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# Serving Transgender People in California:

# Assessing Progress, Advancing Excellence

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The CoE's mission is to provide leadership, capacity building, professional training, policy advocacy, research development, and resources to increase access to culturally competent HIV prevention services for transgender people in California.

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### Introduction and Background

Transgender people are highly vulnerable and marginalized in the United States. Experiences of discrimination are common when seeking to obtain basic human necessities such as employment, housing, and health care, as are reports of violence and harassment (1-8). It comes as no surprise then, given the association of negative health outcomes with stigma and discrimination, that transgender people, and transgender women and transgender people of color in particular, experience severe health disparities across a number of outcomes, including HIV (5, 9, 10).

#### HIV rates among transgender people

Currently there are no national estimates of the prevalence of HIV among transgender populations due to lack of data collection on transgender populations at the national level. Currently, transgender women (and sometimes transgender men) are miscategorized as men who have sex with men (MSM), and there are no population-based studies that provide us with an estimate of the size of the transgender population in the US. However, regional reports of HIV rates have been found to be consistently high among transgender women, especially among Latinas and African-Americans. Rates of HIV among transgender women have been reported in the ranges of 14% to 68%, depending on which subgroup was sampled (11, 12) with 35% in San Francisco (2), 32% in Washington DC (13), 27% in Houston (14), and 22% among MTF ethnic minority youth in Chicago (3). A recent meta-analysis of 29 studies conducted in cities across the United States found that 28% of transgender women tested positive for HIV when results were lab-confirmed, and 12% of transgender women were HIV positive by self-report, a finding that suggests an increased need for testing (15).

In California, transgender female clients of publicly-funded counseling and testing sites have higher rates of HIV diagnosis (6%) than all other risk categories, including MSM (4%) and partners of people living with HIV (5%), and African American transgender women have a substantially higher rate of HIV diagnosis (29%) than all other racial or ethnic groups of transwomen (16). Estimates from California's urban centers also suggest that HIV prevalence rates among transgender women are extremely high, especially for transgender women of color and African American transgender women in particular (2, 15). Regional estimates include 16 - 60% in San Francisco (2, 17-20) and 22 - 52% in Los Angeles (21, 22) with the highest rates consistently being reported among African American transgender women. A needs assessment in San Diego reported 15% of their participants were HIV-positive (23). However, this is possibly an underestimate of the true rates of HIV among transgender women in San Diego because almost a quarter (22%) of their participants did not respond to the HIV status question, only 80% of those who did respond reported ever being tested for HIV, and they had difficulty recruiting sex workers for participation (23).

The California HIV/AIDS Monthly Summary Report as of May 31, 2008 reports that 277 transgender people are currently living with HIV and 556 and living with AIDS. The total number of transgender people living with HIV/AIDS in California is estimated at 833, according to this report. This data does not differentiate between transgender women and transgender men, and is likely to be an underestimate, due to the difficulty in estimating the number of transgender people living in California, the reluctance of transgender people to come out as transgender in testing situations, and the reluctance of transgender people to access testing. It is likely that many transgender people are categorized as 'male' or 'female' in testing situations because the test counselor either fails to ask about their gender, clients report their gender as 'male' or 'female' to reflect their current gender identity, or clients do not disclose their transgender status due to fear of mistreatment by the

provider. Many transgender people who may be living with HIV avoid testing altogether due to fear of a positive diagnosis and/or distrust of service providers due to past negative experiences. A national meta-analysis found that when HIV status was confirmed with lab testing, 28% of transgender women were positive for HIV, whereas only 11% were positive when HIV status was measured by self-report, calling attention to the need for increased testing among transgender women at risk (15).

Very little research has been conducted on the distinct HIV/STD risks and prevention needs of transgender men, despite anecdotal evidence that some transgender men could be at high risk. Transgender men, like other people, claim a variety of sexual orientations and have sex with various types of sexual partners (24). Early research studies that reported HIV prevalence rates among transgender men either did not specify the gender of their sample's sexual partners or have predominately included men that identify as heterosexual (transgender men that primarily have sex with women) (2, 25). The few studies that report HIV rates among samples of transmen have reported 2 – 3% prevalence (2, 13, 24). Due to low reported rates of HIV, there has not been much emphasis on further exploration of HIV risk behaviors among transgender men.

However, some evidence suggests that there is a significant subgroup of transgender men that engage in high-risk sex with non-transgender men and some transgender men who engage in sex work (26). Initial data suggest that many transgender men have sex with non-transgender men and that misconceptions exist about their level of risk of exposure to HIV (20). Because the current California HIV/AIDS Monthly Summary reports do not distinguish between transgender women and transgender men, it is unclear how many transgender men in California are currently living with HIV. Because so little research exists on HIV risk and prevention needs of transgender men and those with gender identities that do not adhere to a binary classification system, much of what we currently know about HIV rates and prevention among transgender people focuses on transgender women.

#### Purpose of the Resource Inventory

The Center of Excellence for Transgender HIV Prevention (CoE) was created in July 2007 with funding from the California Department of Public Health, Office of AIDS, to provide leadership, capacity building, professional training, policy advocacy, research development, and resources to increase access to culturally competent HIV prevention services for transgender people in California. It is a collaborative partnership that combines the unique strengths and resources of a renowned training and capacity building institution, the Pacific AIDS Education and Training Center (PAETC), and an internationally recognized leader in HIV prevention research, the Center for AIDS Prevention Studies (CAPS), both of whom are part of the University of California, San Francisco (UCSF).

Early in its development, the CoE identified the need to synthesize information about existing programs that address HIV prevention needs among transgender people in California in order to identify service needs that are currently being met as well as those that remain unmet. To achieve this goal, we have compiled a Resource Inventory and Service Gap Analysis of transgender HIV prevention programs in California. This report is based on a review of existing literature examining current issues in HIV prevention among transgender people and analysis of data we have collected describing the services that are currently being provided in California. In this document, we describe common barriers and facilitators to successful program implementation and management, outline services that are still needed, identify which subgroups of transgender people are not adequately being served, generate recommendations to inform the allocation of resources, and summarize Best Practices for Transgender HIV Prevention.

### **Methods**

Based on our existing knowledge of transgender-specific HIV prevention programs in California, the CoE staff compiled an initial list of programs to consider for inclusion in the Resource Inventory. We presented this list to the CoE Community Advisory Board (CoE CAB), who reviewed the list and offered information about additional programs to include and contact information for those programs. We then spent several months systematically contacting programs to ensure that the programs were indeed transgender-specific HIV prevention programs and to invite their participation in this Resource Inventory. We also conducted traditional literature and internet searches to identify additional programs, and asked program staff of participating programs to refer us to additional programs that were not yet included. For inclusion, HIV prevention programs were required to be transgender-specific and/or market their HIV prevention services specifically to transgender people. Thus, general transgender support groups, substance abuse treatment programs, social groups, etc. as well as broader HIV prevention programs that may or may not reach transgender people were not included. Future versions of this Resource Inventory may include this broader scope of services to transgender people in California.

To collect data on the programs identified for inclusion, we designed a qualitative questionnaire to gather basic contact and staffing information as well as more detailed programmatic information, such as host organization and transgender program funding, mission statements, specific services provided, priority populations, history of transgender program, number of clients reached, barriers and facilitators to implementation, recruitment and retention issues, and best practices. The full questionnaire is included in Appendix A. The Data Collection Working Group of the CoE CAB was formed to review and pilot the initial draft of the questionnaire. Following the pilot, the format of the questionnaire was revised based on Working Group feedback so that staff from the programs could enter the information directly into the electronic document and return it by e-mail instead of requiring a phone interview for completion. The Working Group determined that this would add to the ease and efficiency of the data collection process since program staff have much of the required information in electronic form, some of which is difficult to recall during an interview. At the end of the questionnaire, we asked program staff to refer us to any additional transgender-specific HIV prevention programs in their area in order to ensure comprehensive coverage.

All information included in this report is based primarily on data collected from program staff of participating agencies providing HIV prevention services to transgender people in California. The agencies varied widely in degree of depth and specificity of their responses to the questionnaire items and not all agencies that were identified for inclusion in this Resource Inventory returned the questionnaire. Basic information about the programs that did not return completed questionnaires was obtained through program websites; however, more detailed information in this report is based only on those programs that participated in the data collection process. Thus, the information presented in this report is limited by the level of participation, accuracy, and detail offered by the agencies themselves. When necessary, the information provided was supplemented by information available on the program's website, or by following up with program staff via telephone or email with questions. An initial draft of this report was reviewed by the CoE CAB to incorporate their suggestions and expertise.

### **Results**

#### Agency characteristics

Questionnaires were distributed to 22 agencies that represent 24 programs that serve transgender clients. (Some agencies provided information on more than one transgender-specific HIV prevention program.) Of the 22 agencies, 16 agencies returned the questionnaire representing 18 distinct transgender-specific HIV prevention programs, yielding a 73% response rate. Five programs are located in Los Angeles County, 10 are in San Francisco County, one is in Santa Clara County, one in San Diego County, and one is located in Alameda County.

Table 1 summarizes the transgender-specific HIV programs we identified in California by location, priority populations, and primary services available. The most current information on these programs is available in the <u>Programs</u> section of our website. All programs specifically prioritize transgender women, and 7 explicitly expressed that they are inclusive of transgender men. (Some programs may provide additional services or include transgender men but did not explicitly indicate so. The data in the summary table is limited by what was reported by the agencies themselves and/or the data available via their website.)

All of the host organizations of participating programs reported that they had conducted or received transgender-specific trainings for staff. Funding and staff varied considerably among agencies. Yearly budgets for trans-specific programming ranged from 0 - 3383,000, with some programs reporting that rather than have funding specifically allocated for separate trans programming, transrelated services are integrated into their larger organization. The average number of staff for transspecific programs was 3 (range: 1 - 8), although most agencies did not report the full-time equivalency (FTE) of their staff, so the actual number of average staff hours per week is likely to be less than 3 FTE. The average number of years since implementation of the trans-specific program was 7.3 years (range: 1 - 14), although many of the older programs reported significantly strengthening or expanding their trans-related programming within the past 2 to 5 years.

Some of these programs are specifically set up to facilitate increased access to mainstream medical services for transgender clients and/or increase the availability of culturally competent care. These programs varied in how they were structured to accomplish this goal. For example, Lyon Martin Health Services and Dimensions Clinic in San Francisco do not have a trans-specific program, but instead integrate transgender care into all of the services provided. Other programs, such as Project STAR (Supporting Transgender Access to Resources) of Family Health Centers in San Diego, Trans Vision of Tri-City Health Center in Fremont, and the Risk Reduction Program of Children's Hospital, Los Angeles, are housed within larger medical centers that provide comprehensive primary care services that are available to transgender clients.

Other programs, such as the Transgender HIV/AIDS Program of the Instituto Familiar de la Raza and the Asian & Pacific Islander Transgender Empowerment (ATE) Program of API Wellness Center, both in San Francisco, are ethnic-specific transgender programs housed within larger social service agencies that serve a specific ethnic group.

### **Table 2.** Programs by type of host agency

### Medical clinics serving trans clients (no trans-specific program)

Lyon Martin Health Services (San Francisco) Dimensions Health Clinic (San Francisco) St. James Infirmary (San Francisco)

### Trans-specific programs housed within large medical clinics

TransVision (Tri-City Health Center, Fremont)
Project STAR (Family Health Centers of San Diego)
Risk Reduction Program (Children's Hospital, Los Angeles)
Transgender Harm Reduction Program (Children's Hospital, Los Angeles)
Transgender Tuesdays (Tom Waddell Health Clinic, San Francisco)

### Trans-specific programs housed within an ethnic-specific social service agency

TRANS:THRIVE (Asian & Pacific Islander Wellness Center, San Francisco)
API Transgender Empowerment (Asian & Pacific Islander Wellness Center, San Francisco)
Serving Transgenders At Risk (Asian Pacific AIDS Intervention Team)
Instituto Familiar de la Raza (San Francisco)
Bienestar (Southern California, multiple locations)
Transcending (Ark of Refuge, San Francisco)

### Trans-specific programs hosted by larger coalitions/organizations

El/La Programa para Trans-Latinas (Mobilization Against AIDS, San Francisco) TransAction and A.S.K. (Friends Research Institute, Los Angeles) TransPowerment (Community Health Partnership, Santa Clara) Transgender health education group (Forensic AIDS Project, San Francisco)

#### Barriers and facilitators to implementation of transgender-specific program

1. Adequate funding is crucial to successful program implementation.

By far, both the greatest barrier and strongest facilitator to successful program implementation cited by participating programs was funding. Applying for funding is difficult for agencies that do not have adequate information about their priority population due to data collection issues that result in underestimation of the size of the transgender community and limited research about the needs of transgender people in their local area. Securing the initial funding for implementation of a transspecific program was especially difficult for those whose host organization administrators and/or funders lacked a sense of urgency about the need for such programming. When the trans-specific program had buy-in from the larger organization, however, that support was cited as a tremendous facilitator to implementation.

When funding is scarce, the ability of trans-specific programs to meet the needs of their clients and provide adequate services is severely limited. Budget cuts are disheartening and deeply felt by programs already operating on a very tight budget, and the de-funding of other local services makes it difficult for existing programs to provide successful linkages to services that are not available at their agency. However, when the host organization of the transgender-specific program has strong funding streams and is able to provide much-needed institutional infrastructure and support, it seems that programs are able to thrive even when their transgender-specific programming budget is relatively modest. Program staff repeatedly cited the need to pursue funding aggressively and continuously to sustain, and preferably expand, their services.

#### 2. Recruitment and retention of appropriate staff is critical, but can be difficult.

Limited funding also serves as a barrier to adequate staffing. Programs reported difficulty finding and retaining staff with the appropriate training and skills for the positions they sought to fill, in part because they are not able to provide adequate compensation. In addition, because funding for salary support is limited, programs are not able to hire enough staff to handle the demands of the work, leading to burnout and high staff turnover. Programs that are able to tie their funding to research and training grants reported less turnover due to their ability to offer more competitive compensation, benefits, and stability for their staff.

It is extremely important that the staff of trans-specific HIV prevention programs reflect the diversity of the clients they serve. However, this also means that transgender staff often struggle with the same types of issues as the clients they serve, such as having had limited educational opportunities, job training, and formal work experience. Additional training, mentoring, and support are often required to support appropriate staff that are also skilled in service provision. Managers and supervisors need to be supportive, flexible, able to provide constructive feedback, and committed to ongoing staff development. Often the managers and supervisors themselves are overworked and underpaid, leaving insufficient time and resources for them to devote to proper management, supervision, and leadership.

Initial training is very important, although what really matters is the support that the staff gets on a day-to-day basis. Ongoing supervision is vital to the success of the staff and the program. Programs need to budget money for training and also account for the extra time it takes to supervise staff who may need a lot of ongoing support to perform their job duties.

- TRANS: THRIVE San Francisco, CA

#### 3. Community involvement in program development can facilitate successful implementation.

Few programs have the resources to conduct thorough needs assessments in their communities, either prior to applying for funding or during the program development phase. Agencies reported that creating a Community Advisory Board facilitated the process of program development and implementation, especially when other types of information about the communities they aim to serve is scarce. Other agencies held focus groups with community participants and gatekeepers to assess needs and inform programmatic decision-making. In general, community support and involvement was cited as a major facilitator to successful program development and implementation.

Many programs reported that as they were developing their trans-specific program, they found that the needs of the community were so high that they felt they were not always able to meet the expectations of the clients they were serving. While the demand was certainly there for the services they hoped to provide, they also felt that clients, as well as staff, were often frustrated by the inability of the programs to meet the wide variety of their clients' even basic needs (employment, housing, school, safety, etc) due to the increased difficulties of violence, discrimination, and transphobia that transgender people face.

#### Barriers and facilitators to recruitment and retention of clients

1. Many transgender people are transient, presenting a challenge to client recruitment and retention.

Some subgroups of transgender communities are particularly transient, such as recent immigrants, youth, those who are homeless, and those with unstable or no employment. Reaching transient people can be especially difficult as eligibility requirements for accessing services increase, such as proof of residency in the city or county where services are offered. Providing proof of residency is difficult for youth who may not be living with their families due to rejection and/or violence, those who do not have access to affordable housing and are living on the streets, with friends, or in hotels, and recent immigrants who may not have established US citizenship. In addition, transgender people who have recently immigrated may avoid seeking services due to fear of discovery of undocumented immigration status. Furthermore, many agencies do not have the resources to offer multilingual services and materials for monolingual, non-English speaking clients.

Incarceration can also lead to difficulties in client retention. Because transgender people are incarcerated at disproportionate rates compared to the general population, services for many clients are disrupted by incarceration and agencies may lose track of clients who are in and out of custody. Substance abuse often leads to incarceration, and if clients are not released directly into a substance abuse treatment program, they frequently relapse and the cycle of incarceration continues.

2. Transgender communities are diverse, and trying to meet all of their varying needs can be extremely difficult.

For agencies in areas where they are one of the only (or perhaps the only) organization serving transgender people, serving diverse clients at the same agency can prove to be difficult, if not impossible. In any community, different groups of transgender people have widely varying needs, identities, and experiences, and attempting to accommodate this variety can be quite taxing on agencies who are trying their best to meet different clients' expectations. Most agencies reported that they primarily serve a particular ethnic group. Even when they did not specifically prioritize a particular ethnic group, some agencies found that once their organizations gained a reputation for serving a certain segment of the population, other groups were less likely to seek services there. The agencies that reported attracting many different ethnic groups, as well as youth and transgender men, were more likely to be larger programs that offer a wide range of medical services, often including primary care and hormone provision, in addition to their HIV prevention services.

3. Past experiences of stigma and discrimination discourage clients from seeking services.

The severe stigma and discrimination that transgender women experience underlie many of the risk behaviors frequently reported in this population (27, 28). The effects of stigma and discrimination, including low self-esteem, economic instability, isolation, distrust of service providers due to past negative experiences, and reluctance to seek services until in crisis mode, can create barriers to providing effective services to transgender clients, including HIV testing. Many agencies noted that it takes time to gain the trust of the transgender community due to clients' past negative experiences

with service organizations, and that if a transgender client has a negative experience or does not get what they are looking for from an agency, they are often unlikely to return in the future.

The personal and social effects of discrimination, low self-esteem and barriers to economic stability are just a few of the issues that cause isolation and make it difficult to reach some clients and provide much needed services.

 Transcending Youth Prevention Program, Ark of Refuge San Francisco, CA In addition to the stigma associated with being transgender, the stigma and denial around HIV risk and the fear of receiving a positive HIV diagnosis leads many transgender people to avoid testing. HIV status is often not discussed among transgender women or their sex partners (20), so HIV prevention programs have the difficult task of creating new norms around discussions of risk and disclosure. In addition, many transgender people are faced with pressing issues of daily survival, such as housing, unemployment, and substance abuse, so HIV prevention or treatment is not seen as a high priority.

4. Hiring transgender staff at all programmatic levels is essential for a transgender HIV prevention program to be successful.

The most frequently cited facilitator to recruiting and retaining clients and addressing the aforementioned challenges is hiring transgender staff, especially those who are well-networked in the community and those who can serve as role models. Transgender clients often feel most comfortable with outreach and program staff who are also transgender, and transgender staff who already have established relationships with the community that the program seeks to serve can be indispensable in terms of recruitment and retention. In addition, transgender staff who have personal experience with many of the same issues that clients face can offer unparalleled support, guidance, and mentorship. Transgender staff who are openly living with HIV can model disclosure about status to help reduce stigma in the community. In addition to hiring transgender outreach workers and front line staff, successful programs involve transgender people at every level and stage of program development to ensure community relevance and engagement. Hiring qualified transgender people as managers, directors, and researchers also sends a strong message to all staff and consumers about your organization's commitment to diversity and supporting highly marginalized communities.

## Service Gap Analysis for Transgender HIV Prevention in California

The Center of Excellence for Transgender HIV Prevention identified the following service gaps by comparing what we know about the HIV prevention needs of diverse groups of transgender people with the data we collected about services currently being provided in California.

One important limitation to note is that service gaps in rural areas are not adequately described by our data, since programs that participated in the Resource Inventory all represented urban regions of California. However, because we were not able to identify any transgender HIV prevention programs in rural locations, we can be fairly certain that there are transgender people living in these areas experiencing isolation and difficulty accessing services.

# 1. HIV prevention programs are currently concentrated in San Francisco and Los Angeles; there is a need for programs that serve other parts of California.

While funding should continue to reflect the epidemic, which is concentrated in urban epicenters, currently there are not adequate services for transgender people that do not live in major metropolitan areas. For the singular programs serving Alameda, San Diego, and Santa Clara counties, there are inherent difficulties in attempting to meet the needs of large, diverse groups in their region. Additionally, in some areas, transportation is an issue for transgender clients seeking services. Transgender people may be spread out across the area or agencies may not be located where transgender people live and work. This sets up a barrier to accessing care for many transgender people who do not have access to cars or money for taxi fare. Currently, many transgender people must travel great distances to access competent primary care services, such as those offered by the Tom Waddell clinic in San Francisco.

# 2. <u>Transgender people who are undocumented or recent immigrants are not adequately being</u> reached by current HIV prevention efforts.

A lot of transgender Latinas do not stay in one place for too long.

EI/La Programa para Translatinas
 San Francisco, CA

Transgender people often migrate to the US seeking refuge from transphobia in their home countries. These recent immigrants are often monolingual, non-English speakers who are fearful of accessing services due to fear of revealing their immigration status. Agencies reported that requiring clients to "show the right papers" acts as a barrier to providing much-needed services. In addition, agencies are under-equipped to provide multilingual services and materials.

3. <u>Service disruption is common when transgender people become incarcerated</u>. There was only one program in California (Forensic AIDS Project of San Francisco) that was identified as specifically serving incarcerated transgender people. Given the disproportionate rates of incarceration, especially among transgender women of color and sex workers (2), and the fact that incarcerated women report unprotected sex while incarcerated (21), there is a strong need for HIV prevention services during incarceration that is not currently being met.

# 4. <u>Current programs are often difficult to access for transgender women engaged in sex work.</u>

Many transgender women (and some transgender men) engage in sex work to simply survive or to supplement their income to fund gender confirming procedures (28). Due to transphobia in education and employment, many transgender people do not have the education or job skills to transition out of sex work (27). Sex work is a demanding lifestyle, requiring people to sleep most of the day in order to do sex work at night, making it is difficult to keep daytime appointments at service agencies. Transgender people who engage in sex work are exposed to physical violence, sexual assault, and police harassment. Sex work may also intensify drug use and

Don't give up. Working with incarcerated populations is challenging since the laws that govern serving incarcerated populations bind us. However, ensuring that people in the community do not forget about those who are incarcerated helps to chip away at the stigma that incarcerated populations face when they return to their communities.

Forensic AIDS Project
 San Francisco, CA

vice versa, when people engaged in sex work use substances to cope with the stress inherent in the work, and then sex work becomes the means for obtaining the substances.

### 5. Transgender youth are often left out of HIV prevention education.

Much of the HIV prevention education available to youth happens within schools, but because transgender youth often drop out due to stigma, harassment, and violence (3, 29), they do not receive this critical information. Many existing programs that purport to serve LGBT youth do not have the capacity to properly address the needs of transgender youth. Transgender youth need access to substance abuse treatment, housing, hormone therapy, GED programs, employment and legal services, and comprehensive sexuality education that includes youth tailored health and HIV prevention messages, services, and programming to increase knowledge, build effective skills, and create opportunities for health promotion and sustaining health lives. Because many transgender youth are simply struggling to survive, HIV is often not their highest priority; for example, recent studies have reported that 26% - 47% of trans youth have attempted suicide (5). Creating services and programs that are comprehensive and reflective of trans youth specific health and wellness needs may be preferable to simple HIV prevention.

### 6. Services and programs for non-transgender partners of transgender people are needed.

Transgender women report diversity in terms of sexual orientation and partner with people of all genders. Very rarely do the partners of transgender people have access to support and HIV prevention information that is specifically relevant to them. It is important that transgender people are able to include their partners in their HIV prevention strategies and support networks. While it is important to support all partners of all genders, the greatest current risk factor for transgender people is their male sexual partners. Transgender people with male partners living in urban areas where HIV rates are high are at greater risk of exposure to HIV because there is a higher chance that male partners will be living with HIV (30).

# 7. Transgender men, especially those who have sex with non-transgender men, have unmet HIV prevention needs.

Programs that provide HIV prevention services to MSM clients need to be educated about the needs of transgender men and their non-transgender male partners. HIV/STD rates among transgender men appear to be about 2%, although very little information is available (25, 26, 31). Although HIV among transgender men appears to be low compared to transgender women, studies of risk behaviors among transgender MSM indicate that more information is needed. If HIV/STD rates are indeed low among transgender MSM, we need to know more about what prevention strategies transgender MSM are currently using and design interventions to support protective factors and keep it low. Intervention strategies may need to specifically target issues around self-esteem, body image, gender identity, communication skills, and HIV prevention education that includes partners of transgender men.

# 8. It can be difficult for agencies to define their priority population, sometimes resulting in omission of certain segments of the population they intend to reach.

API transgenders are a selective community that are fewer in numbers and assimilate into mainstream society, making them more difficult to locate. The more involved and connected a certain staff person may be in the API transgender communities, the more likely these challenges become negligible.

STAR (Serving Transgenders At Risk),
 APAIT
 Los Angeles, CA

Many agencies noted that some segments of the community are more difficult to locate for outreach and service provision, and if they are accessing services, are often not accurately counted in data collection methods. Some clients may identify as 'post-transsexual', or as a 'woman (or man) of transsexual experience', which describes the fact that their current identity is 'female' or 'male', but acknowledges their history of transition. These clients may live as 'stealth', meaning that they do not openly identify as transgender.

In addition, people who identify as "genderqueer", "third gender", and/or people

who do drag or present as female as part of the ball scene may or may not identify as transgender, and agencies often express confusion about whether or not to include them in their priority population.

### 9. Native transgender people are currently underserved.

When population size is taken into account, Native Americans (including American Indians and Native Alaskans) are ranked third in rates of HIV/AIDS diagnosis, according to the CDC's 2005 HIV Surveillance Report. However, current programs for transgender people are not adequately reaching Native Americans. Native Americans are more likely to live in rural parts of California, which may translate into decreased access to services for transgender Native Americans. In addition, due to the diversity of tribal beliefs and cultures, it may be difficult to design culturally specific programs that adequately address the needs of transgender Native Americans.

# **Funding Recommendations**

# 1. <u>Transgender-specific</u>, comprehensive health care at one accessible site increases access to care for transgender people.

Transgender people are in dire need of access to comprehensive, culturally sensitive, and affordable health care. Transgender-specific clinics that offer a range of diverse services are needed, in addition to the integration of transgender competent care in mainstream health service organizations. Many transgender people purchase hormones on the street, underground markets, or on the internet without a prescription, and their use can be unsafe when not monitored by a medical professional. The provision of hormone therapy is neither costly nor difficult, and transgender people's quality of life is markedly improved through appropriate hormone use.

Benefits of setting up comprehensive heath care sites for transgender people include:

- ✓ Hormone provision and supervision provides incentive to address other heath care needs, such as mental health care, substance abuse treatment, HIV care and treatment
- ✓ Providing the means to address these other health care needs at the same site eliminates barriers to care and provides direct linkages to additional services
- ✓ Providing both HIV prevention and care services at one site eliminates the barrier of fear of loss of confidentiality for transgender people living with HIV
- ✓ Allows providers to focus on overall well-being rather than HIV prevention exclusively
- ✓ Support can be provided for those who seek out a physical transition process, including education about transition-related medical procedures and the dangers associated with silicone injections,
- ✓ Non-traditional strategies for care provision can be adopted, such as flexible appointment hours, private appointments, and evening and weekend hours.

### 2. Provision of hormone therapy can increase access to HIV care and treatment.

It is neither costly nor difficult to provide competent care to transgender individuals, and with careful monitoring there are very little negative side effects. In fact, according to many clinicians, quality of life for transgender people is improved through appropriate hormonal therapy.

Tom Waddell Health Center
 San Francisco, CA

Receiving hormones is often an incentive for addressing HIV among transgender women, and hormone provision provides a mechanism for health promotion and prevention of other diseases (32, 33). Primary care providers for transgender people need to enhance their HIV expertise, and vice versa. Every visit should be an opportunity to assess for risks and review prevention strategies with the patient. Transgender people who know they are living with HIV often do not have a regular medical provider or do not see their provider on a regular basis, due to concerns about confidentiality, lack of transgender sensitivity in

services, and past negative experiences with HIV treatment providers. Transgender women express concerns about receiving HIV care somewhere where other transgender women will be, because they fear it will result in the loss of confidentiality. These concerns can be alleviated by providing HIV care in the context of hormone therapy. In addition, HIV positive transgender people need to be educated on the importance of adherence (34).

### 3. HIV testing among transgender people and their partners needs to be increased.

People who know they are HIV positive are more likely to seek medical care and change their behavior. More timely diagnosis of HIV can improve treatment and care, prolong survival, and reduce the spread of HIV. HIV is most often transmitted by people who are unaware of their status (35). Programs need to be reaching those who do not yet know they are HIV positive, connecting those who test positive to care, ensuring continued access to care, and re-emphasizing prevention among those who test positive. Testing is an educational opportunity for everyone, regardless of HIV status. HIV testing needs to be normalized among transgender people and their partners, and barriers to testing must be addressed. HIV status is not shared among transgender women who are engaged in sex work because accusation of HIV positive status can be used as a weapon against other sex workers who are in competition with one another to secure "dates", or paying sex partners. Loss of confidentiality is a major fear among transgender female sex workers, due to the threat of loss of income and means of survival (36). Testing sites need to take this into consideration when planning their services for transgender women.

# 4. There is a need for development of evidence-based HIV prevention interventions that are transgender-specific.

Despite high prevalence rates, public health intervention research has produced no culturally specific, evidence-based HIV prevention interventions for transgender women. Of the few published interventions that have been implemented with transgender women, none have been controlled trials or were rigorously evaluated for effectiveness (37-39).

Given the complex sexual risk factors present among transgender women, HIV prevention programs developed for other populations that are simply adapted to include new language will not ultimately address the cultural context in which risk behaviors occur and in which protective factors develop (40). HIV prevention interventions need to be based on the culture and context that most influence the lives of transgender women. Some unique risk factors may include hormone use, silicone injections, limited employment opportunities, and transphobia. Three programs included in this Resource Inventory were adapted from Evidence Based Interventions (EBIs): Risk Reduction Program at Children's Hospital in LA: Popular Opinion Leader and Adult Identity Mentoring and Bienestar's SISTA: Sisters Informing Sisters about Topics on AIDS.

There are a lack of resources for conducting needs assessments (especially with youth and transmen), evaluating existing programs, and providing competent and on-going technical assistance or consultations for organizations providing services to transgender individuals. Future needs assessments might examine non-HIV-specific activities and resources that may contribute to reducing risk behavior. These needs assessments could then be utilized to inform culturally-specific interventions for transgender people.

### 5. Service gaps need to be addressed.

Service gaps may occur because no services are currently available or because available services are either not appropriate for or not accessible to the priority population. Currently, there are a number of subgroups of transgender communities that are being underserved, including youth, incarcerated transgender people, monolingual non-English speakers (including recent immigrants), Native transgender people, transmen, and partners of transgender people. To address the needs of

transgender people living outside of major metropolitan areas, funding should focus on working with existing programs to better reach and serve clients living in more rural areas. Some possibilities include creating innovative, community based and structural interventions;

supporting programs in building and sustaining a more visible presence on the internet; providing additional support/incentives for patients and clients needing to travel long distances to access services or bring services to communities (such as a mobile van for health screenings); and providing services and resources in multiple languages.

We need our funders to give more money for transgender youth programs that address not only HIV but the co-factors that impact behaviors in this community.

 Transgender Harm Reduction Project of Children's Hospital, Los Angeles, CA

# 6. Hiring and training transgender women in research and programming is necessary for programs to succeed.

I facilitate trainings for transgender participants and invite other trans trainers from the community. Some of our trainings educate trans people to become outreach workers or peer counselors, so it works to give them more employment options.

 St. James Infirmary San Francisco, CA There is a high unemployment rate due to employment discrimination, and lack of job training and educational opportunities. Staff turnover creates a barrier to forming long-term relationships with clients and patients and leads to disruptions in services and impedes trust. Therefore it is critical to support staff development and adequately compensate employees to decrease turnover. Compensation should include medical benefits that are inclusive of transgender health care. In addition, creating paid internships and fellowships focused on transgender health are essential for building capacity in the field and engaging young professionals early in their career.

# 7. Funding should continue to reflect the HIV epidemic, with concentrated efforts on prevention among transgender women of color.

Communities of color represent disproportionately high numbers of new AIDS cases and comprise the largest number of people living with AIDS in the US (CDC, 2006). Race and ethnicity are not risk factors for HIV in and of themselves. Instead, they are markers for other factors that put people at higher risk for HIV, including limited economic resources and unequal access to

The HIV prevention needs of Latina transwomen are multi-layered and need to be addressed by a comprehensive, multifaceted prevention program.

- Bienestar Los Angeles, CA

health care. Many transgender women of color live in the urban epicenters of California (i.e., San Francisco, Los Angeles, and San Diego) and while the funding should continue to reflect this, funding for transgender HIV prevention programs in other parts of California needs to be increased to provide adequate services to transgender people living in more rural areas.

### 8. There is a strong need for increased education, training and communication among providers.

Educating agencies that are providing HIV prevention services to other priority populations (i.e. MSM) about how to serve transgender clients who may seek services there (i.e., trans MSM). Transgender people need to be able to seek all types of health care without fear of discrimination based on gender identity or legal status. To be effective in serving transgender clients and patients, providers must be trained and updated on new HIV prevention trends to tailor their services and practice, better identify transgender individuals and their health needs, share educational information and best practices with other providers, maintain a transgender-friendly schedule, and build local capacity of and establish better linkages to mental health professionals.

## **Best Practices for Transgender HIV Prevention**

The Best Practices for Transgender HIV Prevention are based on the information we have gathered about successful HIV prevention programs that currently exist in California. It is our hope that these Best Practices will strengthen the capacity of agencies that are looking to initiate or improve HIV services for transgender people to implement practices that have already been identified as successful. With access to existing knowledge and experience from thriving programs that already exist in California, we can build on previous learning experiences to efficiently utilize valuable time and resources. We believe that identifying, disseminating, and adapting Best Practices to local communities are vital steps to enabling an effective response to the HIV epidemic among transgender people in California.

These Best Practices assume a basic level of cultural competency in providing services to transgender people. Issues such as using appropriate language and pronouns to address transgender clients, creating forms that are inclusive of varying transgender identities, and creating a safe space for transgender people (e.g. safe and accessible restrooms) have been addressed elsewhere (41, 42). The Best Practices we offer here are specific guidelines for HIV prevention programs that are seeking to develop, expand, or improve services and programming for transgender clients.

### I. Ground your work in the community.

Involving transgender community members has been an asset in getting a clear picture as to the diversity of the community and varying needs each segment of the community may have.

 Project STAR (Supporting Transgender Access to Resources)
 San Diego, CA Involve the community in program planning and implementation to ensure acceptability, appropriateness, and relevance of the intervention to the priority population. Evidence suggests that people are more likely to sustain changes when they are actively involved in bringing those changes about. Programs should be created with extensive participation and involvement of the transgender community. Involve transgender people at all levels of the program, especially those who are well-versed in the specific needs of the priority population. Peer educators and volunteers from the community are invaluable in ensuring community participation and relevance. In addition, provide mechanisms for the community to give feedback and ideas by creating a Community Advisory Board or holding community forums to help unify the program's mission and the community's vision for the program. Be responsive to the feedback you receive

from the community and be willing to change and be flexible in order to enhance your programs and services. Making sure your program and staff are consistently visible in the community builds trust and maintains rapport with clients. It's critical to prioritize collaborations with other programs and service providers to ensure that your knowledge is up to date of available services in the community and your referrals are helpful. Creating forums (in-person or via e-mail list serves) for networking with other service providers can be very useful in terms of sharing information, resources, and problem solving.

### 2. Race and ethnicity: One size does not fit all.

Incorporate racial/ethnic issues that contribute to HIV risk and issues of stigma and discrimination that are specific to transgender people into your program. This is especially important to keep in mind when adapting and translating interventions originally designed for other priority populations, such as women, MSM, and sex workers. Many of these interventions, because they were not originally developed for transgender people, let alone transgender people of color, do not address important risk factors unique to transgender communities. These risk factors may include needle sharing for injection hormones or silicone, or addressing additional life issues such as language barriers and lack of family acceptance, school and employment discrimination, and police violence due to transphobia.

Through formative evaluation, including focus groups and key informant interviews, we collected extensive data about the needs of Latina transwomen in Los Angeles and used this data to adapt and implement the SISTA intervention so that it addresses the linguistic and cultural needs of Latina transwomen.

- Bienestar Los Angeles, CA

### 3. Utilize multidisciplinary approaches to HIV prevention.

Educate and provide services and care through a broader context of health and wellness. Consider approaches that not only prioritize the individual, but also include their families, social networks, schools, communities, and organizations that transgender people live, work, and play in. For example, host events that include non-trans family members, partners, or friends. Building transgender people's support networks can help counteract isolation for both the clients and their loved ones.

Utilize multiple means of publicizing HIV testing and other services and activities, such as posting on popular internet sites (e.g. MySpace, Craigslist), We have a really great space and constant client base present. That has encouraged our collaborations because they know they can reach folks here. For us it is great to have outside folks come in because we can offer a wider range of services to our clients.

- TRANS: THRIVE San Francisco, CA

hosting harm reduction chats, and publishing newsletters. Work to make your publications accessible and relevant by having them available in multiple languages, provide up-to-date information on trans-specific resources, events, and prevention activities.

Create opportunities for empowerment through dialogue about the problems faced by the community and development of solutions. This can provide much-needed social support as well as an opportunity for individuals to move out of a sense of powerlessness and into a sense of strength through community.

### 4. Get the facts: Assess, evaluate and enhance.

Conduct thorough needs assessments and evaluations, and use the data in program planning and improvement. Focus your needs assessments and evaluations on data that is useful to your organization. Even when a full needs assessment is not feasible given the resources of the program, holding an open Community Forum provides an opportunity for transgender community members to

share their needs, concerns, and problems with the program staff. Disseminate information, especially on subpopulations where data is lacking. Integrate the evaluation data in a meaningful way. Request technical assistance.

### 5. Look in all the right places.

Consider the unique needs and circumstances of your priority populations when planning recruitment and retention strategies. Learn culturally appropriate outreach strategies for working with high-risk transgender women, many of whom are homeless, sex workers, and have mental health concerns. In conducting outreach, programs must make an effort to go beyond what is convenient. Outreach staff should bring information and services to the transgender clients in their community whenever possible. Sex workers tend to congregate in specific neighborhoods. It is important to determine where the people are and go to them.

We offer a range of programs that focus on overall well-being and quality of life, such as a cinema club, dances, and artistic performances (i.e. music, poetry, song, theater). Our clients have found the artistic performances are a healing and empowering way to face issues of suffering and trauma, as well as raise awareness in the broader community about the issues faced by Translatinas.

- El/La San Francisco, CA Combining education and entertainment can be an effective strategy to disseminate information and attracting participants. Artistic performances by members of the transgender community, pageants, balls, and other events, can serve as creative outlets as well as effective recruitment strategies and venues for HIV testing and prevention activities.

Retention can be difficult in areas where accessible and safe transportation is an issue. When possible, programs should situate themselves in areas where transgender women live and work. Other approaches to addressing transportation issues can include distributing bus passes and organizing events in popular, safe, and accessible venues for transgender clients. Use of incentives is important to encourage participation of populations who are highly marginalized in which their time is very limited due to survival needs and priorities.

### 6. Increase access to health care for trans people.

The biggest challenge that trans people face with regards to health care is access to culturally competent, affordable health care. This includes trans care and a lack of trained providers outside of most metropolitan areas.

Lyon Martin Health Services
 San Francisco, CA

Transgender people often find it difficult to navigate health care systems or find linguistically appropriate services. Provide support and follow-up on any referrals given. Make sure that transgender people in your area are fully aware of the programs and services that are available to them by marketing your services widely, developing resource guides, and posting flyers for other programs in your area.

In order to make your services more accessible for transgender people, you may have to build flexibility into your service provision, such as making evening appointments available or delivering services directly to your clients through a service van or other mechanism. Incorporating hormone

therapy into primary or HIV care services greatly increases access for many transgender people for whom hormones are a top priority.

### 7. Invest in developing and supporting your staff.

Many transgender women do not have extensive experience in the mainstream work force and need additional support and training. Staff turnover can be high due to demanding expectations and low pay. Emphasizing staff development can empower transgender women to then serve as role models for others.

Build in staff support mechanisms, such as a flexible work hours and team building, to increase staff retention. Organizational leaders should model commitment, passion, and teamwork. Be patient and put a lot of time and resources into staff development.

Empower disenfranchised transgender women and they will learn and grow and then empower themselves and one another.

TransAction
 Los Angeles, CA

### 8. Advocate for structural and systemic change on behalf of trans people.

Collaborate with community partners to advocate for policy development and social change to end institutionalized discrimination. Providers – not just transgender clients and patients – need to combat hostile policies and practices. Programs that serve MSM, especially young MSM, need to be educated about the diversity of transgender communities so that clients that use these services feel comfortable disclosing their true gender identity and risk behaviors. It's critical to crate change that is systemic and structural.

We advocated on behalf of the trans communities in our programming, addressing issues such as police brutality and criminalization of transwomen by working to end the targeting of trans female sex workers by police. We have as much reason as everyone else to be on the street.

Instituto Familiar de la Raza
 San Francisco, CA

Examples include: networking with legislature and policymakers to expand programs in your area; seeking resources and support for immigrants seeking political asylum; participating in service networks and local Department of Public Health planning committees; working for increased insurance coverage for transgender-related medical issues, legal consultation for transgender-related issues and transgender representation in public policy; working with city housing departments to improve the affordable housing crisis; working with local police to improve the working environment for sex workers and reduce police harassment; and advocating to change policies that limit the accessibility of syringes and syringe exchange programs and policies that prevent condom distribution.

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# **Appendices**

### Summary table of Transgender HIV Prevention Programs in California

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### Resource Inventory Program Questionnaire

\*\* Please return this completed form within 1 to 2 weeks. We appreciate your responsiveness and look forward to highlighting your program in our Compendia!

#### **Program Contact and Services Information**

1 Togram Contact and Services Information
The following information will be visible on our website's list of California programs.
Name of Host Organization:
Host Organization Address, City, State, and Zip:
Name of Transgender-Specific Program:
Program Address, City, State, and Zip (if different from host organization):
Program Phone Number:
Program E-mail Address:
Program Website Address:
Specific Services Available: (i.e, HIV and/or STD testing, Clinic services: medical check-ups, vaccinations, gynecological exams; peer counseling, professional mental health services, housing assistance, job placement, services in various languages, training, speaker panels, case management, drug and alcohol recover services, etc):
Primary Contact Person Name:
Title:
Office Address:
Phone:
E-mail:

### **Programmatic Profile Information for Compendia**

The following information is for <u>compilation purposes only</u> and will not be visible on our website. This information will be integrated with information from other programs to inform various reports on the current programming available to transgender people across the state of California.

Not all sections will be applicable to your program; in these cases, please type N/A. For sections pertaining to needs assessments, evaluations, and other types of reports that you may wish to contribute to the Compendia, you may attach those documents and skip those sections.

As soon as we receive your questionnaire, we will schedule a call you to follow-up on your responses and clarify any points of interest. If you wish to answer any of these questions by phone instead of filling them out electronically, feel free to skip those questions and we will record your responses when we talk by phone.

**Host Organization:** This section includes questions about your organization as a whole, not specific to the transgender program.

- 1) What is the mission (or goals) of your host organization?
- 2) What services does your organization provide?
- 3) What priority populations does your organization serve?
- 4) What is the total host organizational funding budget?
  - i) What are the funding sources?
  - ii) What is the breakdown/percentages?
- 5) What is the number of staff in your host organization?
- 6) Have you had any trans-specific training at your organization?
  - i) When was the last one provided?
  - ii) Who provided the training?
  - iii) What were the goals or learning objectives of the training?
  - iv) Where these goals or learning objectives accomplished?
  - v) Did you attend the training?
  - vi) If so, do you think it was it helpful in advancing your organization's capacity to work with trans people?

vii) Do you think it was it helpful in helping your organization be a better work environment for trans staff members?

#### **Transgender-Specific Program**

- 7) What priority populations does your trans-specific program serve?
- 8) How do people access your services? (i.e. through outreach, internet, referrals)
  - i) Has your programs produced any transgender-specific social marketing materials (i.e. brochures, posters, PSAs)?
- 9) What is the funding budget for your trans-specific program?
  - i) What are the sources of funding?
  - ii) What is the breakdown/percentages?
- 10) What is the number of staff for your trans-specific program?
  - i) Are they paid full time staff, part-time staff, and/or volunteers? What are their positions?
  - ii) What are their demographics? (i.e. How well are different ethnic groups and gender identities represented among your staff?)
  - iii) Are any staff trans? If so, are they out as trans?
  - iv) How long has current staff been in their positions?
- 11) How many transgender clients do you serve on a weekly basis?
- 12) What is the mission (or goals) of your trans-specific program?
- 13) When and how did the trans-specific program begin?
- 14) What were some of the barriers and facilitators to implementing a trans-specific program in your organization?
- 15) Are (or were) there any community partners or collaborators involved in the development and/or implementation of your program?
  - i) If so, what have been the barriers and facilitators to successful community collaborations?
- 16) Describe the challenges you have encountered in hiring and retaining staff.
- 17) Describe the challenges you have encountered in recruiting and retaining clients.

i) Are there any segments of the population that you are not currently reaching?

**Program Assessment & Evaluation:** In this section we hope to get some information about how your program began, what data you have collected (or plan to collect) in your community, and how you are currently evaluating your program.

- 18) Is your trans-specific HIV prevention program based on an EBI (Evidence-Based Intervention)? If so, which one?
  - i) Can you describe how you chose the EBI and why?
  - ii) Can you describe the adaptation process?
- 19) Have you conducted any transgender community needs assessment (or any other types of needs assessment) for program planning purposes? (If you have a needs assessment report you will attach, you may skip this section.)
  - i) When did you conduct it?
  - ii) What methods did you use (survey, interviews, focus groups, etc)?
  - iii) Did the needs assessment inform the development of the trans-specific program?
  - iv) What did you find out about the needs of trans people in your area?
  - v) Do you have a written report you could share?
  - vi) Did the needs assessment highlight any specific risk factors, new health issues/concerns, or trends among trans people? If yes, please explain.
  - vii) What did you learn about the needs of transwomen in particular?
  - viii) What did you learn about the needs of transmen?
  - ix) What did you learn about the needs of youth?
- 20) Have you or are you currently evaluating the trans specific program? If so, please describe your current evaluation plan. (*If you have an evaluation plan or report you will attach, you may skip this section.*)
  - i) What resources do you have in place to devote to evaluation? (i.e. funding, staff)
  - ii) What data collection methods are you using?

- iii) How do you ask for and receive feedback from your participants? How do you monitor the process of implementing your program?
- iv) What have you found from your evaluation? Do you have any reports you could share?
- v) What, if anything, have you enhanced or changed because of the evaluation process?

**Lessons Learned, Challenges, and Emerging Issues:** We are looking for programs and community leaders that exemplify the best practices in HIV prevention for transgender communities. This section is your opportunity to share with us the various ways that you and/or your program excel in doing this work.

21) Based on your professional experience what are some best practices you would like to share with health providers working with trans people? What do you feel your program does really well? Why?

Follow up on any strong points previously raised, such as:

- Recruitment & retention
- Collaborations
- Community and/or client involvement in program design, implementation, evaluation, education, outreach, social marketing, etc.
- Building referral networks
- Health care services
- Other resources in area (substance abuse treatment, housing, etc.)
- Client advocacy
- Harm reduction
- Program evaluation
- 22) Please describe the lessons you have learned from doing this work.
- 23) Describe the challenges you have encountered along the way and how you have addressed them.
- 24) What are the biggest challenges that trans people in your community face with regards to health care and HIV prevention and care today?
  - i) Do you have any recommendations for addressing these challenges?
- 25) Can you refer us to other trans-specific HIV prevention programs in California that you know of?

26) We are currently recruiting a new youth member for our Center of Excellence Community Advisory Board. Do you know a youth under 24 that you could recommend for this position?
<b>Thank you for your time!</b> Please email, fax, or send this form to us with any attached documents as soon as possible and we will schedule a call to follow-up with you.
Documents attached:

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