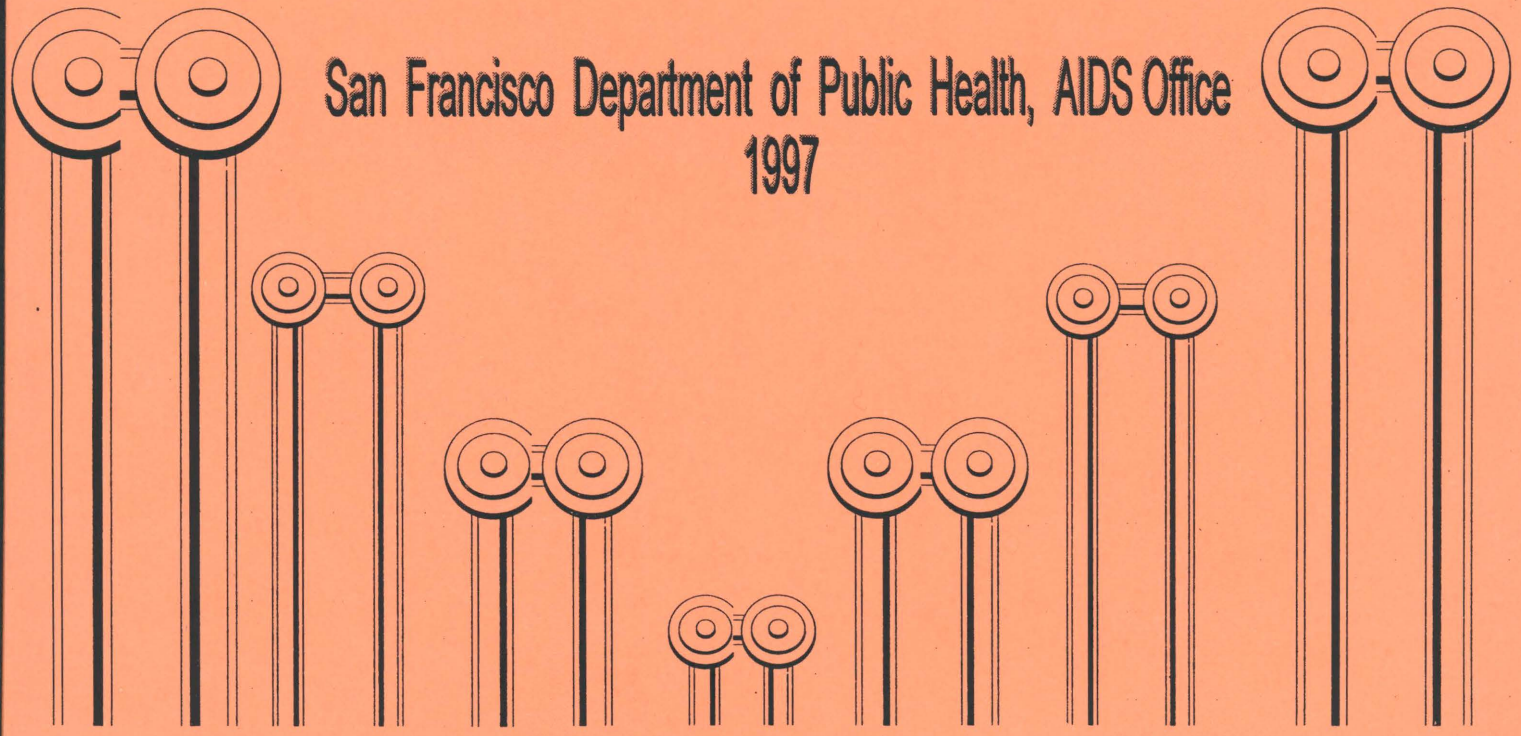


HIV Prevention & Health Service Needs of the Transgender Community in San Francisco: Results from Eleven Focus Groups

San Francisco Department of Public Health, AIDS Office
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(San Bruno), Tenderloin AIDS Resource Center, Tom Waddell Clinic

EXECUTIVE SUMMARY

In 1996, eleven focus groups were conducted to describe the HIV-risk behaviors and access to HIV prevention and health services among transgendered individuals in San Francisco. One hundred HIV-positive and HIV-negative individuals who primarily self-identified as transgender, transsexual, intersexed or the opposite gender from that assigned at birth participated in focus group discussions. One Female-To-Male (FTM) focus group was conducted; the remaining focus groups were mostly Male-To-Female (MTF). One monolingual Spanish focus group was held. Overall, participants were racially and ethnically diverse.

In our analysis of focus group transcripts we found high rates of HIV risk behaviors such as unprotected sex, commercial sex work, and injection drug use. Participants cited low self-esteem, substance abuse, and economic necessity as common barriers to adopting and maintaining safer behaviors. Participants also stated that fear of discrimination and the insensitivity of service providers were the primary factors that keep them (and other transgendered people they know) from accessing HIV prevention and health services.

Based on needs identified in the focus groups, the Transgender Advisory Committee to the AIDS Office developed recommendations for improving prevention and health services for transgendered persons including: implementing a peer-based approach to service provision, training existing prevention and health service providers in transgender sensitivity and standards of care, and developing a coordinated service delivery system.

BACKGROUND

Introduction to the Population

The term *transgender* is used to describe individuals, who, for various reasons, adopt a gender identity that is not congruent with their original physiological status. This group includes non-pre-, partial- and post-operative transsexuals, transgenders, transvestites, crossdressers, and those who are intersexed (born with ambiguous genitalia and/or sex chromosomes). While transgendered individuals all have significant psychological and emotional cross-gender identification, their behavior and sense of personal identity varies. Further, sexual orientation is distinct from gender identity; transgendered persons may be lesbian, gay, bisexual, heterosexual, and asexual.

Some transgendered individuals do not choose to transition into a full-time cross-gender identity because of health and other personal reasons. Life circumstances, such as employment, can also make full-time cross-living difficult or impossible. Other transgendered persons choose to adopt a cross-gender identity as fully as possible, often with the aid of hormones and surgeries. For both transgendered female-to-males (FTMs) and male-to-females (MTFs), transition into the new gender identity may involve a number of steps and can take years. Many transgendered persons are somewhere in the middle of this process, and some may not intend to transition further.

Transgendered individuals may choose hormone treatment, which helps create the appearance of the new gender identity while diminishing characteristics of the old. For FTMs, hormones can create facial hair, deepening of the voice, and increased muscular strength, while diminishing gynecological functions and skin softness, and redistributing body fat. For MTFs, hormones can increase skin softness and body fat, and for some, create breasts and make the voice higher.

There is also the option of "top" and/or "bottom" surgery. For FTMs, top surgery involves a bilateral mastectomy and chest reconstruction or, for very small breasts, liposuction. MTFs can opt for breast augmentation, an Adams apple reduction (tracheal shave), hip enlargement or other plastic surgery. "Bottom" surgery, or genital reconstruction, involves a number of options. FTMs can choose between metoidioplasty (creating a micropenis by severing the suspensory ligaments surrounding the clitoris that has been enlarged with testosterone) and free tissue flap transfer phalloplasty (transferring skin and muscle tissue from the forearm, groin, or thigh to create a penis). Other FTM surgeries include closing the vagina (vaginectomy), removal of the uterus and ovaries (hysterectomy and oophorectomy, respectively), scrotum construction (scrotoplasty), and urethral extension (urethroplasty). Sexual reassignment surgery for MTFs involves vaginal reconstruction (vaginoplasty), penis and testicle removal (penectomy and orchiectomy, respectively), and labia construction (labiaplasty).

The prohibitive costs, risks involved and quality of surgery outcomes keep many transgendered persons from completing sexual reassignment surgery (SRS). This is particularly true for FTMs because there is not currently a surgery option that will create a fully functional penis. Rather than completing SRS, many transgendered individuals opt for hormone treatment alone or

hormone therapy combined with partial surgery (e.g., breast reduction or augmentation). Further, some transgendered individuals choose to adopt a cross-gender identification in the absence of any hormonal or surgical enhancement. This is called the no-hormone/non-operative option. Some people with HIV have been advised to cease hormone therapy and forgo surgery.

Whether transgendered individuals physically pass or not, they may be wary of seeking services because contact with health care providers could bring up difficult psychological issues as well as the possibility of disclosing one's transgender status. Seeking medical care for medical conditions that are incongruous with a person's physiological appearance is particularly difficult. For example, FTMs who have not undergone surgery to remove their uterus, ovaries or vagina may postpone or ignore their gynecological health care needs. Similar barriers exist for MTFs who need care for prostate or urinary tract problems. In addition, many transgendered individuals have had their surgeries in other parts of the world and may not have an established relationship with a medical provider in the United States. Transgendered individuals seeking health and social services are sometimes forced to revert to their original gender in order to obtain services and this may keep them from seeking care. Further, linguistic and cultural differences, coupled with immigration issues, pose further barriers to obtaining services.

Past Research

There is little research which has examined HIV risk and the health, prevention, and social service needs of transgendered persons. Without such information it is difficult to develop appropriate health and prevention interventions and to educate and sensitize service providers. Quantitative studies describing the prevalence of HIV, STDs and risk behaviors often exclude transgendered individuals or do not recruit enough participants to analyze the data on this population separately. However, five studies have *qualitatively* explored the impact of HIV on the transgender community, barriers to effective HIV prevention and health services, and the unique needs of transgendered individuals. They include one study that evaluated the impact of an HIV educational workshop specifically tailored to the transgendered population in Minnesota,¹ a needs assessment conducted in Boston,² two focus groups conducted in San Francisco,^{3,4} and two focus groups conducted in Los Angeles.⁵

Each of the studies collected qualitative data from transgendered individuals or service providers who worked with the transgender community. The results provide a common understanding of HIV risk in transgendered populations including prostitution, alcohol and drug use, internal and external discrimination, poverty, and low self-esteem. However, these studies are limited by very small sample size, lack of racial/ethnic and Female-To-Male representation, and an insufficient analysis and discussion of the data. To address these limitations, eleven focus groups were conducted to determine the primary HIV-related health care, social service and prevention needs of transgendered individuals living in the San Francisco metropolitan area. One focus group comprised entirely of FTM individuals was held and ethnic and racial diversity was obtained in the combined sample. In an effort to maintain sensitivity to transgender-specific issues, The Transgender Advisory Committee to the AIDS Office was involved in the planning, implementation, and analysis of this project.

METHODS

Sampling

As shown in Table 1, ten focus groups were conducted at agencies with existing services for the transgender population and one group was held in a San Francisco County Jail. There was one African American group, one Latina bilingual group, one Latina monolingual Spanish group, and two primarily Asian and Pacific Islander groups. Another group was comprised exclusively of FTM individuals. Most subjects had accessed the participating agency's services previously or had some contact with the agency staff.

Table 1 -- Transgender Focus Group Dates and Locations, 1996.

Date	Agency	# of Participants
6/24	Asian AIDS Project (now known as Asian & Pacific Islander Wellness Center)	9
6/25	Tom Waddell Clinic	11
6/27	Center for Special Problems	11
7/10	Center for Southeast Asian Refugee Resettlement (now known as Southeast Asian Community Center)	13
7/10	Proyecto ContraSIDA Por Vida	12
7/19	Tenderloin AIDS Resource Center	10
7/24	Proyecto ContraSIDA Por Vida	6
7/31	Tenderloin AIDS Resource Center	10
8/01	The Brothers Network (now known as New Village)	7
8/02	San Francisco County Jail - San Bruno	5
8/06	Tom Waddell Clinic	6
		N=100

Procedures

Each group was facilitated by a trained AIDS Office staff person and a member of the transgender community. The facilitators all followed a standardized outline and set of questions. The AIDS Office facilitators did not participate in the discussion, but some of the transgender co-facilitators made comments which were documented in the analysis.

Participants were asked to respond as a group to questions that addressed access to and experience with prevention and health services in San Francisco. Additional questions were asked about improving services and reaching hidden populations. Each participant was given a list of specific prevention interventions and health care services to help guide the focus group discussion. Participants were ensured of complete anonymity and confidentiality, and were told that they did not have to disclose their HIV status if they did not want to. In two groups, participants were actually *discouraged* from disclosing their status. Nonetheless, many self-

disclosed, and it is apparent that the groups were comprised of a mixture of both HIV-positive and HIV-negative individuals. After the focus group was completed, participants were given a twenty dollar stipend and were asked to fill out a short, anonymous demographic form.

All groups were professionally taped by a transcriber who took notes during the discussion. The monolingual Spanish group was transcribed by a Spanish speaking transcriber and was translated by an AIDS Office staff person. Each participant was clearly numbered by the transcriber, except for the group held in the county jail and the monolingual Spanish speaking group. In these two groups, participants were not numbered and could not be differentiated from one another.

Coding and Analysis

The focus group transcripts were read and coded separately by two AIDS Office consultants trained in qualitative analysis. Participants' comments were coded into twenty-eight categories that naturally emerged from the data in the following areas: (1) **psychosocial issues**; (2) **HIV risk behaviors**; (3) **HIV prevention interventions**; and (4) **HIV/AIDS-related services**. Comments were transcribed into the appropriate categories verbatim and were cross-reference if they addressed more than one category.

Comments in each of the aforementioned categories were enumerated and summarized to demonstrate frequency of discussion. Within categories, only comments from unduplicated individuals were enumerated. For example, if one participant made several comments about a particular issue or category, they were only counted once. Participants who made (unduplicated) comments that indicated agreement with a previous comment were counted in the same category as the original participant's comment.

To gather information on participants' involvement in HIV risk behaviors, comments that described risk behaviors were differentiated and counted according to whether the comment was personal disclosure of engagement in a risk behavior and/or whether the comment identified the behavior as a major issue for participants' friends and the transgender community.

Comments about HIV prevention activities and HIV/AIDS-related services were counted if they indicated unmet need (including the need for new services and recommendations for improving existing services). Though there were many more comments describing participants' use and awareness of prevention interventions and HIV/AIDS-related services, only those unduplicated comments suggesting unmet need were counted for this analysis.

DEMOGRAPHICS

One hundred individuals participated in the eleven focus groups. As shown in Table 2, the sample was ethnically and racially diverse. Almost a third of the sample (29%) were born in countries other than the United States and 28% reported that they usually speak a primary

language other than English. The age of participants ranged from 18-66 years with a mean age of 34.7 years. A range of responses were given to self-identified “gender identification” and “sexual orientation”. However, most of the sample was Male-to-Female and self-identified as either straight or bisexual/pansexual. Although participants were not encouraged to disclose their HIV status, nineteen individuals self-disclosed that they were HIV-positive at some point in the focus group discussion.

Table 2 -- Demographic Characteristics of 100 Transgendered Participants, 1996

Characteristic	n=100 (%)
Mean Age	34.7 yrs (range=18-66yrs)
Race / Ethnicity	
White	(37%)
Latino / Hispanic	(24%)
African American	(15%)
Asian / Pacific Islander *	(11%)
Mixed/Multi-ethnic/racial	(10%)
Native American	(3%)
Nativity / Country of Origin	
American Born	(70%)
Foreign Born	(29%)
Declined / Refused	(1%)
Gender Identification	
Transgender (MTF)	(40%)
Transgender	(27%)
Female	(12%)
Transsexual (MTF)	(5%)
Transgender (FTM)	(5%)
Male	(2%)
Intersexed	(2%)
Other	(5%)
Missing	(2%)
Sexual Orientation	
Straight / Heterosexual	(37%)
Bisexual/Pansexual	(22%)
Gay / Homosexual	(19%)
Other	(12%)
Lesbian	(6%)
Missing	(4%)

* Asian and Pacific Islander category included: Chinese (2%); Filipino (2%); Hawaiian (1%); Lao (1%); Vietnamese (1%); not specified (3%).

PSYCHOSOCIAL FACTORS

A number of psychosocial issues that participants felt needed to be addressed before effective HIV prevention and health care services could be delivered were discussed, including: 1) discrimination (general discrimination, discrimination experienced when seeking services, employment discrimination, and housing discrimination); 2) socioeconomic factors (poverty, lack of education and job training, unemployment); 3) transgender-specific health concerns (hormone use, sexual reassignment surgery, mental health/depression); 4) police harassment; and 5) low self-esteem.

Discrimination

Although not asked directly, many participants discussed the prevalence of discrimination in the transgender community. There was a great deal of discussion about discrimination that occurs daily (e.g., going to the store), discrimination that occurs when transgendered individuals seek services, particularly from perceived “lesbian and gay agencies”, health care agencies and substance abuse programs, and discrimination that occurs when transgendered people seek employment and housing.

General Discrimination (33 unduplicated comments)

“It’s not only when you’re trying to apply for a job. You can be at the shopping market, the clothing store, or just walking down the street. You can experience discrimination. I feel that the main issue that we deal with as transgendered persons is ignorance from society. People need to be educated.”

“I think that employment is the issue in the community. It’s an issue that is generated by an even larger issue, and that’s discrimination from society. Discrimination that we receive as transgendered persons, and that’s just in everyday living.”

Discrimination when seeking services at Lesbian & Gay Agencies (20 unduplicated comments)

“A lot of the service organizations exclude us. They focus mainly on the lesbian and gay community. I was at an agency, and these gay boys were just coming and going. I waited two hours, and they just forgot about me! I would rather go to a heterosexual organization and get help from them, than go to a lesbian and gay organization, because a lot of times, the lesbian and gay community does leave us out.”

Discrimination when seeking substance abuse treatment (16 unduplicated comments)

“They told me to go to this treatment place and said everything would work out fine. Nobody said hello to me, and I know them all. It was because I was the only transgender there. They invited me but then they only wanted to rope me in and look at me. For me that felt bad and I got up and got out.”

“I was in a drug program. They kicked me out of my program just today because I said I wanted to come to a transgender meeting... they said transgenders are welcome, but they’re not... and I was doing real good..., sober for 28 days now.”

Employment Discrimination (13 unduplicated comments)

“I have a four year college education, and the minute I step into any business office, with three pages of resume, boom! The door’s already shut in my face, because of my appearance! I have a lot of problems getting employment.”

“I’m on SSI, and I make almost \$800 a month. I have a college education, I’ve owned nightclubs, restaurants, I’ve been an actor, I’ve been a professional all my life. But my choices now are to be on SSI disability and prostitute. I guess some girls can find jobs, but there’s a lot of prejudice out there.”

“You can’t get into retail... nobody wants to put you out front.”

Housing Discrimination (9 unduplicated comments)

“There’s major discrimination through building owners. It took me four months to find an apartment that would accept me besides ‘roach coaches’.”

“I moved out of the Tenderloin after six and a half years... I just got so tired of the harassment and discrimination.”

Socioeconomic Factors

Participants spoke frequently of unemployment, pervasive poverty, and reliance on public assistance. Limited job-skills, little education, and employment discrimination were noted as the most common barriers to securing and maintaining work. Subjects underscored the need for education, job training and job placement programs that target the immigrant and sex worker communities.

Unemployment (24 unduplicated comments)

“If it’s anything that pushes me...into tough, bad things, like drugs or coming up close with AIDS, its the unemployment thing...it affects housing too.”

“What’s going on with me right now is employment. It’s really hard to find.”

“The transgendered people is a very high-risk population, because my own experience has told me that it’s very difficult to find any specific job.”

“The whole scenario of prostitution in our TG community is.... I wish we could be treated like anybody else and have the same job opportunities as anybody else.. and I wouldn’t have to go stand on the damn street...I’m a very intelligent person.”

Poverty (24 unduplicated comments)

“Most of us are on some sort of program assistance. And the money is limited. It has to pay for housing. Your food has to come out of that. Clothing, make-up, everything costs money.”

“As a community we have a greater need for money...traditional insurance programs won’t cover our reassignment surgery, we are low in education, low in job opportunities, discrimination is rampant, and we’re specifically excluded from most private insurance policies...this creates a need for money that sends a lot of girls to the streets.”

Job Training (42 unduplicated comments)

“We need to get off the street and be able to get job training. I’ve been looking for a job because I was gonna give up sex work, but the way it looks, I’m not even gonna be able to give it up because I have no job training.”

“We’re in desperate need of job training ...to upgrade skills and then find employers who will employ us.”

“Have meetings where people such as ourselves could be kept out of prostitution, to train for jobs and things like that, so we’re not susceptible to getting the disease.”

Education (24 unduplicated comments)

“I cannot go to school because I’m HIV-positive, and I’m going to end up being a prostitute again, get arrested, lose my apartment, if I sell my body, or use drugs I don’t have my self-esteem..this whole circle.”

“There’s a lot of girls out there that hasn’t finished school, have no intention on finishing school, they’ve just shot dope all their lives.”

Transgender-Specific Health Concerns

Health concerns that are specific to the transgender community came up frequently including: hormone use, mental health/depression, and sexual reassignment surgery. Discussion of hormone use centered on the difficulty of obtaining hormones, the need for more information about hormones to inform decision-making, the pressure from partners to take hormones to achieve or maintain a particular appearance, and the myriad side effects hormones cause including loss of sex drive for MTFs on estrogen, increased sex drive for FTMs on testosterone, liver damage, increased appetite, and adverse mental and emotional changes. Subjects expressed frustration regarding the lack of knowledge about hormones among medical and other service providers. There was also concern about the unknown effects of hormone use on HIV-positive individuals, and the fact that hormones may not be an appropriate step for every transgender-identified person.

Discussion of mental health conditions in the transgender community included individual expressions of depression, negative experiences with insensitive psychiatrists and other mental health professionals, and lack of access to mental health services. While comments regarding hormone therapy were not enumerated within this category (they are counted in the previous

category), it was often noted by participants that hormone use can have a strong effect on an individual's emotional state.

Discussion of sex reassignment surgery (SRS) highlighted the high cost of procedures, lack of insurance coverage, the negative emotional effects of not being able to complete SRS, inadequate sex reassignment surgery counseling, and the pressure that some transgendered individuals feel to undergo SRS when it may not be the right thing for them to do. Subjects expressed concern about individuals who regretted their surgery and the quality of available surgery.

Hormone Use (53 unduplicated comments)

"I asked my doctor if I could keep using hormones, and he told me yes. Afterwards I heard from another source that they can make you ill... it's confusing"

"You're messing with hormones and one of your girlfriends comes along and asks you why you're doing that. 'Well, because my husband likes it'."

"There's some girls sitting in here right now that should not be taking hormones because they have mental problems they need to be dealing with. The hormones do physical and mental things to you, and these people are already screwed up."

"Some girlfriends that I know put themselves on hormones (from the street), but I told them that's not for me... It's better that they go to the doctor and get checked out first."

Mental Health Concerns and Depression (26 unduplicated comments)

"It wasn't until I had a nervous breakdown that I qualified for service at the Center. If I could've got support beforehand, then maybe by now, instead of spending county money on psychiatric care, I could be paying taxes to the county."

"I called on the phone when I became depressed. I was the first transsexual he had talked to. He had NO clue, no idea what I was talking about with my hormones."

Sexual Reassignment Surgery (14 unduplicated comments)

"There really never has been any kind of sex reassignment counseling per se. You don't have a person where you sit down and go over specifics: are you mentally ready for this change?"

"We get absolutely no help with our surgery. If we want electrolysis, that's out of our pocket. If we want to have the vagina done, that's out of our pocket. If we want to have breast implants, that's out of our pocket."

"I don't feel like I should have to hop on an airline, go all the way to Thailand to get my surgery... I don't want something slipshod. We need good, practical health care."

Self-Esteem

Discussion about the low self-esteem of the transgender community came up frequently in each of the eleven focus groups. Much of the discussion centered on how low self-esteem relates to gender identity, self-worth, and risk taking behaviors. The issue of whether or not transgendered individuals pass, or are given recognition as their preferred gender identity, proved to be a critical factor in building or destroying self-esteem. Participants also stated that society's view of the transgender community takes an enormous toll on their self-esteem, and can contribute to self-destructive behavior.

Self-Esteem (37 unduplicated comments)

“When you have a low self-esteem and this fine guy comes up to you and it's like, ‘I want to have sex with you’ And he's so fine, and you're like, ‘If I don't use a condom, he's not gonna want to do it!’”

“We need a more positive image among ourselves. Everybody else put us down; we shouldn't put ourselves down.”

“Lots of girls and guys in the community have very low self-esteem, mainly because of what happened in their past... growing up in the home, school environment,... any kind of attention, especially being recognized as a woman...and getting treated like dirt by sleazeballs.”

Police Harassment

The harassment of transgendered individuals by police, particularly those engaging in commercial sex work or those (in the MTF community) *presumed to be engaging in commercial sex work* was discussed frequently. Participants described being hassled by police when they were just walking home or to the store.

Police Harassment (24 unduplicated comments)

“They'll stop you, you can be walking anywhere. You won't even be in the prostituting area. They'll grab you, they'll search you, and they'll feel all over you. They don't seem to care. It's like, ‘Well, whatever, boy. Are these real?’ And they'll put their hands all down in your bra, and they'll feel all up in between your legs, and ‘Where is your thing?’ They'll make up a boy name, tell you they're gonna take you to jail, and they'll write anything down on their report saying you tried to rob somebody or something like that.”

“To have some pot-belly cop tellin' me, ‘Somebody didn't know what they was doin' when they issued your driver's license.’ Or threaten to have me strip-searched.”

“I work in the Tenderloin. They [police] harass all the queens who are walking by, giving them tickets just because they're walking by. And they treat you with disrespect. They were calling me names. ‘Homeboy’ and things like that.”

RISK BEHAVIORS

Three primary areas of HIV-related risk behavior emerged from the data: 1) commercial sex work; 2) unprotected sex; and 3) substance abuse. In each of these areas, unduplicated comments were enumerated if they indicated personal engagement in the risk behavior and/or acknowledgment of the risk behavior as common among their friends or in their community.

Commercial Sex Work

Although there were no focus group questions that specifically addressed commercial sex work, this issue was discussed in all of the focus groups except the FTM group. Nearly one-quarter (23%) of the sample self-disclosed that they personally engaged in commercial sex work and one ran a bordello. Of those who were involved with commercial sex work, 57% disclosed that they were HIV positive (Note: This figure is conservative enumeration since individuals voluntarily self-disclosed their HIV status). Among 26% of the sample, commercial sex work was described as a major risk behavior of friends and members of the transgender community.

Participants felt that economic necessity and survival was by far the most common contributing factor to the prevalence of sex work among transgendered MTF individuals. Peer pressure, drug addiction, glamour, and validation of one's gender were other incentives to prostitute. There was a great deal of discussion about commercial sex workers who continue their trade while knowing they are HIV-positive, the need for other employment opportunities for sex workers, the dangers of street work, and the difficult time sex workers often have negotiating condom use with "johns" (customers).

Commercial Sex Work (49 unduplicated comments)

"There's something about the glamour of being on the stroll. It's fast, easy money. Shake your tits, shake your tush, and have some guy slip you twenty, fifty, a hundred dollars. It builds up your self-esteem!"

"It's just a vicious cycle. With no education you go back to what you know best."

"Remember, you are hungry, you haven't had anything for a couple of days, and this jerk comes up and says, 'I have twenty dollars, and I don't want to use a condom.' What are you gonna do? You're gonna take this twenty dollars, and you're gonna deal with this freak."

Unprotected Sex

In all but one group, participants spoke about their own unsafe sexual behavior and unsafe sex within their communities. One-fifth of the sample (20%) self-disclosed that they personally engaged in unsafe sexual behaviors and over one-third (34%) discussed unprotected sex as a major issue among their friends and in their respective community. Participants attributed unsafe

sexual behavior to the following factors: low self-esteem, low self-worth, economic necessity and/or addiction, exploration of their new gender/sexual identity, dishonesty about HIV status (their own or their partner's), increased sex drive (FTMs who were taking hormones), and equating unprotected sex with a deeper relationship than "working".

Unsafe sex (54 unduplicated comments)

"I went out with a guy who I knew was HIV-positive, and I had unsafe sex with him because he showed attraction for me. It's about the self-esteem issue. You feel like you're doomed to live your life all by yourself, so you figure, I might as well go out and have a good time and die from it "

"For gay FTMs, we might be willing to do something with someone that's less than safe, because it's like 'Oh my God, an opportunity to have this gay experience.' I feel that."

"For those of us who aren't prostitutes, if we get recognition by a man as being a woman, sometimes you just grab onto that, and maybe ordinarily you would be cautious. In a case like that you just let it all out, cause someone's accepting you as female."

Substance Abuse

In all but one of the eleven focus groups, there was a great deal of discussion of substance abuse. Almost one fifth of the sample (18%) self-disclosed that they personally had substance abuse problems. Over two-thirds (37%) discussed substance abuse as a major issue among their friends and in their respective communities. Participants felt that the following factors contributed to drug and alcohol abuse: the street lifestyle involving prostitution and drugs, lack of education, low self-esteem, and lack of job opportunities. There was frequent discussion of the need for transgender-friendly treatment programs and needle exchange. FTMs stressed that even when there may be services for transgendered people, there are none that meet their specific needs. For example, although there is a needle exchange site that distributes hormone syringes, it is called the "Women's Site" and many FTMs were not aware of and/or were not accessing this program.

Substance Abuse (55 unduplicated comments)

"I said, 'I'm shooting up on heroin, I'm shooting up on speed. I been using one needle for almost a week. I've done another guy.' And they told me that's how I received HIV."

"I have a girlfriend; at one time she was the most beautiful-est woman in the world! She was even modeling for Ebony Fashion Fair, and she had contracts for beauty products. Now she's living' in a hotel and smokin' crack! And that's the only thing she talks about! 'Please give me hit!' But she has no support."

"A lot of the transsexuals I know who are prostitutes are having unprotected sex and they're also shooting up... and sharing needles."

HIV PREVENTION

Participants made many comments regarding the HIV prevention services they use and interventions that they feel are essential and helpful. However, the objective of this project was to determine those expressed needs which are not available or adequate at this point in time. This section highlights the discussion of *unmet* service needs. Participants made several comments about the unavailability of or the need to improve the following HIV prevention interventions: 1) Venue-Based Individual Outreach; 2) Media; 3) Risk Reduction Counseling and Education; 4) Single and Multiple-Session Groups; 5) Venue-Based Community Outreach; 6) HIV Counseling and Testing; and 7) Needle Exchange.

Venue-Based Individual Outreach

Unduplicated comments about venue-based individual outreach that indicated unmet need and recommendations for augmenting existing street outreach services were enumerated. Participants spoke of the difficulties reaching both FTM and MTF persons and the need to reach the sex partners of transgendered individuals. They underscored the value of street-based education, particularly when conducted by transgender community members empowered as outreach workers. Participants also expressed the need for the availability of a range of safer sex materials, so that assumptions are not made about the sexual behaviors of different transgendered individuals.

Venue-Based Individual Outreach (55 unduplicated comments indicating unmet need)

"Do outreach and different types of things, and just build it up to make it something big for the whole community, not just the gay community."

"We need to create an outreach program and have more of the transgender community trained around issues of HIV and AIDS, where there are stipends, and have the transgenders go out into the community and do the street outreach."

"I've visited some of the glory hole areas of the city. It's probably the least safe environment, but most safe for me, in terms of being able to present myself as a gay man and not have that challenged. I'd like to see social outreach that deals with the social issues of our identities. Most of us can't pick guys up in the same way that other gay men can. Maybe we are more drawn to things that maybe we wouldn't do if we had some other options."

"When I was a dyke, safe sex people would come just with dental dams. Now I go to gay men's events and there'd be no dental dams, only condoms. And I think both should be present at all times. Just in doing that you're eliminating assumptions about sexual activity."

Media and Multiple Gender Groups

Participants discussed the need for media campaigns that educate the transgender community, and underscored the value of media efforts which target hard-to-reach populations. Subjects would like to see transgender-specific HIV prevention messages in the media, including FTM-specific messages. Participants would also like to see widespread media campaigns designed to educate the general community about transgendered persons and their issues. Much disdain was expressed about the “tabloid freaks” who frequent some of the talk shows and do not fairly represent the transgender community, but may be the public’s only exposure.

Media (36 unduplicated comments indicating unmet need)

"My friend and I have never been exposed to any AIDS prevention. It's already a day late and a dollar short for transgenders. Gays don't think of us as gay, we don't think of ourselves as gay, so we ignore half of the advertising that's out there, because it doesn't apply to us."

"We need more press, television; people don't know our issues."

"You always see AIDS posters, with two women together or two men together, or a man and a woman, but you never see another transgender person with another man, or woman or another transgender person."

Individual Risk Reduction and Education

Participants underscored the need for HIV prevention education for transgendered people and their partners. MTF individuals expressed the need for counseling and education that builds their self-esteem and FTMs emphasized the need for HIV education that offered validation of themselves as sexual men with new gender and sexual identities. Many participants expressed concern that their specific issues and identities are not addressed in individual counseling sessions. It was suggested that training HIV counselors and educators about transgender issues would help improve the efficacy of current risk reduction and education efforts. Some participants also indicated the need for educational materials in languages other than English.

Individual Risk Reduction (33 unduplicated comments indicating unmet need)

"We need to educate and counsel the men, the heterosexual-identified male clientele."

"I would like to see more counseling that addresses gay FTMs in a more direct way."

"There needs to be a sufficient level of safety to talk about things like getting penetrated in your vagina. I'm telling you, we [FTMs] are doing everything with everybody out there. In every possible combination you can imagine. It's important that those identities and those sexual experiences be validated, so people fucking *respect* themselves enough, and know that they're *worthy* of respecting their own boundaries."

Single and Multiple Session Groups

Discussion of transgender single and multiple session groups centered on the need for a space for transgendered persons to talk about the issues and problems that they face. Participants felt that support groups can be an effective tool for HIV prevention education and a means for building self-esteem. There was discussion about the ways that support groups can educate about HIV, hormone use, and SRS, and can offer an excellent opportunity to help clients build job skills to facilitate a transition out of commercial sex work. Participants also suggested the development of specific groups for FTMs (including gay FTMs), youth, and those who speak languages other than English.

Single & Multiple-Session Groups (27 unduplicated comments indicating unmet need)

"The more we talk about this, the more I really am feeling that some kind of support group-type environment would be really useful for us to have a space where we can talk about the really specific things that are different from straight genetic men and gay genetic men, the real specific issues around increasing sex drive, and trying to re-create an identity for ourselves as sexual men."

"The Pooch Factory, and Make-up Forever [transgender support groups], the reasons for them is to empower people, so that they can be more accepted. It takes 'em into risk reduction. It has a lot more qualities than a lot of people think. If I could've kept the funding..."

"There are a lot of gay men who feel like, 'Well, I'm gonna get it anyway, so why bother?' And I, for the first time in my life, have experienced that. Feeling like, 'Oh, I'm a gay man now, in San Francisco. Of course I'm gonna get it.' I think it would be really helpful for us to have groups where we can go and sit and talk about this, or just be able to say, 'Well, I feel like this.'"

Venue-Based Group Outreach

Discussion of venue-based group outreach highlighted the need for public forums as a means of bringing visibility to transgendered persons and their issues. Participants also stressed the importance of community events for building a community support system. Some suggestions for transgender-specific community events included street theater, educational forums, community dances, beauty pageants, rallies, potlucks, and garage sales.

Venue-Based Group Outreach (15 unduplicated comments)

"I believe that educating the public, holding workshops, community events, letting the public know what we're all about, is going to help a lot."

"Create a transgender theater, so we can have people express themselves as they are!"

HIV Counseling and Testing

Discussion of HIV counseling and testing centered on the difficulty and frustration of accessing HIV antibody testing, and the insensitivity of many counselors who work with transgendered clients. Participants described counselors who made assumptions about clients gender by not differentiating MTF clients from gay men or FTM clients from butch lesbians. Some participants stressed that they would prefer it if service providers asked, rather than assumed, their gender identity. The need for transgender-specific options for gender identity on demographic forms was also highlighted.

HIV Counseling and Testing (10 unduplicated comments indicating unmet need)

"In any of the prevention services, there's always a questionnaire or something. And there's never a slot for us. Just like, until recently, there was never a slot for lesbians. Every time I've gotten tested, I've run across people looking at me, deciding that I'm female, or deciding whatever, and then determining what my actions are, without asking me. Don't assume what my activities are, based on how you perceive me."

"There should be one central number you can call for an AIDS test, where someone can direct you depending on what part of the city you're in. There's a lot of people who just, 'oh heck with it,' and don't get tested."

Needle Exchange

Though many participants discussed the prevalence of injection drug use in the transgender community, needle exchange was not discussed as an area of great unmet need. A number of participants indicated that they and/or their partners utilize the needle exchange program, and some stated that they volunteered for the needle exchange program or referred clients to it. However, participants did state that most needle exchange sites do not have needles that can be used for hormone injection and FTMs expressed interest in a needle exchange site specifically targeting them.

Needle Exchange (5 unduplicated comments)

"The needle exchange is wonderful. I'd hate to think of all the people who'd have AIDS...Most drug users, they're usually broke, and they just wouldn't spend money on their appliance. When I first started out, I didn't even know you're supposed to use a new point every time, and I was using the same points six or seven times."

HIV HEALTH SERVICE NEEDS

Although many of the focus group participants were not HIV positive, there was a great deal of discussion about the HIV health service needs of the transgender community. The main HIV health services that participants felt were lacking or needed improvement were: 1) Primary Medical Care; 2) Client Advocacy; 3) Buddy Companion/Peer Support Groups; 3) Mental Health Services; 5) Substance Abuse Treatment; 6) Housing; 7) Case Management; and 8) Language Translation.

Primary Health Care for Transgendered Individuals Living with HIV

By far, the most common area of unmet service need for transgendered people living with HIV was primary medical care. Many comments were made about physicians' lack of knowledge about the effects and potential dangers of taking hormones and seeking sexual reassignment surgery for those who are living with HIV. HIV-positive participants stated that they receive extremely confusing messages from medical providers and felt that they need more information about hormone therapy and sexual reassignment surgery to make more informed decisions.

Discussion of the need for improved general health services for people living with HIV centered on a lack of knowledge about new treatment modalities such as protease inhibitors, the need for more education regarding infection and re-infection, more assistance with maintaining healthy lifestyles and behaviors, greater inclusion of transgendered persons in AIDS clinical trials, and the need for affordable, accessible, and transgender-friendly health care services. A number of participants expressed a desire for comprehensive health services that would include HIV health care. This "one-stop shop for transgendered health services" would make services more convenient to access and lead to a greater likelihood of utilization. However, a minority voice expressed the need for decentralized services, which would keep services for the transgender community from being ghettoized.

The FTM-specific focus group and the group conducted in the jail identified unique needs of the FTM and incarcerated populations. The FTM focus group expressed concern about the lack of knowledge of medical providers regarding FTM-specific HIV issues (even among transgender-sensitive providers), and the need for more services specific to the FTM population. There was a lot of discussion about the discomfort that medical providers exhibit when dealing with men with gynecologic needs.

Incarcerated individuals living with HIV indicated that their living situations are often substandard, and this affects their health. Incarcerated participants felt that their special needs are often ignored and they endure a great deal of discrimination and poor treatment which is harmful to their suppressed immune systems.

Hormone Use and Sexual Reassignment Surgery: 33 unduplicated comments

“A lot of doctors discourage transgenders who are HIV-positive to go through sex reassignment surgery because it would suppress the immune system. I personally see getting hormones and getting stuck, and I’m not really going anywhere. I feel like I’m in limbo, taking hormone therapy and not able to have the operation. It’s affecting my self-esteem and the way I see myself. I think a stronger self-esteem would be a better way to cope with the virus.”

“I asked my doctor if I could keep using hormones after I found out I was HIV-positive and he told me yes, but then I heard from another source that they can make you ill.”

“They took my hormones away from me cause I’m HIV.”

“The doctor will manage the hormones and tell you how many T-cells you have. Instead of helping you, your T-cells are just dropping on the floor with hormones.”

General Health Services: 27 unduplicated comments

“Clinical trials for HIV-infected people, very few if any include transgender persons.”

“Another thing we really need is nutritional information. If your system is deteriorating, there are certain things that you should not do anymore. You can’t keep eatin’, drinkin’, partyin’, and doing drugs and stuff like you used to. There seems to be a great lack of education of people who are HIV-positive.”

“They [the clinic staff] are up on all of the HIV stuff, but they don’t want to see us [transgenders] there.”

A Comprehensive Transgender Health Care Clinic: 11 unduplicated comments

“I would like to see a health program open that is specific to the needs of the transgender population. Serve nothing but transgender persons. I would like for that agency to be culturally sensitive.”

“That’s the benefit of going to one place; they have your records and know what’s going on with you.”

FTM-Specific Health Care Issues: 10 unduplicated comments

“And I found out that because of the testosterone, I’ve started the menopausal thing. The lining of the walls of my vagina and cervix, the tissue’s getting like really thin. When I was talking to the doctor about it, she had to bring in two other docs because she didn’t know how to deal with me.”

“They [health care providers] know about MTF issues but not FTM. I just changed my testosterone last week because they didn’t know that the kind I was on had these certain effects.”

Primary Medical Care in the Jail System: 6 unduplicated comments

“When they found out I was HIV-positive, they stuck me in a cell all by myself. It was 110 degrees in that cell, I’m not exaggeratin’. I had to sit there with my feet in the toilet. And so instead of taking the guy who raped me and putting *him* into isolation, they took me, because I’m transgender and put *me* into isolation.”

“They should get a personal ward just for HIV only, and not let us roam freely with the broken windows with the air comin’ in. You got to patch up the windows, eat cold food, which is not good nourishment to the body. And runnin’ up back and forth in the cold air, cause we in the shower for five minutes and then we got to rush back to a cold cell.”

Buddy Companion/Peer Support Groups

Discussion about support groups centered on the need for a space for HIV positive transgendered people to talk about the social, medical, and mental health issues they face. Participants underscored the value of support groups in facilitating self-esteem, increasing access to health care, and encouraging educational outreach to endocrinologists and other health service professionals. While participants stated a need for individual emotional and practical support services (buddy companion), most of the comments addressed the need for group peer support services.

Buddy Companion/Support Groups: 29 unduplicated comments

“A lot of my transgender girlfriends that are HIV-positive, a majority of them have no resources, and they go straight down the tubes again as far as their health, their weight, their takin’ care of themselves. I believe that most of the transgenders that are HIV-positive need an outlet, such as support groups.”

“There are hundreds of support groups in the City, but there isn't an FTM HIV support group. I've heard things here today that I identify with, that I've never heard before. That says how little is available to us.”

Mental Health Services

Concerns about hormone therapy and sex reassignment surgery dominated the discussion of mental health issues. There was also a great deal of discussion about the need for mental health counseling for HIV-positive individuals who are instructed not to seek hormone therapy or sexual reassignment surgery. Discussion of mental health included the lack of transgender-sensitive services to deal with the mental strain of being transgendered, societal and familial prejudice and discrimination, self-acceptance, and high rates of suicide.

Mental Health Services: 25 unduplicated comments

"I don't think the mental health system is at all prepared to accept us or deal with us."

"Accessibility into the mental health service is really, it's restrictive! You have to get what they call 'clustered' and in order to get clustered, you have to go over there acting like some raging maniac!"

"That mental health treatment is very important for the young girls out here, taking these hormones like they're candy, and Honey, it'll come back to you."

Client Advocacy

Participants felt that benefits counseling and legal assistance were the two areas of client advocacy with the most unmet need. Assistance with the application and appeals process in order to secure federal government assistance was discussed frequently.

Client Advocacy: 20 unduplicated comments

"I'm trying to get my SSI pulled back together because there's a law that affects me as a drug addict, don't you get cut off if you don't reapply? And I found out yesterday that I am HIV-positive."

"I walked into this town with my SSI case, and when I got told on the phone that this clinic had their own lawyer, or had access to one, when I got there, I just got dumped! And got told that the lawyer would be jammed up for four months. And I needed a lawyer right then and there. We need more access to lawyers."

"If I'm sick and the clinic is all full, I have to go across town... and if I don't have bus tokens I'll have to crawl there and you have to have below 200 t-cells to get SSI...being on GA is not hacking it, you'll live in a flea bag hotel... if you want to change your life you've got to change your medical situation... seems like people would want me to keep my body with high t-cells, my whole system being good and keep going in that direction, instead of tearing me down."

Substance Abuse Services

Participants expressed concern about the lack of available transgender-sensitive recovery services, discrimination and lack of personal safety in existing recovery services, and the lack of sensitivity and knowledge about FTM issues among substance abuse programs and providers.

Substance Abuse Treatment: 19 unduplicated comments

“We need detox programs and halfway houses that are transgender-specific.”

“I know a lot of FTMs in the community that are struggling with drug and alcohol issues, and there is no in-patient, or really adequate out-patient treatment available in San Francisco to meet the needs of FTMs. Testosterone is a drug. For many of us that are in recovery, it’s a scary drug, in the sense that it can trigger other issues.”

“A lot of guys are out there using, and there's nowhere to go.”

Housing

Discussion about housing issues included a number of complaints about the lack of available housing for HIV positive transgendered individuals. There was a lot of discussion about substandard housing options and discrimination by building owners based on gender identity or gender presentation.

Housing: 15 unduplicated comments

“I’ve spent two years waiting for my housing and now my number is 2,004, so I don’t believe that the housing list (CHIPS) moves, and I’m never going to get housing.”

“I really don’t think they should stick a person with HIV down on Sixth Street in one of those gloomy, gloppy, roach-and-rat hotels. That is the one thing that will kill a person, because that is nothing but depression. If you’re going to fix anything up, they should fix those raggedy hole-in-the-walls.”

“They want to stick you down there for twenty-eight days, but then they want you to move out of the hotel for a week so you can’t become a resident.”

Case Management

Participants stated that there is a lack of awareness about existing health and social services. Many people described accessing a service by fluke, because they “happened to be in the right place at the right time”. Other comments included the need to advocate for oneself in order to access services, and the specific need for transgender case management services.

Case Management: 14 unduplicated comments

“I had four case managers in order to access the services that I’m having today.”

“When you get out [of jail], it’s all so overwhelming that a lot of people don’t know about or connect with available services.”

“I think that if they knew that services were available, they would be able to get help, and not get the run around.”

Language Translation

This category indicates the stated need for the provision of services and materials in languages other than English. It is important to note that the number of times language translation was identified as an unmet need is probably conservative because there was only one group conducted in Spanish and there were no groups held in any Asian or Pacific Islander languages.

Language Translation: 10 unduplicated comments

“They invited me to several support groups, but there's the language barrier. There are a lot more in English. Why not Spanish? Why don't they ask us? Why isn't there a Latina group?”

“We need flyers and resources all in Spanish.”

ISSUES RELATED TO PROVIDING HIV PREVENTION & HEALTH SERVICES

Hiring Transgendered Staff

Participants felt that low self-esteem, mistrust, and fear of discrimination keep transgendered persons from seeking prevention, health and social services. Throughout the focus group discussions participants stated that it would be easier to access health and prevention services if there were more transgendered individuals on staff.

Hiring Transgendered Staff (37 unduplicated comments)

"When I see all these agencies who are being funded all this money to do transgender prevention, and provide transgender services, I really find it hard, when I see that some of these agencies are funded to hire four and five outreach workers. And they hire all these outreach workers, and not one of them is transgender."

"I've had clients come from an agency, and they're talking about the staff calling them 'boy' and 'he', and asking them questions, like why they want to do that. If they're going to be serving transgender persons, they should be obligated to make sure that their staff is trained on transgender sensitivity issues, and that their staff is transgender."

"We're transgendered men. We might fall into other categories, but there's nothing that's being directed at us. When I hear that an agency is transgender friendly, it sometimes means that there's no transgenders on staff. The book's gotta be written, with us as the subject."

Training of Existing HIV Health and Prevention Service Providers

Participants also spoke about the need for transgender sensitivity training for health and social service providers. Most participants felt that existing providers would not be able to meet the unique needs of this community without more training.

Training of Existing Providers: 35 unduplicated comments

"They [providers] know about MTF issues but not FTM. I just changed my testosterone last week because they didn't know that the kind I was on had these certain effects. One of us had to find out after two and a half months of treatment."

"We're an abomination to society, to the medical and health community. Medical and mental health services are not educated about transgender people. If they're not educated, how can the community get educated from them?"

"Make mandatory sensitivity trainings to all service agencies that come in contact with transgender clients."

TRANSGENDER ADVISORY COMMITTEE RECOMMENDATIONS

The Transgender Advisory Committee to the AIDS Office reviewed the focus group analysis and developed recommendations for improving HIV prevention and health services for the transgender community. The Advisory Committee concluded that prevention and health services could be improved by implementing a peer-based approach to service delivery, training prevention and health care providers, coordinating existing services, and ensuring documentation of services provided.

Peer Approach to Service Provision

Implementing a peer-based approach to service delivery was thought to be one of the most efficient and effective ways to improve prevention and health care services for the transgendered population. The focus group results demonstrate that many transgendered people do not participate in prevention activities or seek services because of mistrust and fear of discrimination from non-transgendered staff. Hiring and training MTF and FTM transgendered individuals as support group facilitators, client advocates, substance abuse counselors, media campaign coordinators, case managers and outreach workers could facilitate access to services for the transgender community. Employing transgendered staff would also provide jobs to a community which has suffered severe employment discrimination.

Service Provider Training

Service providers are in great need of transgender sensitivity training. The development of guidelines for service provision (particularly for HIV-positive individuals who want to pursue hormone therapy and sexual reassignment surgery) is a critical component of such training efforts. A training unit responsible for developing and implementing in-service trainings should be formed to ensure that systematic training of all service providers takes place on an ongoing basis.

Program Coordination and Documentation of Services

More partnerships between HIV education, health service, substance abuse, mental health, housing and food programs need to be developed to integrate services for transgendered clients. Such partnerships should be coordinated with jail and prison release programs to ensure that incarcerated individuals are connected with needed services when released. To ensure that agencies funded to provide services to the transgender community successfully reach this population, documentation of the number of clients served should be required. Such documentation is a necessary component of ensuring adequate service provision.

STUDY LIMITATIONS

The focus group study design introduces a number of limitations that should be addressed. The small sample size (n=100) and non-probability sampling methods compromise the ability to generalize our findings to transgendered persons in San Francisco. In addition, since only one group was conducted in a language other than English (the Spanish-speaking group) and only one FTM-specific group was held, the issues of transgendered persons who speak other languages and FTM individuals may not be adequately captured in this report. It is also worth noting that the study population was largely made up of individuals who have some access to services since all the focus groups were conducted at agencies providing HIV prevention or care; their responses may not represent transgendered persons who are not accessing services.

Despite the aforementioned limitations, this focus group study represents one of the first in-depth descriptions of HIV-related prevention and social service needs of the hard-to-reach, often invisible, and stigmatized transgender community in San Francisco.

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