### TRANSGENDER HIV/AIDS HEALTH SERVICES

Best Practices Guidelines

he Transgender HIV Health Services Best Practices document is dedicated to the clients of the HIV Health Services system, the transgender community in the San Francisco Eligible Metropolitan Area, and to all the providers who devote themselves to providing services to the members of the transgender community affected by the HIV/AIDS epidemic.

Sincere gratitude goes out to all who contributed to the process of developing the Transgender HIV Health Services Best Practices. Special thanks goes to the Working Group members and consumer focus group participants who contributed their knowledge and experience to make these Best Practices practical and worthwhile. We would also like to thank Michelle Long, Viva Delgado and Jenna James for their painstaking review of the draft document, as well as Paula Fener for her innovative approach to this guide's design.

#### Transgender Health Services Working Group Members

Marcus Arana Jennifer Awa Cecilia Cheung **Chuck Cloniger** Jeanna Eichenbaum Tamika Gonzales Isela Gonzalez Janetta Johnson Billie-Jean Kanios JoAnne G. Keatley Kate Monico Klein Dani Marie Kleist Lori Kohler, MD Alexander Lee Linette Martinez, MD Tei Okamoto Lydia A. Sausa, PhD

#### Project Staff

Michelle Long, Director, HIV Health Services Christopher Gortner, Administrative Analyst, HIV Health Services

For questions, concerns or comments, please contact Christopher at Christopher.Gortner@sfdph.org

#### **Project Consultants**

Willow Schrager, Research Associate Linda Tran, Research Assistant Aimee F. Crisostomo, Research Assistant Michelle Magee, Senior Vice President

**Design and Production** 

Paula Fener, Lion's Paw Design



li	ntroduction
0	Developing the Best Practices Document
ł	lealth Literacy
C	Communication and Language
1	1istrust and Stigma
T	ransgender Culturally Competent Environment
C	Collaborative Practice and Social Network
T	ransgender Needs Assessment Focus Group
A	Appendices
	A. Summary of Standards and Practices
	B. Literature Review of Best Practices for Transgender Care
	C. Bibliography
١	Notes



## introduction [INTRODUCTION]

The HIV epidemic continues to exert a disproportionate impact upon transgender persons in the San Francisco Bay Area. Up to 5,000 transgender individuals call the Bay Area their home, and statistical evidence indicates an alarming HIV prevalence rate of 23.8% among male-to-female transgender persons. In 2003, 68% of transgender AIDS cases were people of color. In addition, transgender persons with AIDS are more likely to use injection drugs and other substances, and are younger on the average, with approximately 27% between the ages of 20 and 29 years. Transgender persons also experience disproportionate rates of periodic or chronic homelessness, sex work for survival, as well as a myriad of issues related to violence, poverty, stigmatization, prejudice, and social isolation.

In 2000, HIV Health Services, San Francisco Department of Public Health, received a two-year grant from the Department of Health and Human Services (HRSA), HIV/AIDS Bureau (HAB), Title III Capacity Building Grant Program to develop a transgender cultural competency training program. The Transgender Cultural Competency Training Project was developed to address disparities in access to services for HIV positive transgender clients and to assist providers to improve the delivery of services to the transgender community. Efforts initiated with these funds came to fruition in the Project's second year when the California State Office of AIDS partnered with HIV Health Services and the Pacific AIDS Education and Training Center to develop the first state-wide, twoand-a-half-day conference on transgender care and prevention. The conference *Equality and Parity: A Statewide Action for Transgender HIV Prevention and Care* proved a resounding success, attracting over two hundred care and prevention professionals, as well as consumers, from throughout California.

One of the highlights of the Conference was a robust discussion among participants about the lack of standardized guidelines for serving transgender persons and the need for Best Practices which could help to expand and improve the quality, scope, effectiveness, and outcomes of HIV-specific transgender care services. These guidelines would also serve as a keystone for implementing transgenderspecific services and for treating and serving transgender persons.

In 2005, HIV Health Services again applied for and was granted a HRSA Title III Capacity Building Grant to develop HIV-specific transgender Best Practices guidelines. HIV Health Services partnered with the consulting firm of Harder + Co and a tremendous, hard-working advisory board comprised of seventeen renowned transgender care and prevention experts. Together, over the period of a year, we developed an innovative and broad-based best practices guidelines that could be applied at various different levels of organizational development.

The result is this document.

We sincerely hope the Transgender HIV Health Services Best Practices will assist providers to better understand and serve the needs of their transgender clients, and that our efforts will help pave the way for further dialogue about, and future refinement of, HIV services for transgender people nationwide.

Sincerely yours,

Michelle Long Director of HIV Health Services

**Christopher Gortner** *Project Coordinator* 

### developing the best practices document [Developing THE BEST PRACTICES DOCUMENT]

In the spring and summer of 2006, Harder & Company Community Research was contracted by the San Francisco Department of Public Health, HIV Health Services, to develop a Best Practices guide for providing health and social services to transgender people living with HIV/AIDS. The Best Practices document emerged from a collaborative effort that included the participation of community members, clinicians, service providers, and advocates for the transgender community of San Francisco.

#### Working Group

Community members and providers with experience providing health and social services to the transgender community were invited to participate in a working group whose purpose was to serve as an advisory committee for developing the Best Practices document. Sixteen participants were recruited to participate, including clinicians, case managers and advocates, all with specific expertise in transgender care issues. The working group members shared their expertise by reviewing drafts of the document and providing valuable insight and feedback to ensure that the Best Practices guide would be useful for providers serving the transgender community.

### Literature Review

A literature review of Best Practices for transgender care was conducted to inform the development of the Best Practices document. Existing materials and articles containing HIV and non-HIV specific care and treatment guidelines from various jurisdictions were gathered from San Francisco providers and through the Internet. In addition, general information on effective service provision strategies for transgender populations was included in the literature review. Please see Appendix A.

### Focus Group

In addition to the literature review and soliciting input from the working group, this document was informed by a focus group of transgender persons living with HIV/AIDS who are consumers of services. The purpose of the focus group was to discuss issues related to the health needs of transgender individuals living with HIV/AIDS, and to identify ways to improve the delivery of services to this community. Topics covered in the discussion included service accessibility and participants' service utilization patterns, their experiences with the system of care, and recommendations to better reach and serve the transgender community. Findings from the focus group, which was conducted in March 2006, are included in this document.

### HIV/AIDS Among Transgenders in San Francisco

According to the 2004 San Francisco HIV Prevention Plan, the overall prevalence and incidence of HIV among transgendered populations remain high.

In particular, the male-to-female (MTF) transgender community is disproportionately affected by HIV. Furthermore, African American MTF transgendered persons have the highest HIV prevalence (33%) and incidence (17.5% per year) in San Francisco, compared to other racial/ethnic groups.

The purpose of the focus group was to discuss issues related to the health needs of transgender individuals living with HIV/AIDS, and to identify ways to improve the delivery of services to this community. As of December 2005, more than 400 AIDS cases have been reported in the transgender community. Of these, 63 percent were among people of color, according to the 2005 San Francisco Department of Public Health HIV/AIDS Epidemiology Report.

HIV risk behaviors among some members of the transgender community include unprotected sex, commercial sex work, and injection drug use (Clements, et al. 1999). In addition, persons are less likely to maintain healthier behaviors due to barriers associated with low self-esteem, economic necessity, and substance use. Among African American MTF transgender persons, one study noted that a likely mode of transmission of HIV is unprotected receptive anal intercourse and that a likely source of the virus is men who have sex with men (MSMs) (Clements-Nolle, et al., 2001).

# health literacy

Healthy People 2010 defines health literacy as the degree to which individuals can obtain, process, and understand basic health information and services they need to make appropriate health decisions. Health literacy also refers to the degree to which patients can communicate their health concerns, as well as their ability to navigate through health systems. The following standards are intended to facilitate improved health literacy among transgender clients/patients. They are also intended to ensure that providers are proactive partners in their client/patient health by: 1) assessing their clients/patients' ability to comprehend health information; and 2) making sure that their clients/patients truly understand the health information and services they receive, especially as related to transgender health.

## Standard 1:Provider awareness of specific<br/>transgender health issues and needs

Providers should develop comprehensive knowledge of health and social needs among transgender clients/patients. Providers should be able to talk to their clients/patients about a range of health and social issues that impact HIV care and their overall well being, including:

- Hormone therapy, including underground street hormone use and trends
- Gender confirmation surgery
- Appearance modification, such as use of silicone injections
- Tucking and binding
- Gender identity disclosure with partners or other individuals in the client's/patient's social network
- Mental health issues, such as depression and suicide
- Medication adherence
- Substance use issues
- Partner disclosure of HIV status
- Various categories of potential sexual partners (primary, casual, anonymous, sex work partners), each with differing risk behaviors, and the ability to discuss these behaviors with patients/clients
- Prevention of HIV transmission and other sexually transmitted infections (STIs)
- Domestic violence and hate-motivated violence
- Sex work
- Discrimination and stigma

- Self esteem issues and self-efficacy issues
- Homelessness
- Immigration issues

Providers should also be familiar with other service providers within their agency or other service provider for referral who have expertise on transgender issues.

## Measure Detailed documentation maintained through staff development files, staff training logs, etc.

## Standard 2Client awareness of specific transgender<br/>health issues and needs

Providers play a significant role in making sure that clients/ patients fully understand the health information given to them. Clients/patients who demonstrate health literacy skills are better able to make informed decisions that impact their health and are more likely to engage with their providers in addressing their health needs. Providers should ensure that their clients/patients have and understand information specific to transgender health and care. In particular, providers should make sure that clients/patients understand how certain health issues may or may not affect HIV/AIDS treatment.

For example, providers should be able to discuss and assess clients'/patients' knowledge on the following issues:

- General health care and maintenance
- Effects of hormone therapy
- Gender confirmation surgery

- Appearance modification, such as use of silicone injections, street use of silicone
- Tucking and binding
- Mental health issues, such as depression and suicide
- Partner disclosure of HIV status
- Their own and partners' HIV and STI prevention needs
- Self esteem issues
- Domestic violence
- Discrimination and hate-motivated violence
- Medication adherence
- Immigration concerns
- Gender identity disclosure to partners and/or other individuals
- Measure

Documentation in client/patient files of client/patient awareness of specific health issues and needs that impact his/her care.

### Standard 3 | Harm reduction

Providers should offer support and education to clients regarding substance use, including underground market hormones and silicone injections, by employing harm reduction strategies. Discuss harm reduction strategies with patients/clients.

## Measure Documentation in client/patient files of harm reduction strategies discussed.

### Standard 4 | Referrals and comprehensive resource lists

As part of improving health literacy among transgender clients and positively impacting health outcomes, providers should ensure that clients/patients have sufficient information about transgender health and social services in the community. In addition, when making referrals to other agencies, providers should be aware of the particular agency's cultural competence with transgender clients/patients.

- Providers should develop a comprehensive list of resources and referrals for transgender health services.
- Providers should be actively involved in making referrals and making sure that clients/patients follow up on referrals made.
- Providers should refer clients to a specific contact person at the referral agency. Having a point of contact at the agency to which a patient is being referred is important for follow-through and for helping the patient feel comfortable and more likely to access care.
- Providers should discuss with the client/patient whether or not it is important to disclose his or her gender to the agency and what he or she wants to disclose regarding his or her gender identity.
- When making referrals, providers should speak directly with the provider to whom a patient is being referred and talk to him or her about the particular needs of the transgender patient.

## **Measure** Documentation in client/patient files of all referrals made; frequently updated inventory of referral resources.

## communication and language

Communication is a key component to achieving and improving health literacy. Communication and language barriers affect consumers' abilities to communicate with providers and their understanding of health concepts and procedures. Barriers to effective communication can also limit consumers' ability to adequately advocate for their health. The following standards specifically address communication and language barriers that transgender clients/patients encounter. These standards ensure that providers utilize gender neutral language and that agencies as a whole are inclusive of transgender clients/patients.

### Standard 5 | Use of inclusive and gender neutral language

The following guidelines were developed by the Tom Waddell Health Center. They ensure that providers utilize gender neutral language:

- Address clients/patients with respect and courtesy.
- Address clients according to their presenting gender and when in doubt, politely ask.
- Ask clients what name they prefer to be called and address clients accordingly.
- Do not make assumptions about a patient's/client's anatomy or about names for the patient's anatomy.
- Use pronouns that are appropriate to the client's gender identity.
- As part of being respectful of patients, do not ask questions that are not related to the patient's health. Do not ask personal questions for the sake of curiosity.
- Acknowledge that some questions may touch on sensitive or personal subjects.
- Ask questions in a non-judgmental manner.
- Attempt to use words that the patient/client uses, prefers, and understands, particularly for anatomy, sexual activities or other sensitive matters.
- If you don't understand a word or reference, politely ask him or her to explain.

### **Measure** Client/patient satisfaction surveys that address client/patient comfort with providers in the agency completed annually.

### Standard 6 | Use of inclusive and gender neutral agency forms

- Develop agency forms that are inclusive; for example, intake and assessment forms should provide for optional self-identification in all categories of gender identity, sexual orientation, marital, partnership and family status.
- Allow patients/clients the option to identify their biological gender separate from their gender identity.
- When challenges around gender identification arise due to reporting requirements for State or Federal governments or for the purpose of billing insurance companies, explain the situation to the client/patient and discuss how to proceed.

## **Measure** Client/patient satisfaction surveys that address client/patient comfort with agency procedures completed annually.

## mistrust and stigma [MISTRUST AND STIGMA]

Mistrust and stigma limit health literacy in that they potentially hinder communication and create biases between clients/patients and providers. Mistrust and stigma may also lead to high risk behaviors. Transgender people living with HIV/AIDS are subject to multiple stigmas including stigmas surrounding HIV and gender identification. Research indicates that fear of discrimination and stigma may keep a transgender person from seeking health care and disclosing information once in care (Clark, et al.). In addition to mistrust of the health care system, transgender individuals may have experienced rejection by medical practitioners. Building a relationship with clients/patients based on trust and open communication is necessary to address mistrust and stigma. Addressing these barriers is integral to keeping a patient/client in care and helping patients/clients feel comfortable with disclosing sensitive information to providers, which is important to ensuring that his or her specific needs are met. The following section outlines strategies providers can use to address mistrust and stigma with their clients.

### Standard 7 | Confidentiality of client information

- Assure clients/patients that client data will remain confidential, including information about sexual orientation and gender identity issues.
- Inform clients/patients that they have the right not to disclose personal information.
- Assure clients/patients that the information they disclose will only be used to ensure that their health needs are appropriately addressed.
- Be aware that patients may be engaging in high risk behaviors including sex work, substance use, silicone injection, and use of underground market hormones. Providers should support an environment where patients feel comfortable speaking openly about their behavior without fear of being judged or reported.
- Remember that sometimes confidential topics cannot be discussed in the presence of others (e.g, partners, family members, friends).

## **Measure** Documentation of client/provider communications specific to confidentiality in client/patient files.

## Standard 8Building and engaging in a trusting<br/>relationship with clients/patients

- Be aware that clients/patients may be dealing with issues of low self esteem or depression. Make an attempt to check in with the client/patient about how he or she is doing. Speak in an encouraging manner and take an interest in the individual as a whole.
- Remind clients/patients of the available resources and referrals.

Approach the client/patient in a way that allows the client/patient to feel acknowledged as a person, while recognizing the limitations of the interaction.
 Be sympathetic to the challenges that living as a transgender person brings; therefore, be open with the patient and explore what those challenges are. Give patients an opportunity to talk and share. Try to provide emotional support.
 Measure Client/patient satisfaction surveys that address client/patient comfort with providers completed annually.

### transgender culturally competent environment [TRANSGENDER CULTURALLY COMPETENT ENVIRONMENT]

Creating a welcoming, culturally competent, and responsive place where patients/clients feel comfortable and safe is an important aspect of keeping clients/patients in care. Clients/patients are more likely to continue going to an agency where they not only feel their needs are being met, but also where they feel respected. A transgender culturally competent environment applies both to physical space and overall agency culture. The following standards provide strategies for ensuring that agencies establish and promote an inclusive, non-discriminatory place for both staff and clients/patients.

### Standard 9 | Non-discrimination policies and procedures

Post written non-discrimination policies and complaint procedures, in the primary languages of clients/patients, in conspicuous and accessible places throughout agency.

**Measure** Detailed non-discrimination policies and complaint procedures posted and visible in accessible places throughout the agency.

### Standard 10 | Staff training

Ongoing staff training is an important part of promoting an agency culture that is supportive and inclusive of transgender clients/ patients. Increased awareness of the specific needs and issues faced by transgender patients/clients among staff at all levels of the agency supports culturally competent client care. The following are recommended staff training topics related to transgender care:

- Transgender-specific services—Both clinical and direct staff members should be aware of transgender-specific services provided at their agency as well as at other agencies in the community.
- Communication training—Train staff in the use of culturally appropriate language. Staff members should be comfortable asking a transgender patient questions such as "What gender do you identify with?", "What term do you use for this part of your anatomy?" and asking patients/clients questions regarding disclosure of HIV status with partners.
- Ongoing training on sexual orientation and gender identity issues, transgender culture and its diversity, and health issues faced by transgender people.
- Training on sexual and other forms of harassment, as well as domestic violence and anti-discrimination laws.

	• Transgender health-specific training—training on health issues specific to transgender individuals such as hormone therapy and medical complications related to hormone use.
	• Training on health implications of appearance modification practices such as silicone injections.
	• Training on health implications of binding and tucking.
	• Training on resources available for transgender clients, including support during transition, such as legal assistance for legal name and identity change.
	In addition, staff members who express interest or have experience serving transgender patients/clients may be asked to take the lead and support new staff in providing culturally competent care.
Measure	Documentation of all completed trainings and training participants on file
Standard 11	Ensuring staff diversity
	• Staff should reflect the diversity of the population being served

- Staff should reflect the diversity of the population being served and the population the agency would like to serve.
- Hire staff who have expertise in transgender issues and with whom clients can identify.
- Develop collaborative networks with individuals who have expertise in transgender issues.

# **Measure** Written hiring policies indicating agency's anti-discrimination policy and desire to employ qualified, diverse candidates. Documentation that hiring committee or other decision maker(s) are informed of said policies before each new hire.

### Standard 12 Creating a safe and comfortable agency space

- Provide gender neutral or unisex restrooms.
- Display posters and literature supportive of transgender people.
- Ensure that the receptionist (or the first person with whom a client would interact) is comfortable working with transgender people and is appropriately trained.
- Attempt to locate agency in close proximity to where clients live.
- Monitor waiting room areas to ensure that spaces are free from violence and harassment, and ensuring there is a plan of action should these occur.
- Offer transgender sensitivity training to clients/patients.

## **Measure** Client/patient satisfaction surveys that address client/patient comfort in agency setting.



# E

### collaborative practice and social network [ COLLABORATIVE PRACTICE AND SOCIAL NETWORK ]

Collaboration among providers is necessary to ensure a seamless system of care where transgender clients/patients can access the services they need in order to achieve positive health outcomes, and minimize their sense of isolation. Collaborative practice promotes ongoing communication between providers involved in service delivery to any individual. Social network refers to individuals or groups that patients/clients rely on for emotional and social support. Social networks can be made up of family members, friends, neighbors, partners, and other members in the community and can have an impact on the health and well-being of clients/patients.

### Standard 13 | Collaboration among providers

- Ensure that clients are connected to other support services such as case management, mental health services, and client advocacy services such as benefits counseling, legal assistance, employment assistance, and housing assistance.
- Establish collaborations with other agencies that have expertise in providing transgender health and social services. Formal and informal collaborations can be encouraged through case conferences, listservs concerning transgender health and care, etc.
- **Measure** Documentation of client's/patient's involvement with other agencies in client/patient files; frequently updated assessment of collaborative partners and of transgender services expertise within the agency.

### Standard 14 | Supporting a social network

- Discuss with patients/clients the needs of their partners around HIV issues such as prevention, disclosure, and adherence to treatment.
- Allow patients/clients the option to involve the participation of domestic partners and family members, as defined by the client, in intake, assessment, and case management and treatment plans.
- Inquire about patients' social support network that may include friends and family members and find out from patient any ways his or her support network could be improved.
- Encourage patients/clients to follow up on referrals for support groups and other services in the community as appropriate for the individual patient's/client's needs.

• Encourage patients/clients to connect with other people in the community (e.g., through support groups) in addressing common needs such as gender presentation and learning the basics of legal name change.

## **Measure** Documentation of discussions about client/patient social network in client/patient files.



### transgender needs assessment focus group [TRANSGENDER NEEDS ASSESSMENT FOCUS GROUP]

In March 2006, Harder Company Community Research conducted a focus group with 10 transgender people living with HIV/AIDS. The group took place at the Tenderloin AIDS Resource Center, a service organization in the Tenderloin neighborhood. Recruitment involved posting fliers at selected HIV/AIDS organizations in the Tenderloin and requesting the help of community providers. Transgender Working Group Members, an advisory group of local providers, were also asked to distribute fliers and encourage eligible clients to participate.

### Purpose

The purpose of the focus group was to discuss issues related to the health needs of transgender individuals living with HIV/AIDS, and identify ways to improve the delivery of services to this community. Topics covered in the discussion included service accessibility and participants' utilization of services, their experiences with the system of care, and recommendations to better reach and serve the transgender community.

### Participants

Nine of ten participants were HIV-positive, eight of whom reported to have disabling symptoms. One participant reported to be HIV-negative. The majority (n = 6) of participants were African American or African Black, two were multiracial, one was White, and another was Native American. Three participants identified as male-to-female transgender, two identified as intersex, one person identified as male, and another participant identified as female-to-male transgender. The remaining three participants identified two genders each: male and male-to-female transgender (n = 2), and female and intersex (n = 1). Sexual orientations among this group were also diverse. Four participants identified as straight, bisexual, and lesbian. The average participant was 46 years old.

At the time of the focus group, six participants were living in single room occupancy (SRO) hotels, and one participant was living at a relative's home, while another currently stayed at a homeless shelter. The majority of participants (n = 7) lived in the Tenderloin. Eight participants reported not working at the time of the focus group. Four were on full disability, three had applied for disability, and one participant mentioned he was retired.

Topics covered in the discussion included service accessibility and participants' utilization of services, their experiences with the system of care, and recommendations to better reach and serve the transgender community.

### Service Utilization

Other services participants reported utilizing were housing, money management, peer advocacy, primary health care, home health care, and case management. When asked which services in the Care system they use, participants most frequently mentioned food services, substance use and mental health services. Other services participants reported utilizing were housing, money management, peer advocacy, primary health care, home health care, and case management. Although one participant expressed strong opposition to mental health services, four participants shared that they were actively looking for a therapist or had used mental health services in the past. They mentioned seeking the service to cope with difficult experiences and alleviate frustrations. As one participant explained, "It gives a release." Another added, "I need someone to just talk to. There are times I get into deep depression."

When asked for the reasons why they don't access other services, participants simply replied they didn't need them. One member of the group remarked, "I don't use it because I don't need it." Another person responded that personally "[I would] rather talk to my doctor than a mental health person...[A therapist] is not helping. He's just listening to me." A third participant commented that the reason for not utilizing services was his/her lack of SSI benefits.

### Service Accessibility

Most participants felt they were aware of all services in the Care system. When accessing services, the majority of participants agreed that the location of a service was very important. They shared concerns of having to walk long distances. As one participant asserted, "[Location matters] because you may not live there, and it's a long walk, and money is hard." In addition to the time spent getting to an appointment, participants talked about feeling tempted to use drugs while traveling to a farther location: "[You could be walking to your appointment] and then something throws you off like getting tempted to do drugs. You want to make it, but those things make it hard." Therefore, participants agreed that Care services should be located very near their residences, "like across the street." One participant added, "Services in the TL [Tenderloin neighborhood] is important."

Several participants agreed that the time of day services are offered also makes a difference. They felt services for transgender people should be offered 24 hours a day. One reason for the request was also centered on trying to avoid substance use: "I am trying to change my life and better myself. I'm not trying to come here and see people do drugs; seeing that triggers me." Another participant felt having 24 hour access to services would better service her mental health needs.

### Experiences with the Care System

Overall, participants felt providers were sensitive to greeting them respectfully and using appropriate language such as pronouns. One participant shrugged off the question, saying "We're in San Francisco, and usually the services are politically correct." The group agreed, and another member elaborated, "If you come in as a woman, they will say 'she.' When we come in with our personas, they give us our respect. I personally haven't had problems with coming in with makeup or a dress, I haven't have any problems with people."

Participants also agreed intake and other required forms were respectful and do not require any revisions or additional questions. Yet on a deeper level, participants felt providers do not understand the transgender community. One participant expressed frustration in having to repeatedly explain to providers her situation because the provider may not understand. The individual vented, "It gets very tedious explaining why you did this because some people don't follow the way you think." Going even further, another participant felt

Going even further, another participant felt attempts to understand the community were pointless because "nobody understands," continuing, "it doesn't matter who the person or provider is, they don't understand. We have a unique life. " Although focus group participants agreed that Care providers usually address them with appropriate language and respect, they felt providers do not understand the needs of the transgender community. attempts to understand the community were pointless because "nobody understands," continuing, "it doesn't matter who the person or provider is, they don't understand...We have a unique life. Even if we come to express ourselves, they don't understand." This participant later agreed the focus group was "a start."

When asked what things make them feel comfortable in an organization, one participant replied "a typical greeting" would suffice, while others described a clean, professional environment, with clean bathrooms and "legit magazines for all ethnicities." A couple of people mentioned that they liked service providers that provided food or healthy snacks in the waiting room. Others expressed that they didn't like it when HIV/AIDS organizations serve a broader population or let people hang out or sleep at the agency. One member of the group alleged, "They're not treating people. People are sleeping and haven't taken baths." Another participant argued, "I respect that there are services for people other than HIV. But…now we are in the background and stand in the rain with homeless people." Another person agreed, "Now people living with HIV are on the back burner."

Participants reported sometimes feeling unsafe when sharing space with other clients. As one person explained, "We go in and people make remarks about gay and TG and fights break out. I don't want to be around that." Participants also felt uncomfortable in organizations with unsecured bathrooms that are often used for substance use: "It makes me think about [doing drugs], having been there...it's not respectful."

### Recommendations

Although focus group participants agreed that Care providers usually address them with appropriate language and respect, they felt providers do not understand the needs of the transgender community. One recommendation to address this concern was to educate and train providers to learn more about the transgender community. Mentioned more often, participants stressed hiring transgender persons as providers. As one person asserted, "There are lots of services, but they need to hire more TGs because we have different concerns. They are different from men, different from women, and we need more TGs in those places to help us because they know where we are coming from." This point was reiterated numerous times during the discussion.

Other recommendations for providers included approaching transgender clients with respect and with a positive attitude, trying to understand what she or he is going through, and appropriately referring the client to other services as needed. One participant commented, "If they can't help you, they should refer you. Don't send us to the wrong place." Another offered a similar sentiment, asserting, "Just to make sure they know what they are talking about and not just guessing and referring you to some place without knowing what the other place does. Make sure they know what they're doing."

On a systems level, participants expressed not feeling recognized or represented as a community. One person noted, "[In] the pamphlets, the pictures have men and women, but not TGs."Participants agreed that greater efforts should be made to include and reach out to the transgender community, particularly in public media like brochures and billboards.

#### Summary

Overall, transgender participants were aware of Care services available to them. Location and time of day services are offered were key factors in their ability to not only access services, but also to avoid substance use. Participants talked of a service environment that offers educational magazines and healthy snacks and that defends its clients from harassment and exposure to substance use. Other prominent themes that stood out during the discussion were participants' desire to feel included and respected as a community, coupled with a feeling that providers do not and may never understand them. Recommendations included offering providers training on transgender issues, hiring more transgender service providers, and including the community in public campaigns. In summary, participants felt like "the TG community should get more respect."

### appendices [APPENDICES]

Summary of Standards and Practices

Literature Review of Best Practices for Transgender Care

Bibliography

**Transgender HIV Health Services Best Practices Guidelines** 



## appendix a [summary of standards and practices ]

STANDARD	MEASURE
1. Provider awareness of specific transgender health issues and needs	1. Detailed documentation maintained through staff development files, staff training logs, etc.
2. Client awareness of specific transgender health issues and needs	2. Documentation in client/patient files of client/patient awareness of specific health issues and needs that impact his/her care.
3. Harm reduction	3. Documentation in client/patient files of harm reduction strategies discussed.
4. Referrals and comprehensive resource lists	4. Documentation in client/patient files of all referrals made; frequently updated inventory of referral resources.
5. Use of inclusive and gender neutral language	5. Client/patient satisfaction surveys that address client/patient comfort with agency providers completed annually.

STANDARD	MEASURE
6. Use of inclusive and gender neutral agency forms	6. Client/patient satisfaction surveys that address client/patient comfort with agency procedures completed annually.
7. Confidentiality of client information	7. Documentation of client communications around confidentiality in client/ patient files.
8. Building a trusting relationship with clients/patients	8. Client/patient satisfaction surveys that address client/patient comfort with agency providers completed annually.
9. Non-discrimination policies and procedures	9. Detailed non-discrimination policies and complaint procedures posted and visible in accessible places throughout the agency.
10. Staff training	10. Documentation of all completed trainings and training participants on file.
11. Ensuring staff diversity	11. Written hiring policies indicating agency's desire to employ qualified, diverse candi- dates. Documentation that hiring committee or other decision maker(s) are informed of the policy before each new hire.
12. Creating a safe and comfortable agency space	12. Client/patient satisfaction surveys that address client/patient comfort in agency setting.
13. Collaboration among providers	13. Documentation of client/patient involvement with other agencies in client/patient files; frequently updated review of collaborative partners and of transgender services expertise within the agency.
14. Supporting a social network	14. Documentation of discussions about client's/patient's social network in client/ patient files.



# **11X** BE REVIEW OF BEST PRACTICES FOR TRANSGENDER CARE ]

ARTICLE	SOURCE/YEAR	DESCRIPTION	MAIN POINTS AND STATISTICS
Community Standards of Practice of Quality Health Care Services for Gay, Lesbian, Bisexual and Transgendered Clients	GLBT Health Access Project, Boston, MA www.glbthealth.org	Standards and specific indicators address both agency administrative practices and service delivery components including the following areas: personnel, clients rights, intake and assessment, service planning and delivery, confidentiality, and community outreach and health promotion.	<ul> <li>The standards are summarized below:</li> <li>Standard 1: Establish written non-discrimination policies</li> <li>Standard 2: Support and encourage visibility of GLBT employees.</li> <li>Standard 3: Equal employment opportunities for GLBT of all ages.</li> <li>Standard 4: Comprehensive policies are implemented to prohibit discrimination in the delivery of services to GLBT clients and their families.</li> <li>Standard 5: Ensure a comprehensive and easily accessible procedures for clients to file and resolve complaints alleging violations of policies.</li> <li>Standard 6: Intake and assessment procedures meet the needs of GLBT of all ages and their families.</li> <li>Standard 7: All agency staff have a basic familiarity with GLBT issues as they pertain to services provided by the agency.</li> <li>Standard 8: All direct care staff are competent in identifying and addressing specific health problems and treatment plans include and address sexual orientation and gender identity where it is a necessary and appropriate issue in client care.</li> <li>Standard 10: Client data including information about sexual orientation and gender identity.</li> <li>Standard 11: Agency shall provide appropriate safe, and confidential treatment to GLBT minors unless the agency's services are inappropriate for all minors.</li> </ul>
ARTICLE	SOURCE/YEAR	DESCRIPTION	MAIN POINTS AND STATISTICS
---	---	---	---
			<ul> <li>Standard 12: The agency shall include GLBT and their families in outreach and health promotion efforts.</li> <li>Standard 13: The composition of the agency Board of Directors and other institutional bodies shall encourage representation from GLBT communities.</li> <li>Standard 14: Agency community benefits programs shall include GLBT people in the communities the agency serves. The four principles that guided the development of these standards were: 1) the elimination of discrimination on the basis of sexual orientation and gender identity; 2) the promotion and provision of full and equal access to services; 3) the elimination of stigmatization of GLBT people and their families; and 4) the creation of health service environments where it is safe for people to be "out" their providers.</li> </ul>
Recommendations for Health Service Organizations to Improve Their Services for Trans Clients	Sausa, Lydia, PhD. Human and Sexuality Educator, Trainer, & Consultant. Jan. 2006 www. Iydiasausa.com	Focuses on structural and organizational changes that can be made in order to provide culturally competent services for transgender clients.	<ul> <li>Provides specific recommendations for health service organizations in various areas of organization and suggests training needs in areas including:</li> <li>Policy and forms (e.g., address needs of intersex persons, include as part of intake question "What name do you prefer to be called?")</li> <li>Appropriate language use (e.g., train staff to use genderneutral language with clients and to not assume the sexual orientation of a TG client)</li> <li>Creating a safe environment (e.g., include trans specific literature in waiting area, hire openly TG persons, provide gender inclusive restrooms)</li> <li>Client education and outreach (e.g., collaborate with TG community to develop and administer a needs assessment in your community)</li> <li>Establishing resources (e.g., create a TG resource guide with information on TG specific services or TG friendly services)</li> </ul>
Transgender Health	Feldman, Jamie, MD and Bockting, Walter, PhD. <i>Minnesota</i> <i>Medical</i> <i>Association.</i> July 2003, Vol. 86.	Presents a literature- based review of the health needs of the transgender patient.	<ul> <li>Focuses recommendations/suggestions for medical providers in the following TG-specific health issues:</li> <li>Presentation <ul> <li>TG persons may present in a variety of ways, thus patients best explore transgender issues in a setting of respect and trust.</li> </ul> </li> </ul>

ARTICLE	SOURCE/YEAR	DESCRIPTION	MAIN POINTS AND STATISTICS
			<ul> <li>Providing services that are respectful requires using the appropriate names and pronouns, reassuring patients about confidentiality, educating clinic staff and colleagues regarding potentially sensitive physical exams and tests.</li> <li>Health History         <ul> <li>Because TG persons may utilize hormonal or surgical interventions, a throrough history of TG-specific interventions is essential. Providers should develop TG-specific history that inquire about sex reassignment surgery, hormone therapy (including herbal hormones and medically unsupervised use of hormones), and therapy/counseling.</li> </ul> </li> <li>General Health Maintenance         <ul> <li>Health maintenance for TG patients should be based on age, family, and personal health risk factors, and the organs present.</li> <li>Physical exams should be structured based on the organs present rather than the perceived gender of the patient.</li> <li>General health maintenance measures such as smoking cessation, hepatitis B vaccination, exercise, and calcium supplementation are especially important for the TG patient.</li> </ul> </li> <li>Mental Health         <ul> <li>MH maintenance is important and should include depression screening and helping patient connect with TG support services.</li> <li>Sexual Health including screening for HIV and STDs, including Hepatitis B and C, and high risk behaviors such as having multiple partners, engaging in sex work, sharing needles to inject hormones, and not using condoms regularly.</li> </ul> </li> <li>Recommendations were also made in regards to issues that arise from TG hormone therapy such as familiarizing one's self with the standards of care, developed by the Benjamin International Gender Dysphoria Assoc., for treating gender identity disorder including hormonal and surgical interventions (www.hbigda.org/soc.html); working closely (hormone</li> </ul>

ARTICLE	SOURCE/YEAR	DESCRIPTION	MAIN POINTS AND STATISTICS
ARTICLE Recommended Standards of Practice for the Provision of Quality Health Care and Social Services for Gay, Lesbian, Bisexual, and	SOURCE/YEAR City of Tucson Commission on Gay, Lesbian, Bisexual, and Transgender Issues. Revised January 2005.	DESCRIPTION • Purpose of document is to provide a set of recommended guidelines for service providers to help them better meet the needs of	<ul> <li>provider/medical provider administering hormone therapy and the patient) with a therapist trained in treating gender identity issues; and having familiarity with hormone medications, usual dosages, and side effects.</li> <li>The article also discusses medical conditions associated with TG hormone therapy including Type 2 diabetes mellitus, cardio-vascular disease, venous thromboembolic disease, liver abnormalities, hyperprolactinemia, osteoporosis, and cancer.</li> <li>Presents four goals for organizations to strive for with help of the recommendations: elimination of bias and descrimination on the basis of sexual orientation and gender identity in the delivery of services; promotion and provision of full and equal access to services by GLBT clients and patients; elimination of stigmatism of GLBT persons and their families; and creation of human service environments where it is safe for GLBT</li> </ul>
Bisexual, and Transgender Clients	www. pimamedical society.org/ gender.php	<ul> <li>meet the needs of their GLBT clients and patients.</li> <li>Also intended to provide a list of criteria providers can use to measure their effectiveness in meeting the needs of GLBT population.</li> </ul>	<ul> <li>persons to disclose their sexual orientation and/or gender identity.</li> <li>Document provides a series of questions to help organizations assess how well their policies and procedures serve GLBT populations.</li> <li>Questions cover range of topics: anti-discrimination policy, intake forms, serving domestic partners and family members of GLBT patients, grievance procedures, staff training on GLBT issues including social stigmatization, and staff training on cultural competency.</li> <li>The following recommended standard (brief summary) of practice and client rights are presented:</li> <li>Standard 1: Comprehensive polices are implemented to prohibit discrimination in the delivery of services on the basis of sexual orientation and gender identity.</li> <li>Standard 2: Agency has written policy against discrimination in categories of gender identity, sexual orientation, marital, partnership and family status.</li> <li>Standard 4: Procedures are in place for filing and resolving complaints alleging discrimination based on sexual orientation or gender identity.</li> </ul>

ARTICLE	SOURCE/YEAR	DESCRIPTION	MAIN POINTS AND STATISTICS
			<ul> <li>Standard 5: Staff training addresses cultural diversity, harassment and anti-discrimination; staff are familiar with these issues as they relate to sexual orientation and gender identity and its effects on case management and treatment plans of GLBT clients.</li> <li>Standard 6: Direct services staff are trained on how, when, and where to make appropriate referrals for health care, social services, and community resources for GLBT clients and their families.</li> <li>Standard 7: Clients are ensured the confidentiality of their records including information about sexual orientation and gender identity.</li> <li>Standard 8: GLBT youth clients are provided with appropriate legal limits as defined by state statutes.</li> </ul>
Crossing to Safety: Transgender Health & Homelessness	Healing Hands (a publication of the HCH Clinicians' Network). Vol. 6, No. 4. June 2002.	<ul> <li>Discusses the challenges that homeless transgendered persons encounter.</li> <li>Article highlights Tom Waddell Clinic which provides Transgender Tuesdays, a 4 hour/week primary clinic providing multidisciplinary care including hormone therapy for self-defined transgender people.</li> </ul>	<ul> <li>TG persons who are homeless experience multiple stigmas. Besides being poor, they may be ethnic or linguistic minorities, may be estranged from their families, and may be estranged from their country of origin, having experienced discrimination and intolerance.</li> <li>Unable to gain employment, many TG may turn to survival sex, increasing risk for STDs and violence.</li> <li>Homeless TG persons are frequently harassed by shelter residents.</li> <li>Lack of insurance among homeless TG limits health care access.</li> <li>The Tuesday clinics emphasize a harm reduction philosophy towards providing hormone therapy and increasing access to primary and preventative care. Without access to hormone therapy in a controlled medical setting, providers found that TG people would continue to use injected hormones purchased on the street or from medical providers who did not monitor their use.</li> <li>Tom Waddell Clinic developed a standard for prescribing hormones that diverges somewhat from the traditional standards of care of HBIGDA: "informed consent of self- identifying transgender individuals with the mental capacity to understand the possible risks as well as limits to therapeutic benefits."</li> <li>Creating a transgender-friendly clinic:</li> <li>Educate medical providers and staff about gender variance (e.g, provide regular in-service training on TG issues)</li> </ul>

ARTICLE	SOURCE/YEAR	DESCRIPTION	MAIN POINTS AND STATISTICS
			<ul> <li>Create a safe and comfortable environment (e.g., provide unisex bathrooms)</li> <li>Use GLBT-sensitive language (e.g, avoid personalizing body parts)</li> <li>Provide respectful, compassionate care (e.g., be non-judgemental)</li> <li>Incorporate hormone therapy into primary care</li> </ul>
The Transgender Community Health Project	San Francisco Department of Public Health, February 18, 1999.	A quantitative study designed to assess HIV risk among MTF and FTM transgendered persons in San Francisco.	<ul> <li>MTF individuals reported high levels of lifetime HIV risk behaviors including: sex work, unprotected receptive anal sex, and ID.</li> <li>Over one third (35%) of MTF participants were infected with HIV and among African Americans, almost two thirds (63%) were HIV positive.</li> <li>HIV prevalence was low (&lt;2%) among FTM participants and current risk behaviors were infrequent.</li> <li>A history to unsafe receptive anal sex was reported by 28% of FTM participants, and among those who reported a history of injection drug use (18% of sample), 91% shared syringes.</li> <li>Based on findings, there is need for effective HIV prevention and harm reduction interventions for MTF transgendered individuals. Interventions should target African Americans individuals b/c of high HIV prevalence among this group.</li> <li>Recommendation made to hire transgendered people to provide HIV prevention to reach individuals most in need of services.</li> </ul>
Not 'just' a friend— Best practice guidance on health care for lesbian, gay, and bisexual service users and their families	Royal College of Nursing and UNISON, UK (no date of publication)	According to authors, many of the principles in the guide also apply to best practice in the care of transgendered service users, but emphasize that the issues are not all the same.	<ul> <li>Next of Kin—Many people in same sex relationships are concerned about the refusal of health care workers to acknowledge their partner, denying them visiting rights and access to information.</li> <li>Confidentiality and Documentation—Providers should maintain client confidentiality including information on patient's sexual orientation and gender identity.</li> <li>Other Family Members—Health care workers must respect the family relationships of clients whether the relationships has legal status or not.</li> </ul>

ARTICLE	SOURCE/YEAR	DESCRIPTION	MAIN POINTS AND STATISTICS
<i>HIV Prevention and Health Service Needs of the Transgender Community in San Francisco</i>	Clements et al. International Journal of Transgenderism, 1999.	Eleven focus groups were conducted in 1997 with 100 MTF and FTM transgendered individuals living in SF. Findings describe the level of HIV risk behaviors and access to HIV prevention and health services among the group.	<ul> <li>HIV risk behaviors such as unprotected sex, commercial sex work, and injection drug use were common.</li> <li>Barriers to maintaining safer behaviors included low selfesteem, economic necessity, and substance abuse.</li> <li>Many participants did not access prevention and health services because of insensitivity of service providers and competing priorities.</li> <li>Recommendations made by participants for improving services include: hiring TG persons to develop and implement programs and training providers in transgender sensitivity and standards of care.</li> <li>Participants identified unmet needs related to HIV prevention interventions: peer based street outreach; transgender specific risk reduction and education (e.g., need for counseling and education that builds their self esteem and counseling that directly addresses their new gender and sexual identified unmet needs related to HIV health services. They noted a need for primary health care for transgendered individuals living with HIV, emphasizing the need for increasing provider knowledge about the effects and potential dangers of taking hormones and seeking reassignment surgery for those living with HIV. There was also a need for support groups for HIV-infected transgendered individuals to help improve self-esteem and increase access to health care, and encourage healthy lifestyles.</li> </ul>
Primary HIV Care for Transgender People	Kohler, Lori, MD. Department of Family and Com- munity Medi- cine, UCSF. (no date)	A comprehensive Powerpoint presentation training for medical providers.	<ul> <li>The goal of treatment for TG people is to improve their quality of life by facilitation their transition to a physical state that more closely represents their sense of themselves.</li> <li>Barriers to medical care for TG people: geographic isolation, social isolation, fear of exposure/avoidance, denial of insurance coverage, stigma of gender clinics, lack of clinical research/medical literature</li> <li>Regardless of their socioeconomic status, all transgender people are medically underserved.</li> <li>TG women are at especially high risk for poverty, HIV disease, addiction, and incarceration.</li> </ul>

ARTICLE	SOURCE/YEAR	DESCRIPTION	MAIN POINTS AND STATISTICS
			<ul> <li>Low self esteem leads to HIV risk behaviors especially among MTFs (e.g., sex work, drug use, unprotected sex, underground hormones, sex for hormones, silicone injections, needle sharing, and abuse by medical providers)</li> <li>Hormone therapy for transgender people is a primary care issue.</li> <li>Access to cross-gender hormones can improve adherence to treatment of chronic illness, increase opportunities for preventive health care, improve self esteem, prevent suffering and risk taking, and lead to social change.</li> <li>Author provides guidelines for initial provider visits with transgender patient: review history of gender experience, document prior hormone use, review patient goals for transition, address safety concerns, assess social support system, and assess readiness for gender transition.</li> <li>Providers should assess patient comfort with physical exam and provided a problem oriented exam only. Providers should avoid satisfying own curiosity.</li> <li>HIV and Hormones:</li> <li>There are no significant drug in interactions with drugs used to treat HIV</li> <li>Several HIV medications change the levels of estrogens</li> <li>Cross gender hormone therapy is not contraindicated in HIV disease at any stage.</li> </ul>
Transgender Health Care (various)	Transgender Health Program, Vancouver BC. www.vch.ca/ transhealth/	Various articles and information about clinical care for transgender	<ul> <li>Adolescent Care Practice Protocol</li> <li>Clinical Advocacy</li> <li>Hormonal Feminization/Masculinization</li> <li>Primary Medical Care</li> <li>Surgical Feminization/Masculinization</li> <li>Speech/Voice Change</li> </ul>



## appendix c

Clark, ME, et al. (2001) The GLBT Health Access Project: A State-Funded Effort to Improve Access to Care. *Am J of Public Health* 91(6): 895-896).

Clements-Nolle K., et al. (2001) HIV prevalence, risk behaviors, health care use, and mental health status of transgender persons: Implications for public health intervention. *Am J Public Health* 91(6):915-921.

Clements K., et al. (1999) HIV prevention and health service needs of the transgender community in San Francisco. *Int J Transgenderism* 3(1+2).

Feldman, Jamie, MD and Bockting, Walter, PhD (2003). *Transgender Health* [report]. Minnesota Medical Association. Vol. 86.

GLBT Health Access Project. (2001). *Community Standards of Practice of Quality Health Care Services for Gay, Lesbian, Bisexual and Transgendered Clients.* Available from the GLBT Health Access Project, Boston, MA. www.glbthealth.org .

Healing Hands. (2002). Crossing to Safety: *Transgender Health & Homelessness.* Vol. 6, NO. 4. A publication of the HCH Clinicians' Network.

HPPC. (2004) 2004 San Francisco HIV Prevention Plan.

Kohler, Lori, MD. (no date) *Primary HIV Care for Transgender People.* Department of Family and Community Medicine, University of California, San Francisco.

Royal College of Nursing and UNISON, UK (no date of publication). *Not 'just' a friend— Best practice guidance on health care for lesbian, gay, and bisexual service users and their families.*  San Francisco Department of Public Health (1999). *The Transgender Community Health Project.* 

San Francisco Department of Public Health (2004). *The Transgender Cultural Competency Training Project: Transgender Care Update Spotlight on Cultural Competence.* 

Sausa, Lydia, PhD., *Recommendations for Health Service Organizations to Improve Their Services for Trans Clients.* 

City of Tucson Commission on Gay, Lesbian, Bisexual, and Transgender Issues. (2005). *Recommended Standards of Practice for the Provision of Quality Health Care and Social Services for Gay, Lesbian, Bisexual, and Transgender Clients.* www.pimamedicalsociety.org/gender.php.

San Francisco Department of Public Health, HIV Health Services. *The Transgender Cultural Competency Training Project: Transgender Care Update Spotlight on Cultural Competence.* 2004.

San Francisco Public Library. *TRANScending Identities: A Bibliography of Resources on Transgender and Intersex Topics.* 2005.

Arlene Istar Lev. *Transgender Emergence: Therapeutic Guidelines for Working with Gender-Variant People and Their Families.* 2004.

Murray D. Scheel and Claire Eustace. National Lawyers Guild and City & County of San Francisco Human Rights Commission. *Model Protocols on the Treatment of Transgender Persons by the San Francisco County Jail.* 2002.

Tom Waddell Health Center. Protocols for Hormonal Reassignment of Gender. 2001.

Kaiser Permanente National Diversity Council. *The Culturally Competent Care Handbook.* 2000.








