is no housing free of drugs. There are a lot of drugs in the area. I'm an addict in recovery.

Health Status

Health care

Data from the 2005 Needs Assessment showed that women, in general, had different health seeking and health access behaviors from the rest of the HIV positive population in the SF EMA. Of particular concern, the 2005 Needs Assessment showed that women and transgender women ranked health care utilization and needs considerably lower than the rest of the population of PLWHA (see *Figure 2*).

This follow-up Needs Assessment found that overall, the large majority (94 percent) of the women had health coverage (see *Figure 8*). Most reported that they had Medi-Cal (88 percent), 18 percent reported using Medicare, three percent each had a county-funded plan (San Mateo County) or chose private pay, and 12 percent reported that they had some other type of health coverage (see *Figure 9*).



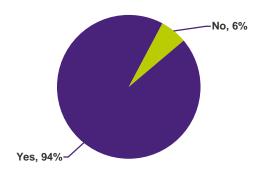


Figure 9. Reported types of health coverage (n=33)

Type of health coverage	% (n)
Medi-Cal	87.9% (29)
Medicare	18.2% (6)
County-funded (San Mateo)	3.0% (1)
Private pay	3.0% (1)
Other	12.1% (4)

Figure 10. Where participants receive their medical care most often (N=35)

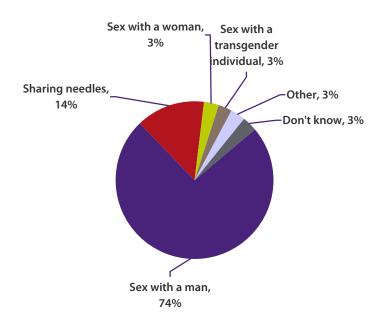
Type of medical facility	% (n)
Community Clinic	51.4% (18)
SF General Ward 86	42.9% (15)
UCSF	8.6% (3)
VA Medical	2.9% (1)
Other	2.9% (1)

Participants were asked where they receive their medical care most often (see *Figure 10*). About half (51 percent) stated that they receive their care from a community clinic such as Clínica Esperanza or Edison Clinic in San Mateo. Forty-three percent reported receiving care at SF General's Ward 86. Another nine percent stated that they go to UCSF to receive medical attention, and three percent selected "Other." (*Please see the Focus Group section of the report for specific comments about health care facilities and the type of care women reported receiving.*)

HIV Transmission

Interview participants were asked to identify the most likely way they were infected with HIV. The majority, almost three-quarters (74 percent), said they were infected by having sex with a man. This was followed by sharing needles at 14 percent. Other ways women reported being infected included having sex with a woman, having sex with a transgender individual, "Other," and "Don't know" (see *Figure 11*).

Figure 11. Likely way women were infected with HIV (N=35)

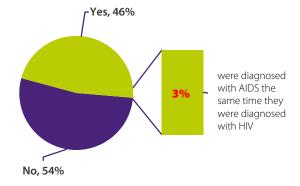


The majority of the participants, 63 percent, reported being HIV positive with disabling symptoms. Over half (57 percent) of participants have been living with HIV for more than ten years (see *Figure 12*). Nearly half (46 percent) have been diagnosed with AIDS; of those, three percent were diagnosed with AIDS at the same time they were diagnosed with HIV (see *Figure 13*).

Figure 12. Length of time living with HIV (N=35)

Length of time	% (n)
Less than 10 years	42.9% (15)
Between 10 – 20 years	42.9% (15)
More than 20 years	14.3% (5)
TOTAL	100.0% (35)

Figure 13. Percent of participants who have progressed to AIDS (N=35)



Health Seeking Behavior

Although the majority of the women reported visiting a doctor within a month after testing positive, eleven percent stated that they waited more than a year for their first visit with a doctor after testing positive.

Almost a quarter (23 percent) of the interview participants stated that there was a period of time when they went for more than one year without visiting a doctor or visiting a clinic. Importantly, all stated that they returned to and continue to receive HIV care. Reasons interviewees returned to care included getting sicker (14 percent); being interested in staying healthier (6 percent); getting blood work done (3 percent); or having a change in income (3 percent). Several women had other more personal reasons such as watching a friend become severely ill or having a friend urge them to get care from a doctor. As one woman explained, "My friend passed away and the case managers who worked with my friend started talking to me and I was interested in talking with them too. They suggested that I seek out care."

When asked when their last health care visit occurred, almost all (94 percent) stated that it was less than six months ago. The majority, 83 percent, also reported that they currently see a medical doctor on a regular, ongoing basis (see *Figure 14*).

Figure 14. Health care visits (N=35)

	% (n)
Last healthcare visit was less than six months ago	94.3% (33)
Women who currently see a medical doctor on a regular basis	82.9% (29)

In order to get a better idea about their regular health seeking behavior, participants were asked if they had missed any medical appointments in the last year. Two-thirds (66 percent) responded that they had missed an appointment. Of this percentage, the largest proportion (43 percent) stated that they missed their appointment because they were too sick to go, including several who also reported missing appointments due to drugs or alcohol. The next most common reason for missing medical appointments was forgetting or having a scheduling conflict (30 percent). Only one person stated transportation as a reason for missing appointments.

Participants were asked to identify the main reason they go to the doctor. Although some said that they only go when they are sick, the vast majority responded that they go for regular check-ups and to get blood work done for T-cell counts. Some women mentioned that they also go for other preventive measures:

I go for Pap smear, breast check, get vitamins to get my energy up, and for blood work because I'm anemic, and check my T-cell count.

To make sure everything is cool as far as my physical health, and ask my doctor questions and get information about my health.

To recover my health, feel more energized physically and mentally.

Others had more personal reasons for seeking care:

I truly love my children, which is why I'm strong and try to stay strong in the face of all the problems. It's worth it to stay healthy because of my children. If I get ill, who will take care of them and love them like I do? That's why I want to keep fighting for my life.

In addition to primary care, participants identified dental and mental health care as the health care or medical services they depend on the most.

Interviewees were asked to describe the primary health care challenges, barriers or needs they face as HIV positive women. Similar to their comments about housing, the women voiced a perception that there were more services for HIV positive men, and stated that they would like more services geared towards understanding women and the transgender community:

[There should be] more groups for women so they can come out and talk about their problems.

I think that mammograms and pap smears are very, very important. Our immune system is ravaged. Some women who are not clean and sober might not know what's going on with their health. I think they should have that kind of requirement to have [gynecological] tests and easily access these tests, for example through a mobile van or through outreach people. When doing outreach on the streets and SROs, they should knock on women's doors and offer the tests.

There is not enough health care services for women. For example there are not enough mental health groups for women. Specific support groups for women to talk about health issues. There seems to be a lot more groups for men compared to women. I think that women are a little bit more skittish in participating in something. They need to get the word out.

As was described in the interviews with transgender women:

I think transgender women especially need more doctors that understand the relationship between hormone therapy and HIV/AIDS therapy. I don't feel like there's enough of that. They don't know what's going on in our community right now – a lot of girls are getting sick, and the only difference with our population is that we take hormone therapy. Nobody seems to know anything about it. I love my doctor, but I don't really feel that she knows enough about having HIV and other disabilities so I always get referred out to other doctors and that very much gets frustrating.

Not a lot of doctors are familiar with transgenders or transgenders who are HIV positive, and some have biases.

With the transgender community, a lot of people are kind of scared, and to let them know not to be scared and to get the help – it's out there, there are services out there. A lot of girls are scared to go to the doctor. Maybe [there should be] an ad campaign that would make [transgender women] not so scared.

I think as far as transgenders go, [providers] need to be more aware of what we're going through and our experience.

Some women also described moving to San Francisco to overcome challenges and barriers to health services they experienced when they lived in other cities and states:

[T]here was nobody to talk about [HIV]. I was in Chicago. I didn't think about seeing a doctor. I was in denial.

Decision to take care of my health. I moved from Massachusetts to San Francisco to get better health care.

It really has not been [challenging] for me. SF is HIV friendly unlike a lot of [states] like Texas and Louisiana.

Overall Health

On a scale rating their current health status from poor to excellent, the majority of the women rated their health from fair to good. Over half of the women (51 percent) reported that their health was "fair" and 29 percent rated their health as "good" (see *Figure 15*).

Figure 15. Women's rating of their health status (N=35)

Health Status	% (n)
Excellent	8.6% (3)
Very good	8.6% (3)
Good	28.6% (10)
Fair	51.4% (18)
Poor	2.9% (1)
TOTAL	100.0% (35)

Severe Need

"Severe need" was defined by the HIV Health Services Planning Council on June 28, 2004. To be considered severe need, an individual must meet all of the following criteria:

- **Disabled** by HIV/AIDS or with symptomatic HIV diagnosis
- Active substance use or mental illness
- Poverty, defined as an annual federal gross income equal to or less than 150 percent of the Federal Poverty Level.

Based on the above criteria, for the purposes of reporting outcomes from this study (as well as the 2005 Needs Assessment Survey), active substance use was defined as those who are current users of illicit substances (34 percent of respondents) and active mental health was defined as those who have been diagnosed with a mental illness in the last two years (77 percent of respondents).

Based on this definition and the data that was collected from the interviews with women, just over half (51 percent) were considered to be in the severe need category (see *Figure 16*). Among those in the severe need category, 44 percent were African American/Black; 22 percent were of mixed race; 11 percent were White; 11 percent Hispanic/Latino; 6 percent Asian/Pacific Islander; and another 6 percent chose "Other" (see *Figure 17*). Among African American/Black women, the majority (57 percent) was considered severe need (see *Figure 18*). This trend was also true for White and mixed race women where the majority, 67 percent, in both race categories was considered severe need (see *Figure 19* and *Figure 20*).

Figure 16. Women meeting criteria for severe need (N=35)

Severe Need	% (n)
Yes	51.4% (18)
No	45.7% (16)
Missing data	2.9% (1)
TOTAL	100.0% (35)

Figure 17. Women meeting criteria for severe need by race/ethnicity (n=18)

Race/Ethnicity	% (n)
African American/Black	44.4% (8)
Mixed Race	22.2% (4)
Hispanic/Latino	11.1% (2)
White	11.1% (2)
Asian /Pacific Islander	5.6% (1)
Other	5.6% (1)
TOTAL	100.0% (18)

Figures 18-20. Women meeting criteria for severe need within race/ethnicity

Figure 18. African American/Black women with severe need (n=14)

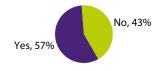


Figure 19. White women with severe need (n=3)



Figure 20. Mixed race women with severe need (n=7)



Among the interview participants, 56 percent of those who identified as female were considered severe need and 44 percent of those who identified as MTF transgender met the severe need criteria (see *Figure 21*). Within transgender women, however, the majority (62 percent) were found to be severe need compared to 48 percent of those who identified as female (see *Figure 23*).

Figure 21. Women meeting criteria for severe need by gender (n=18)

Gender	% (n)
Female (non-transgender)	55.6% (10)
Transgender	44.4% (8)
TOTAL	100.0% (18)

Figures 22-23. Women meeting criteria for severe need within gender

Figure 22. Non-transgender women with severe need (n=22)

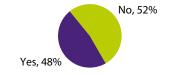
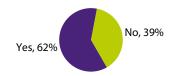


Figure 23. Transgender women with severe need (n=13)



Domestic Violence and Abuse

For this follow-up Needs Assessment study focusing on women of color and transgender women, the topic of domestic violence and abuse was briefly explored in order to get a sense of its effect on women's health seeking behavior. All the participants – regardless of if they had experienced any abuse or domestic violence – were asked if they had ever had a discussion about physical or emotional abuse or domestic violence with a health or counseling professional. The majority, 85 percent, indicated that they had had such a discussion. Among those women, 71 percent reported that they discussed abuse or domestic violence with a social worker or case manager, and just over half (51 percent) reported that they had a discussion with a medical doctor. Another 37 percent reported that they had a discussion with a peer advocate; 31 percent with a health educator, counselor or treatment counselor; and 26 percent with a health professional other than a medical doctor (see *Figure 24*).

% (n)

Social worker/case manager 71.4% (25)

Medical doctor 51.4% (18)

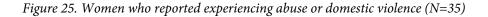
Peer advocate 37.1% (13)

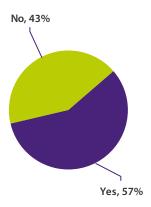
Health educator/treatment counselor 31.4% (11)

Health professional other than doctor 25.7% (9)

Figure 24. Discussions about abuse or domestic violence (n=30)

Over half of the women (57 percent) reported that they have experienced emotional or physical abuse or domestic violence (see *Figure 25*). The largest proportion (29 percent) reported that the abuse was from a partner/spouse or significant other. About 10 percent reported that they had been abused by a family member. It is also worth noting that 14 percent declined to say who abused them. (*Also see Focus Group information on abuse and domestic violence.*)





Ninety percent reported that they were able to find some kind of support for the abuse they had experienced. When asked if experiencing abuse or domestic violence prevented them from seeking care or services for HIV, only 14 percent reported that it did.

Transgender women expressed more concern about experiencing abuse and domestic violence than non-transgender women. The data support this: among those who identified as female, 46 percent responded that they had experienced abuse. In contrast, among transgender women, over three-quarters (77 percent) stated that they experienced abuse.

Substance Use

In the 2005 Needs Assessment, substance use among women and transgender individuals stood out as a topic that needed further exploration. In this follow-up study, interview participants were asked if they had needed substance use counseling or treatment since being infected with HIV. The majority (57 percent) indicated that they did. Among those who needed services, 85 percent reported that they received services (see *Figure 26*). Among those who did not receive services, one person observed, "*It's hard to find services in San Mateo*," while others said that they have information about services but have not accessed them yet. Among those who have received services, 71 percent said they received individual counseling or therapy; 71 percent said they went to group counseling or therapy; and 41 percent said that they received inpatient services. Sixty-five percent also said that they received medication for psychological or behavioral issues (see *Figure 27*).

Figure 26. Women who indicated that they needed substance use treatment since infected with HIV (N=35)

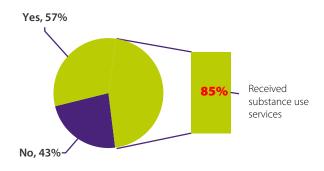


Figure 27. Types of substance use treatment received

Type of service	% (n)
Individual counseling/therapy	70.6% (12)
Group counseling/therapy	70.6% (12)
Medication	64.7% (11)
Inpatient services	41.2% (7)

When asked what substance use support services they depended on the most, many of the participants described the treatment and support services they receive at specific organizations such as Lyon Martin Women's Health Services, Walden House, Ferguson Place and STOP. Many also mentioned the importance of group therapy and meetings such as AA, NA, and support groups at the organizations listed earlier. Regarding group therapy, women remarked:

I depend a lot on going to groups and putting myself out there, and listening to what other people have to say.

For my recovery, my AA and NA at various places including SFGH and Ozanam and support groups for HIV at Continuum, and a support group for women at the shelter.

I go to a transgender group every Tuesday at API. They teach about safe sex and don't share needles.

Women were asked to identify the biggest challenge or barrier they had faced related to receiving substance use services. Although most reported that they were satisfied with the type of services that they can receive in the SF EMA, many women reported that being in treatment alongside men was a barrier for them. This was a common theme for many other services as well. Many of the women expressed that they would prefer services geared toward women only or transgender women only:

I think they already know about it, but privacy and women should be separate from men when it comes to the treatment.

They need more women's programs because my friends need more programs.

A special program for women who have substance abuse issues. I have a brother who is alcoholic and he's enrolled in a very good program. There should be something like that for women.

Related to this, women also expressed some vulnerability related to being around men in regards to substance use and treatment for substance use:

In the Tenderloin, the men prey on your weaknesses. You have to be careful who you associate with, that's why I run to Oakland in the daytime.

Women are more vulnerable to drugs than men.

Substance use leaves you open to physical violence and rape because your judgment is impaired.

Women should be aware of men who cannot be trusted – they look nice, but a lot of them are abusive. Providers should support women and be able to refer them to [substance use] therapy. A lot of women who have been abused don't want to go because they feel embarrassed and scared. It helped me a lot being able to talk with a therapist.

Regarding substance use, interview participants were asked if they had ever used illicit substances and if they currently use those same substances. Among drugs that women had ever used, the majority (69 percent) reported using crack/cocaine. This was followed by marijuana at 57 percent, crystal meth at 34 percent, heroin at 31 percent and speedball at 26 percent.¹ Other drugs were used to lesser extent (see *Figure 28*). In total, about one third (34 percent) of the participating women reported that they are current substance users. Among those women who are currently using drugs, marijuana, crack/cocaine, crystal meth and prescription drugs used recreationally are the drugs of choice.

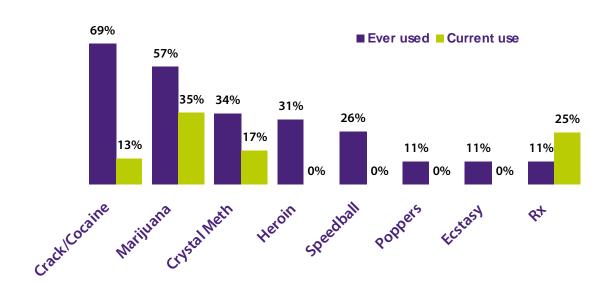


Figure 28. Substance use type – ever used and current use

¹ Participants were also asked about current alcohol use. Alcohol use was not included in this analysis due to the fact that it did not distinguish occasional use from frequent or regular use. This distorted the current substance use data. In the future, frequency of current use will be asked of the participants.

Focus Group Findings

Five focus groups were conducted in the SF EMA for this follow-up study. The focus groups targeted the following groups of women in order to elicit in-depth information: African American/Black women, Spanish speaking Latina women (one group in San Francisco and one group in Redwood City), Transgender women, and an open focus group which was open to any women of color or transgender women of any race (see *Figure 29* and *Figure 30*).

Figure 29. Focus groups held and number of women in attendance

Focus Group	Number Attended
African American/Black	6
Latina (SF)	5
Latina (Redwood City)	5
Transgender	11
Open	5
TOTAL	32

Figure 30. Demographics of focus group participants (N=31)*

Gender	% (n)
Female	54.8% (17)
MTF transgender	38.7% (12)
Male	3.2% (1)
Intersex	3.2% (1)
Race/Ethnicity	
African American	45.2% (14)
Hispanic/Latino	32.3% (10)
Asian/Pacific Islander	9.7% (3)
Mixed Race	9.7% (3)
White	3.2% (1)
Sexual Orientation	
Heterosexual	63.3% (19)
Gay/Lesbian	23.3% (7)
Bisexual	10.0% (3)
Other	3.3% (1)

Income	
0 - \$9,570	48.3% (14)
\$9,571 - \$14,355	31.0% (9)
\$14,356 - \$19,140	6.9% (2)
\$19,141 - \$23,925	
\$23,926 - \$28,710	3.4% (1)
\$28,711 - \$36,280	3.4% (1)
Age	
Participants' ages ranged from 33 – 72 years. The average age was 45 years.	

^{*}Note: one participant did not provide demographic information

The focus groups primarily addressed the topics of health services, abuse/domestic violence and stigma. The following key themes emerged across all five focus groups:

Health care

- Participants identified primary care and mental health services as their principal health needs.
- Overall, participants were very satisfied with their primary care.
- Barriers to healthcare included transportation, long waiting lists for dental and vision services and discrimination from certain non-HIV focused providers.
- Many women expressed a desire for support groups for HIV positive women.
- Several participants noted a need for more mental health services and other services in Spanish and Asian languages.

Abuse and Domestic Violence

- Many participants had personally experienced domestic violence, physical abuse or emotional abuse.
- Experiencing abuse discouraged several participants from disclosing their HIV status to others.
- Most have been able to find support.
- Participants expressed a need for more domestic violence services for transgender women.

Stigma

- Most participants identified HIV-related stigma and fear of discrimination as major concerns.
- Many participants had experienced discrimination and/or rejection first hand.
- As a result of the above, many participants reported no longer disclosing their HIV status beyond their primary service providers.

- Several women in different focus groups expressed stigma-related difficulties in receiving emergency services.
- Participants agreed that the insensitivity of providers and the stigma that still exists could lead them to put off much needed care.

The following are the more specific and detailed findings from each of the five focus groups.

Focus Group with African American Women

A total of six women participated in this focus group. Participants have been living in San Francisco anywhere from ten to 38 years.

HIV Health and Service Needs

Participants identified housing as integral to living a healthy life. They also agreed that they need a place ("a women's HIV club") where women living with HIV can hang out, socialize, share information and resources, and feel comfortable. One participant added that this would be a place where women do not have to hide the fact that they are HIV positive and "a place where you are not asked so many questions and people don't look down on you." Participants concurred that such a place or "club" would promote healthier living by bringing women together. One participant who was recently released from jail noted that she does not know of a place for women on parole to go to for support, whereas she has observed that there are such services for men.

In addition to primary care, participants also thought that mental health services, dental care, OB/GYN, nutrition, and eye care are all important health needs. To stay healthy, some of the women exercise, refrain from smoking, and keep in the company of good friends. One participant added that in order stay healthy, she keeps in touch with her children and focuses on her goal of someday reunifying with them.

Accessing HIV Care and Service Use

Six of the participants receive primary and HIV care at Ward 86 and one participant goes to the UCSF Positive SHE program. Participants have been seeing their primary care providers from four to nine years and continue to be very satisfied with the services they receive. They commented:

I am very pleased. I will not change anything for the world.

I feel like they [providers at Ward 86] are part of my family. She shows me love...and I feel good about having my doctor's support.

I wouldn't trade my doctor for anything in the world. San Francisco has pretty good services, not just for health, but emotional, substance abuse...You just have to get out there and participate.

Three of the participants added that being able to access all the services they need in one place has been especially important. Also, the women thought that it was helpful that they are able to see their health care provider on a weekly basis.

Barriers to Care

Participants identified several barriers to accessing care including transportation and issues related to confidentiality. One participant shared her concerns regarding confidentiality in emergency departments. She reported that during one visit, providers spoke loudly and indiscreetly about her positive HIV status. Other

participants commented that they have had similar experiences. One participant concluded, "Doctors and nurses [in emergency departments] are not sensitive when you got HIV." Another woman added, "They act like we got a plague." One participant shared an experience where she felt that the provider had made assumptions that she was either a drug addict or a prostitute because of her HIV status. Participants agreed that the insensitivity of providers and the stigma that still exists could lead them to put off much-needed care.

You want to tell them what your status is. But they treat you like you're dirty. The [ER] doctor brings a bunch of doctors in, and then he says 'all of you, she has HIV.' The people coming in, walking through there hear him – it's embarrassing you know, and sometimes it makes you want to cry. So I put off going to the Emergency Room and I get real sick like I did last week.

HIV and Stigma

In addition to discrimination they felt from providers, some participants also talked about HIV-related stigma they have experienced from family members. One participant said that she only discloses her HIV status to a few people so as to avoid rejection and feeling hurt. Participants agreed that stigma around HIV is common in the African American community and that talking about HIV is considered taboo. They identified ignorance and closed-mindedness about HIV as factors contributing to this attitude in the community. Participants suggested that education about HIV could help address the stigma surrounding HIV/AIDS in the African American community.

Domestic Violence, Abuse, and HIV

Participants spoke extensively about their experiences with physical abuse as it relates to being HIV positive. One woman concluded, "That's why a lot of Black women don't say they have HIV since you [get] beat down." Another commented, "Women get beaten every day for letting people know that they are HIV positive." Participants offered several suggestions for improving support for women who experience abuse and violence due to their HIV status. They agreed that there is a need for more advocacy services for women facing domestic violence and for sensitivity training for police and paramedics regarding HIV and domestic violence. Lastly, participants agreed that it would be helpful to have women represented in the police department who are familiar with HIV and mental health issues.

Caregiving and HIV

Three of the participants reported that they have part-time caregiving responsibilities for young children in their families (e.g., godson, grandson, etc.). While one of the women expressed a desire for more support around understanding young children, especially boys, the other participants did not express a need for additional caregiving-related support.

Recommendations from Participants

Participants suggested several ways to improve HIV services and to reduce stigma related to HIV/AIDS. Participants spoke about creating a "women's HIV club" where women could socialize and share information, and expressed a need for more advocacy services for African American women who experience abuse and domestic violence. Participants added that sensitivity training for emergency personnel and police as well as increased HIV/AIDS education in the African American community would be especially helpful in reducing the stigma that HIV positive African American women face.

Conclusion

The women in this focus group were generally satisfied with the health and HIV related services they were receiving. All of the participants had been with the same health care provider for a number of years and continue to have positive experiences. Participants identified several barriers to accessing care including transportation, lack of confidentiality, and discrimination from providers in certain service settings such as emergency departments. Participants also shared experiences of stigma from family members, noting that talking about HIV continues to be taboo in the African American community. Participants also shared that it is common for women in their community to experience abuse and violence because of their HIV status. They suggested that education could help to address this issue as well as the stigma that women living with HIV continue to face.

Focus Group with Latina Women Living in San Mateo County

This focus group was conducted with San Mateo County residents at the AIDS Community Research Consortium (ACRC) in Redwood City. Participants were recruited from the San Mateo County AIDS Program and ACRC. The group was held in Spanish with five participants who have been living in San Mateo County between one and ten years.

HIV Health and Service Needs

Most participants identified either primary care or mental health care as their principal medical need. Participants emphasized the importance of having access to high quality medical care, as well as the valuable role that mental health services, including psychotherapy and support groups, play in maintaining one's overall health. One participant observed, "A support group...helps you accept yourself, because if you don't accept yourself first, how are others going to accept you?" In addition, participants shared that they stay healthy by eating well, getting enough sleep, not drinking or using drugs, and keeping a positive attitude.

Access to Care and Services Used

All participants reported that they receive primary care through the Edison Clinic in San Mateo and noted that they visit their doctor for routine check-ups every two to three months – or more often if they become sick. A number of participants mentioned receiving mental health services and attending an HIV support group at the Edison Clinic. Participants also spoke about their experiences receiving dental and vision care. Two participants noted that they had a nutritionist and a health educator, and one participant receives donations from ACRC's food bank.

Overall, participants were highly satisfied with their primary care at the Edison Clinic. Participants noted that they have been treated well by the clinic staff, and one participant commented that the clinic doctors "have an immediate solution for whatever problem we come with." Another participant remarked, "I have a doctor who lacks only wings to make her an angel." Regarding mental health care, participants explained that the services

they have received have been helpful, but that they would like more mental health services to be available. Participants spoke at length about the value of support groups not only for emotional and moral support, but also for sharing experiences and information about services and medications. One participant expressed, "These women give me strength—30 years with this illness and they keep on going...that pushes me to do the same."

Barriers to Care

While participants described very few barriers to accessing primary care at the Edison Clinic, they reported that it was difficult to access services that are not located at the Edison Clinic. Participants explained that they are referred offsite for dental and vision services, where they often face long wait times or waiting lists. One participant described waiting all day for a dental appointment, and another explained that when she tried to get an eye care appointment she was told there were no available appointments until the next calendar year. A third participant stated that she was made to pay for an offsite eye appointment that her primary care doctor told her would be free; as a result, she remains hesitant to receive services beyond her primary care at Edison Clinic.

One participant also spoke about her negative experiences receiving primary care at the Willow Clinic, explaining that she subsequently switched her primary care to the Edison Clinic even though it is farther away from her home. In addition, participants also spoke about the importance of having Spanish speaking service providers.

HIV and Stigma

Stigma related to HIV was a significant concern for most participants. One participant noted, "We think that other people will reject us because of what we have," and another participant added, "There is so much fear in saying that you're positive." Participants explained that this fear has been exacerbated by discrimination and rejection they have experienced from family members as well as service providers. For example, several participants recalled hearing family members make discriminatory comments about people living with HIV/AIDS; as a result, most participants have not disclosed their HIV status to their families. One participant spoke about facing rejection from her partner's family members – rejection that "is enough to destroy a human being." In addition, a number of participants described feeling singled out when they observed doctors washing their hands repeatedly when examining them or putting on gloves when handling a urine sample. Consequently, many participants have decided not to disclose their HIV status to anyone beyond their primary doctors and support group members. One participant suggested that doctors should be more cognizant of patients' fears and take proactive steps to encourage newly diagnosed patients to seek support services in order to reduce their isolation.

Domestic Violence, Abuse and HIV

When asked to speak about domestic violence and abuse, two participants reported that they had experienced emotional abuse and/or domestic violence related to their HIV status. Both participants were abused by their former husbands and described living with the abuse for many years before ending their relationships and seeking help through counseling and classes about domestic violence. Although both participants were able to find help, they explained that their experiences further discouraged them from disclosing their HIV status to others.

Caregiving and HIV

An additional two participants stated that they had children for whom they were responsible and commented about the relation between health and women's caregiving responsibilities. One participant maintained, "It is really important that there are services especially for women, because they have many more responsibilities than men." Another participant added that women tend to prioritize their children's needs over their own medical needs.

Recommendations from Participants

When asked how services for women living with HIV could be improved, participants reiterated the value of support services and were enthusiastic about the idea of a Spanish language support group for women with childcare provided. One participant noted that a women's support group would be important because, "You don't talk about the same topics with men and women that you would talk about with just women." Participants explained that this is in large part due to women's family responsibilities; one participant commented that an HIV positive man is most often "fighting only for himself, not for his kids."

Participants were also very much in favor of creating employment opportunities for HIV positive women. "It's important to receive assistance," noted one participant, "but it's like we're getting too comfortable having everything at our reach," adding that many people feel ashamed to ask for help. Participants suggested a hands-on job training workshop where women could gain skills such as sewing and embroidery, and from there be able to produce goods and earn money. Working, participants explained, makes them feel valuable and is also a way to relax. One participant asserted, "We need to say, 'I am worthy. I can.' I don't need anyone to look down on me for having this weight [HIV]." Another participant observed that when she was working, "those were my hours to not know anything about the world." A third participant added that an employment organization for women living with HIV/AIDS would be especially helpful because many HIV positive women are afraid to seek work, either out of fear that others will discover their status, or out of concern of accidentally infecting others. As one participant expressed, "Before knowing that I had the virus I felt different – with greater motivation to go out and look for a job." Lastly, one participant recommended that there be more studies about women and the side effects of HIV medications.

Conclusion

Overall, participants reported being very pleased with the primary care at San Mateo's Edison Clinic. Participants pointed out several obstacles to accessing dental and vision care, including long wait times and costly services. Several participants mentioned receiving mental health services, and one participant noted a desire for additional mental health services. Participants spoke at length about their fear of rejection based on their HIV status, a fear that has been heightened through first-hand experience with discrimination and abuse. Key suggestions from participants included creating a Spanish language women's support group and developing employment opportunities for HIV positive women through hands-on job training workshops.

Focus Group with Latina Women Living in San Francisco

This focus group was conducted with members of a women's support group at the Mission Neighborhood Health Center. The group was held in Spanish and had five participants, all of whom have lived in San Francisco for at least ten years.

HIV Health and Service Needs

When asked to indicate their principal health and medical needs, most participants pointed to primary care and mental health care, noting that connecting with health services is "indispensable." The AIDS Drug Assistance Program (ADAP), dental and vision care, and gynecological check-ups were also mentioned as essential health services. Participants also identified legal and housing assistance as important benefits that can affect one's health and wellbeing. In addition, participants commented that eating well, exercising and staying stress-free are necessary steps toward leading a healthy life.

Access to Care and Services Used

All participants reported receiving regular primary care through clinics and hospitals including Ward 86 (San Francisco General Hospital), Clínica Esperanza (Mission Neighborhood Health Center), and Kaiser. One participant explained that she sees her doctor for routine check-ups every three months, while another mentioned seeing her doctor mainly when she feels sick. Participants were very pleased with the services they received at Ward 86 and Clínica Esperanza. One participant stated, "Ward 86 is a very good place for me," observing that there, for the first time, "I felt like [my doctor] treated me like a real person." At Clínica Esperanza, noted one participant, "They treat you like a queen." Other participants commended the prompt attention they have received from Clínica Esperanza and added, "Here they treat you with love and care – we need more human warmth."

In contrast, participants were very dissatisfied with services they have received through Kaiser. One participant who has since switched her care to Clínica Esperanza felt that when she was diagnosed at Kaiser, "They treated me so badly – when they told me, they didn't prepare or counsel me." Another participant described that at Kaiser, "I feel like I'm nothing more than a number with HIV," adding that although she has Kaiser insurance, she often chooses to go to Clínica Esperanza instead.

Participants also mentioned receiving mental health services, ADAP, dental care, gynecological check-ups, and legal assistance regarding immigration. Some also attend support groups at Clínica Esperanza and the San Francisco AIDS Foundation, although participants wondered why support group attendance remains low.

Barriers to Care

Participants observed several obstacles related to accessing medical care and other support services, including long waiting lists for benefits and communication barriers with service providers. A number of participants reported that they are not able to self-refer to mental health services, which makes it difficult to obtain immediate care. One participant commented, "If you go with a nervous breakdown, if you need someone to listen to you, in these moments there's no services." Participants also noted that they have encountered long waiting lists for vision and specialist care. In addition, several participants spoke about instances of miscommunication with doctors. For example, two participants described being told repeatedly that their physical pain was psychological in origin – an experience that made one participant feel that "the doctors don't give us a channel for us to tell them exactly what we're feeling." Several participants also mentioned difficulties accessing emergency care at San Francisco General, where the wait time is long and they are often not able to see their regular doctor.

Participants also discussed challenges related to receiving housing assistance, commenting, "Housing is very limited, and this is related to health, because if we're not living well, this affects us." One participant also mentioned that not having access to a gym made exercising difficult, and participants agreed that they would like more services available in Spanish. Finally, one participant suggested that lack of information about

available services and fear of disclosing one's HIV status may prevent women from utilizing available services and claimed that several HIV related benefits have been cut because of disuse.

HIV and Stigma

In addition to discussing system-level barriers to care, participants reported being strongly affected by stigma related to HIV. For example, one participant stated, "You can't tell someone you're infected because they immediately label you as a prostitute or a drug user...as women, society labels us in this way." Another participant expressed that after being diagnosed, "I didn't want to see anyone, I was scared that everyone would know that I had [HIV]...it was a trauma that I carried with me – I hid from people, I lost friends, I didn't answer the phone..." Similarly, another participant commented that after she told one of her friends that she was HIV positive, the information spread to her employers and she was fired from her job, leading her to isolate herself from her friends: "From that date on," she explained, "my friends are not my friends – the contact I have with others...is my communication with God and my children." Other participants agreed that they do not disclose their HIV status beyond their service providers and support group members out of fear of discrimination and rejection.

Several participants also indicated that they have been treated unfairly by service providers. At Kaiser, for example, one participant felt that emergency staff members acted nervous around her upon finding out her HIV status. Another participant felt that hospital staff asked inappropriate questions about how she contracted HIV and treated her like she was "a curiosity." Other participants agreed that they have been looked down on in health care settings; one participant commented, "It's like putting salt and lemon on a wound and it burns…it distresses us, we feel ashamed, embarrassed, hurt."

Domestic Violence, Abuse and HIV

When asked to speak about domestic violence and physical or emotional abuse, two participants reported that they had been abused by their former husbands. Both participants noted that they received subsequent psychiatric support. A third participant observed that many women are afraid to report abuse and added that while there are existing domestic violence shelters, many victims of domestic violence do not receive sufficient follow-up emotional support.

Caregiving and HIV

Participants were also asked to elaborate on their experiences being HIV positive and caring for dependents. Two participants spoke about the psychological burdens of caring for children and/or grandchildren. As one participant explained, "We have HIV. We are mothers, women, housewives, and neither society nor doctors understand this. We have a long list of duties, we work 24 hours a day, seven days a week…" Because of the daily stresses of raising children and living with HIV, participants emphasized that having access to mental health services for themselves and their children is paramount. One participant also noted that access to employment is essential, stating, "As a single mother, I have always depended on my job."

Recommendations from Participants

At various points during the focus group, participants highlighted the importance of mental health care, both for themselves and for their children, and spoke about the need for accessible mental health services. One participant also mentioned that she would like more Latino doctors, "so they understand us." Another participant added that it would be helpful to have more Spanish language services and information, noting that it can be difficult to work with interpreters. In addition, a number of participants reported confronting immigration-related problems and said they would like more legal assistance. Finally, one participant observed

that service providers are not always aware of the benefits available to people living with HIV/AIDS and suggested that information about available services and benefits be more widely disseminated.

Conclusion

Most participants reported that they had access to and were satisfied with their primary care, with the exception of participants who have received services through Kaiser. A number of participants described having difficulty obtaining mental health care and noted that long waiting lists made it difficult to access vision and specialist care. Many participants felt strongly impacted by the stigma surrounding HIV, and several participants spoke about their experiences dealing with domestic violence and raising children. Key suggestions for improving services for HIV positive women included increasing the availability of mental health services for women and their children, offering more legal assistance regarding immigration issues, and providing more Spanish language information about available services for people living with HIV/AIDS.

Focus Group with Transgender Women

A total of eleven women participated in this focus group. Participants have been living in San Francisco between 5 months and 42 years.

HIV Health and Service Needs

Participants were asked to share what they need to lead a healthy life. Participants identified the need for hormone therapy, sexual reassignment surgery, dental services, and substance use services including detox centers. Participants also mentioned the need for stable housing, rental subsidies, and transgender-friendly shelters. One participant commented, "There are quite a few transwomen living on the street. Having a bed to sleep in is 'health.'" Another woman added that having a place to live was especially important in terms of being able to refrigerate medications.

Participants agreed that it was important that providers be familiar with the specific needs of transgender women. One participant remarked, "[In San Francisco], we have quite a few places that say they will work with transwomen and biological women. But when you go there... they don't really help transwomen." However, this person also thought that she was receiving the services that she needed through her current health care provider. She commented, "But I would say for me across the board, I always get what I need...We have a few clinics that on specific days are meant only for transwomen."

Participants also noted that many transgender women have psychiatric and mental health needs. Some participants suggested the need for transgender mental health providers who understand the transgender population. One participant explained, "We want at least one or two transgender psychiatrists available in the city...to have someone that can relate to us."

Accessing HIV Care and Service Use

Participants reported receiving health services at a number of agencies including South of Market Health Center, Magic Johnson Clinic, Tenderloin Health, 360 Positive Health, the VA Hospital, Tom Waddell Clinic, Glide Health Clinic, and UCSF. Most participants reported that they were very satisfied with the health services they receive and attributed their satisfaction to the positive relationships they have with their providers. They commented,

It's about having good communication with your doctor.

My primary care provider has empathy and compassion.

I have been with my physician for seven years. I am very comfortable with him, I can talk to him, and that's where I get my hormone shots...I go there because I get everything I need.

One participant who spoke positively about Tenderloin Health, expressed, "...it's convenient, in the neighborhood, and [the] nurse practitioner is real, real good." Another focus group participant who receives services at the Magic Johnson Clinic, shared, "I like it since they are very sensitive to the needs of transgenders. They even do Pap smears for transgenders."

In addition to health services, participants also mentioned accessing a range of services including case management, nutrition counseling, peer education, food vouchers, rental subsidies, and mental health counseling. Overall, participants agreed that the services they receive have met their needs and are an important part of maintaining their health and well-being.

Barriers to Care

Participants identified several barriers to care including transportation, long waiting lists for housing, unfriendly reception staff at some agencies, and long wait periods during appointments. Participants also agreed that discrimination can be a barrier to receiving services. Specifically, three participants reported having experienced discrimination at a private dental provider, Western Dental, leading one participant to forego much needed dental services. One of the participants also remarked that she did not like that she was addressed as 'Sir'.

Lastly, participants shared their thoughts about receiving services from Centers of Excellence, or CoEs, in San Francisco. One participant explained that a patient can access a number of health services under one roof; a CoE, she explained, "basically has everything". While most participants have had positive experiences accessing all of their health-related services from single agencies, one participant noted that not all agencies provide the same quality of care. She concluded, "If you have the wrong agency then you're in trouble." Another participant noted, "Now since we have to go to one agency, it gives people less options, especially if that one agency cannot give the right services."

HIV and Stigma

Several participants noted that they have experienced rejection and isolation related to their HIV status, primarily from family and friends. One woman articulated,

We all go through it, especially when we first find out [being HIV+] and we go to our family members. A lot of family members will disown you, don't want anything to do with you, don't want to be close to you.

One focus group participant described having felt discrimination from paramedics, and others agreed that HIV-related stigma could affect whether one seeks health services. One of the women expressed, "If you don't feel comfortable, you won't go. You might miss appointments."

Domestic Violence, Abuse, and HIV

Participants were asked whether they or other HIV positive women they know have experienced emotional, economic or physical abuse or violence with an intimate partner. More than half of the participants reported having experienced abuse. One participant suggested, "There should be some kind of specialist for domestic violence and violence against transgenders. Transgender women take the beating because they have nowhere

to turn to." Two participants shared that they received support from Lyon Martin Women's Clinic; one participant specified that the clinic helped her get into a shelter and provided counseling. Another participant observed that Lyon Martin Women's Clinic is the only place in the city that provides support for transgender women experiencing abuse and violence. She commented, "There needs to be at least one or two more places that a person can turn to. There are so many places for women who have violence enacted against them, but for transwomen, there is really nothing." Additionally, participants liked the idea of having a 24-hour emergency hotline specifically for transgender individuals.

Caregiving and HIV

Focus group participants were asked to describe any challenges they have experienced related to being caregivers living with HIV. One focus group participant is currently providing care for and raising three children. However, she has not needed nor sought out any services for support related to her role as a caregiver. Another participant who was a caregiver for her husband sought support from Lyon Martin Women's Clinic. She described how her case manager and the clinic helped her cope with the responsibilities of caring for her disabled husband, stating, "I would confide in them and talk to them about what was going on. Sometimes, I had too much on my plate. They would tell me to try to break it down. You can't do everything in one day."

Recommendations from Participants

Participants shared several recommendations for improving access to services for transgender women living with HIV. Many participants agreed that having a central clearinghouse for information about resources and services would be helpful. One participant specified the need for information about where to receive hormone therapy and sexual reassignment surgery. A few participants also said that it would be helpful if agencies provided medical appointment reminders. Lastly, as mentioned previously, participants agreed they would like more transgender providers – especially mental health providers – serving the transgender population. One woman suggested, "Get someone who has been down in the trenches where we have been. Get one of us who became something."

Conclusion

Overall, the women in the focus group were very satisfied with the health care and support services they were receiving. Most participants described positive relationships with their primary care providers and felt that their health-related needs were being met. Discrimination and stigma were identified by participants as significant barriers to receiving care, along with long wait periods during an appointment, transportation, and unfriendly reception staff. Some of the participants have experienced violence or abuse and suggested the need for a 24-hour emergency hotline and more support services for transgender women facing violence. Participants offered several suggestions for improving access to HIV care and services, including a central clearinghouse for information about resources, medical appointment reminders, and providers who are sensitive to the needs of the transgender population.

Open Focus Group

A total of five women participated in this focus group. Two of the women were African American and three were Asian American transgender women.

HIV Health and Service Needs

Participants identified affordable housing in a clean and sober environment as essential to leading a healthy life. In addition, one participant added that it is important for people to receive support in maintaining sobriety. She commented, ""When [people] are clean and sober, they concentrate on what they need in life like their health…they will go to appointments." Participants also agreed that having a stable income and having health insurance are important. One participant specified the need for support groups for transgender women. Another woman added that transgender women need positive role models in the community from whom they can learn how to lead healthy lives. Having been a sex worker for many years, she continued, "I want to do outreach and work with the transgender community just because I think they need it. You know they need some positive role models, and I think the girls can relate to me because I was in that type of scene."

Accessing HIV Care and Service Use

Participants reported receiving services at a number of agencies, including Kaiser, Tom Waddell Clinic, Ward 86, Tenderloin Health, API Wellness Center, and St. Mary's Hospital.

All participants reported that they were very satisfied with the health services they were receiving and spoke highly about their relationship with their provider. One woman asserted, "It's important to have a connection with your provider." Several participants who receive care at Ward 86 added that feeling comfortable at the agency is also important. At Ward 86, the participants liked the massages and refreshments that are offered to patients in the waiting room.

In addition to health services, participants also utilize a range of services including case management, housing assistance (e.g., rental subsidies), legal assistance, and mental health services. The women spoke extensively about the value of case management, explaining that a case manager is an advocate who can help with obtaining SSI, medical insurance and information about resources such as support groups. Some of the women also shared that they rely on their case manager for emotional support. One participant stated, "It's really important to connect with your case manager. She's the one you are going to talk about everything with."

Barriers to Care

When asked to identify barriers or challenges to accessing care, participants talked about the difficulties they experienced accessing care at San Francisco General Hospital's emergency department. Participants felt that the crowded waiting room, the long wait time to see a provider, the unwelcoming presence of police, and aggravated patients could hinder people from going to San Francisco General Hospital to receive emergency medical attention.

Additional barriers identified by participants included not feeling comfortable sharing personal information with certain providers and having to go to different agencies for care. One woman expressed that she would like to establish a single provider for all of her health needs: "I just need one place to get health care – everything that I need – primary care, HIV care, everything." Others agreed that having a single provider is important because receiving services at different places is "hectic" and often requires repeating personal information to several different providers. Participants also noted that many transgender women are afraid to access health services. One participant shared that taking the initial step to "even just go and [get care]" took some time. She added,

In the transgender community, a lot of the girls don't get the medical attention that they need. For me, my health deteriorated. We don't go because we are scared. The girls in the community won't go and get help until it's really serious.

While participants agreed that certain aspects of the health care system make it difficult to access care, they also noted that consumers play a role in making sure that they receive the services they need. One focus group participant explained, "...it is upon us to do our job because the case workers, they call you, they set an appointment for you...but if I don't want to go I will do something like not answering the phone. It is about ourselves too." Another participant concurred, "If you need those services, you have to make it part of your schedule." Lastly, one participant described encountering language barriers when accessing services. She explained that she often does not understand written materials in English, and shared, "The language makes me feel like I want to give up. The language issue is important when my doctor gives information."

HIV and Stigma

Most participants described experiencing stigma from family members related to their HIV status. One participant spoke about an experience that ultimately led her to isolate from her family, and another participant spoke about the burden of having to constantly explain her HIV status to her family. She shared,

I have to explain it [HIV] every day, whether to my family or friends or whatever. It's [stigma] not going away for me. I am dying to go to my family... What keeps me away is that I have to explain this...I have to have the courage to explain to them, and I have to continue to be positive and be strong, no matter what they say to bother you.

Participants concluded that HIV related stigma is caused by ignorance about HIV/AIDS, and expressed a strong need for people to be more informed about HIV.

Domestic Violence, Abuse, and HIV

Participants were asked to speak about physical, economic, or emotional abuse with an intimate partner. One participant who was physically abused by a former partner shared her experiences. She received support from the police, who she said were very helpful and referred her for additional support from Casa de las Madres in San Rafael. Casa de las Madres provided her with a safe place to stay, financial assistance, diapers and clothing, and assistance getting into permanent housing.

Conclusion

Overall, focus group participants reported being satisfied with the health care services they receive and attributed their satisfaction to the positive relationships they had with their providers. Participants also liked having a place to go to for services that was friendly and welcoming. In addition to primary care, many participants also receive case management, substance use services, mental health services, legal assistance, and housing assistance. Participants identified a number of barriers to accessing care, including language barriers, not feeling comfortable sharing personal information with providers, and having to go to multiple agencies for services. Despite these barriers, focus group participants maintained that their general and HIV-health related needs are being met and are satisfied with the quality of the services they receive.

Recommendations

This follow-up to the 2005 Needs Assessment examines and explores the needs of women of color and transgender women of any race or ethnicity in the SF EMA. The key findings presented in this report bring together the qualitative and quantitative data to enable users of this report to help allocate resources appropriately.

The following recommendations are based on the key findings and discuss possible actions and projects that may be considered for HIV positive women of color and transgender women.

- Increase both cultural and linguistic competency regarding HIV positive women of color among service providers. In both the interviews and focus groups women expressed how their experience being HIV positive is different from men and how their cultural and linguistic backgrounds affect living with HIV. Many participants discussed how women are less open about their HIV status than men, and therefore require more privacy in regards to the services they receive. For some women, less openness regarding their status had to do with "shame" within their culture as expressed by the Latina, Asian and Native American women in particular. They are less able to be open about their status around friends and family. Latina and Asian women also expressed language barriers they experience when receiving services and especially appreciate the type of services they receive from organizations such as API Wellness and Clínica Esperanza.
- Conduct outreach and training on HIV/AIDS standards of practice and cultural competency to emergency service providers. Women had many positive things to say about the service providers that they see on a regular basis; however, they discussed negative experiences they have had with emergency service providers such as EMTs, paramedics, and emergency room personnel. Such negative experiences may be curbed or prevented with specific training on HIV/AIDS standards of practice and cultural competency training.
- Consider setting aside housing and developing or raising awareness of other services, such as treatment for substance use, for women only (separate from men). Based on the study findings, many of the women articulated a need for making services available for women only, i.e., services that are exclusive to women and separate from men. Women cited reasons of safety, privacy, and unique gender and cultural issues for this need. One example of such services that received many positive remarks was San Francisco General's Ward 86, where Thursdays are devoted to services for HIV positive women.
- Increase efforts towards maintaining affordable clean and sober housing for HIV positive women to support their recovery. Many women discussed the importance of having clean and sober housing to aid them in their recovery efforts. Women discussed experiences where they were in a housing environment where other residents were using drugs while they were in recovery.
- Increase awareness of abuse and domestic violence services, especially for transgender women.

 Although the data did not find that abuse and domestic violence was necessarily a barrier to seeking

HIV/AIDS health services for most women, the majority reported that they had experienced abuse. In particular, transgender women expressed concern about abuse they observe and experience, and how to seek help and support for abuse and domestic violence.

- → Plan and conduct outreach efforts specifically targeting HIV positive women in the SF EMA about available health and social services. Although there are HIV/AIDS health services available to women in the SF EMA, based on the interview and focus group findings women do not seem to be fully aware of the resources available to them. There also seems to be a perception that outreach and services are targeted more towards men.
- → Encourage service providers and organizations to organize support groups for HIV positive women of color. Many women felt that having women's support groups may help to increase awareness and utilization of health and social services for HIV positive women and make them feel more comfortable about dealing with their HIV status.