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## Fast Facts

- Studies reveal high HIV prevalence rates among transgender women in the United States.
- Black/African American transgender women are more likely to have HIV than transgender women of other races/ethnicities.
- Many social and structural factors pose challenges to preventing HIV among transgender people.

## Terminology

*Transgender* is an umbrella term for persons whose gender identity or expression (masculine, feminine, other) is different from their sex (male, female) at birth. *Gender identity* refers to one's internal understanding of one's own gender, or the gender with which a person identifies. *Gender expression* is a term used to describe people's outward presentation of their gender.

## The Numbers

Because data for transgender people are not uniformly collected, information is lacking on how many transgender people in the United States are infected with HIV. However, data collected by local health departments and scientists studying these communities show high levels of HIV and racial/ethnic disparities.

- In 2013, a meta-analysis (Baral et al.) reported that the estimated HIV prevalence among transgender women was 22% in five high-income countries, including the United States.
- Findings from a systematic review (Herbst et al.) of 29 published studies showed that 28% of transgender women had HIV infection (4 studies), while 12% of transgender women self-reported having HIV (18 studies). This discrepancy suggests many transgender women living with HIV don't know their HIV status.
- In the systematic review, black/African American transgender women were most likely to test HIV positive, compared to those of other races/ethnicities: 56% of black/African American transgender women had positive HIV test results compared to 17% of white or 16% of Hispanic/Latina transgender women.
- Among the 3.3 million HIV testing events<sup>a</sup> reported to CDC in 2013, the highest percentages of newly identified HIV-positive persons were among transgender persons.
- Although HIV prevalence among transgender men is relatively low (0-3%), a 2011 study (Rowniak et al.) suggests that transgender men who have sex with men are at substantial risk for acquiring HIV.

## Prevention Challenges

Individual behaviors alone do not account for the disparate HIV diagnoses among transgender people. Many cultural, socioeconomic, and health-related factors contribute to these diagnoses and prevention challenges in transgender communities.

**Sexual behaviors and factors that may contribute to the high risk of HIV infection** among transgender people include receptive anal sex without a condom or medicines to prevent HIV, a high prevalence of HIV in sexual networks, sex with multiple partners, and exchanging sex for drugs or money.

**Other factors that contribute to high rates of HIV** among transgender people include drug and alcohol abuse, mental health disorders, incarceration, homelessness, unemployment, lack of familial support, violence, stigma, discrimination, limited health care access, and negative health care encounters.

**Many transgender people face social rejection and marginalization** that excludes them from participating and functioning in society. Lack of legal recognition of gender identity can result in the denial of educational, employment, and housing opportunities. Some transgender people who experience poverty rely on sex work to meet their basic survival needs.

**Insensitivity to transgender identity can be a barrier** for those who are diagnosed with HIV and seek quality treatment and care services. Research shows transgender women with diagnosed HIV infection are less likely to be on antiretroviral therapy (ART) or achieve viral suppression. Furthermore, few health care providers receive adequate training or are knowledgeable about transgender health issues and their unique needs.

**Transgender-specific data are limited.** Currently, many federal, state, and local agencies inaccurately collect data about individuals' sex and gender. Using the two-step data collection method of asking for sex assigned at birth and current gender identity can help to increase the likelihood that transgender people will be accurately identified in HIV surveillance programs.

**Behavioral HIV prevention interventions** developed for other at-risk groups with similar behaviors have been adapted for use with transgender people; however, their effectiveness is still unknown. There is a need for effective interventions that address the multiple co-occurring public health problems in transgender persons.

**Transgender men's sexual health has been understudied.** Additional research is needed to understand HIV risk behavior among transgender men, especially those who have sex with men.

## What CDC Is Doing

CDC and its partners are pursuing a **high-impact prevention** approach to achieve the goals of the *National HIV/AIDS Strategy: Updated to 2020* (<https://www.aids.gov/federal-resources/national-hiv-aids-strategy/nhas-update.pdf>) and maximize the effectiveness of current HIV prevention methods among transgender people. Activities include:

- Funding community-based organizations (CBOs) to enhance their capacities to increase HIV testing, link transgender persons with diagnosed HIV infection to medical care, increase referrals to partner services, and provide prevention and support services for transgender persons at risk for or diagnosed with HIV.
- Supporting health department demonstration projects (<http://www.cdc.gov/hiv/funding/announcements/ps15-1506/index.html>) that provide pre-exposure prophylaxis (PrEP) (<http://www.cdc.gov/hiv/risk/prep/index.html>) support services and data-to-care activities prioritizing gay and bisexual men and transgender persons at substantial risk for acquiring HIV, particularly persons of color.
- Providing support and technical assistance to providers that help CBOs enhance structural interventions for transgender people (e.g., condom distribution, community mobilization, HIV testing, and coordinated referral networks and service integration).
- Developing *Act Against AIDS* (<http://www.cdc.gov/actagainstaids/>) communication materials to reach transgender people, including campaigns such as:
  - *Doing It* (<http://www.cdc.gov/actagainstaids/campaigns/doingit/index.html>), which encourages all adults to get tested for HIV and know their status, and includes images (<http://www.cdc.gov/actagainstaids/pdf/campaigns/doingit/getmaterials/posters/doingit-chandimoore.pdf>) and testimonial videos featuring transgender leaders.
  - *Let's Stop HIV Together* (<http://www.cdc.gov/actagainstaids/campaigns/lsht/index.html>), which raises awareness about HIV and fights stigma, and includes the stories (<https://www.youtube.com/embed/9XXsTvYj22U>) of transgender women.
  - *HIV Treatment Works* (<http://www.cdc.gov/actagainstaids/campaigns/hivtreatmentworks/index.html>), which encourages people living with HIV to stay in care, and features a transgender woman's story (<https://www.youtube.com/embed/jo4KbnPrhEw>) of staying healthy while living with HIV.
- Through its Capacity Building Assistance initiative, CDC is working with the Center of Excellence for Transgender Health to support National Transgender HIV Testing Day. This day recognizes the importance of routine HIV testing, status awareness, and continued focus on HIV prevention and treatment efforts among transgender people.

### Additional Resources

**CDC-INFO**  
1-800-CDC-INFO (232-4636)  
[www.cdc.gov/info](http://www.cdc.gov/info)

**CDC HIV Website**  
[www.cdc.gov/hiv](http://www.cdc.gov/hiv)

**CDC Act Against AIDS Campaign**  
[www.cdc.gov/actagainstaids](http://www.cdc.gov/actagainstaids)

<sup>a</sup> An HIV testing event is one or more HIV tests performed with a person to determine that person's HIV status. During one testing event, a person may be tested once or multiple times.



**HRSA**  
Ryan White & Global HIV/AIDS Programs

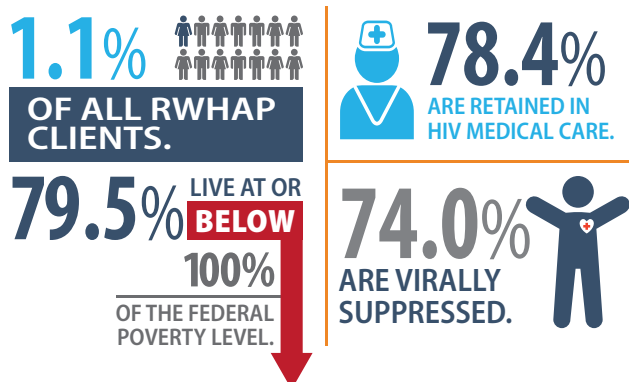
## Ryan White HIV/AIDS Program

May 2016



### TRANSGENDER CLIENTS, 2014

#### Ryan White HIV/AIDS Program Transgender Client Fast Facts



The Ryan White HIV/AIDS Program (RWHAP) works with cities, states, and local community-based organizations to provide HIV care and treatment services to an estimated 512,000 people (2014) who are uninsured or underinsured. RWHAP serves low-income and vulnerable populations of people living with HIV (PLWH). The majority of RWHAP funds support primary medical care and essential support services. A smaller but equally critical portion is used to fund technical assistance, clinical training, and research on innovative models of care.

A critical population served by RWHAP is transgender individuals. In 2014, approximately 1.1 percent of the more than half a million clients served by the Program were transgender. Below are more details about this RWHAP client population:

- ▶ **The majority of transgender clients served by RWHAP are racial and ethnic minorities.** Approximately 88 percent of transgender clients are from racial and ethnic minority populations. About 53 percent of transgender clients identify as black/African American, which is

greater than the national RWHAP average (47 percent). About 30 percent identify as Hispanic/Latino, which is also greater than the national RWHAP average (approximately 22 percent).

- ▶ **The RWHAP transgender client population continues to increase in age.** One in five RWHAP transgender clients is aged 50 and older. An additional 28 percent are aged 40 to 49 years old.
- ▶ **About 10 percent of transgender clients have unstable housing situations.** This is greater than the national RWHAP average (about 5 percent).
- ▶ **The majority of transgender clients are low income.** More than 79 percent of transgender clients served by RWHAP live at or below 100 percent of the federal poverty level. This is significantly greater than the national RWHAP average (64 percent).
- ▶ **Lack of health care coverage affects transgender clients served by RWHAP.** Approximately 27 percent of transgender clients have no health care coverage, which is greater than the national RWHAP average (about 25 percent).

Medical care and treatment improves health and decreases transmission of HIV. 78 percent of transgender clients receiving HIV medical care are retained in care, which is slightly less than the national RWHAP average (approximately 80 percent). 74 percent of transgender clients receiving HIV medical care are virally suppressed, which is significantly less than the national RWHAP average (81 percent).<sup>1</sup>

<sup>1</sup> Retention in care is based on data for PLWH who had at least one outpatient ambulatory medical care (OAMC) visit by September 1 of the measurement year, with a second visit at least 90 days later. Viral suppression is based on data for PLWH who had at least one OAMC visit and at least one viral load test during the measurement year and whose most recent viral load test result was less than 200 copies/mL.





**DRAFT****2016 Proposed Idea**

(Applicant must complete this two-page form as it is. Agency identifying information must be removed or the application will not be reviewed. Please read the attached documents before completing this form: 1.) HRSA HIV-Related Glossary of Service Categories to understand federal restrictions regarding each service category, 2.) Criteria for Reviewing New Ideas, and 3.) Criteria & Principles to Guide Decision Making.)

**THIS BOX TO BE COMPLETED BY RWPC SUPPORT STAFF ONLY**

# 2 Control Number Date Received 02/13/17  
 Proposal will be reviewed by the: Quality Assurance Committee on: 02/16/17 (date)  
 Priority & Allocation Committee on: 02/23/17 (date)

**THIS PAGE IS FOR THE QUALITY ASSURANCE COMMITTEE**

(See Glossary of HIV-Related Service Categories &amp; Criteria for Reviewing New Ideas)

1. SERVICE CATEGORY: Transportation (Medical Transportation)  
 (The service category must be one of the Ryan White Part A or B service categories as described in the HRSA Glossary of HIV-Related Service Categories.)  
 This will provide **unknown will need staff assist** \_\_\_\_\_ clients with \_\_\_\_\_ units of service.
2. ADDRESS THE FOLLOWING:
  - A. DESCRIPTION OF SERVICE: Cab Vouchers to access transportation for PLWHA with safety issues such as Trans-gender, Homeless, people experiencing domestic violence and others, as determined by case manager or Dr.
  - B. TARGET POPULATION (Race or ethnic group and/or geographic area): See above.
  - C. SERVICES TO BE PROVIDED (including goals and objectives): To eliminate barriers to accessing HIV core Medical Service providers in the EMA/HSDA. This services can only be used to travel to/from HIV medical services.
  - D. ANTICIPATED HEALTH OUTCOMES (Related to Knowledge, Attitudes, Practices, Health Data, Quality of Life, and Cost Effectiveness): Lack of transportation is the 5th most commonly-cited barrier among PLWHA Rank #2 w/in the 5 support services, most commonly-cited was lack of transportation (trans. study 2013) Transportation eliminates barriers to care, thereby supporting PLWHA in continuous care  
 Transportation supports linkage to care, Maintenance/retention in care, and viral suppression.

3. ATTACH DOCUMENTATION IN ORDER TO JUSTIFY THE NEED FOR THIS NEW IDEA. AND, DEMONSTRATE THE NEED IN AT LEAST ONE OF THE FOLLOWING PLANNING COUNCIL DOCUMENTS:

<input checked="" type="checkbox"/>	Current Needs Assessment (Year: <u>2016</u> )	Page(s): <sup>22-23</sup> Paragraph: <u>1/Tab1</u>
<input checked="" type="checkbox"/>	Current HIV Comprehensive Plan (Year: <u>2017</u> )	Page(s): <u>81</u> Paragraph: <u>1/Tab2</u>
<input checked="" type="checkbox"/>	Health Outcome Results: Date: <u>FY 2017 Serv. Cat. Info.</u>	Page(s): <u>1</u> Paragraph: <u>*</u>
<input checked="" type="checkbox"/>	Other Ryan White Planning Document: Name & Date of Document: <u>Transgender Study 2013</u>	Page(s): <u>6</u> Paragraph: <u>1&amp;2/tab3</u>

**RECOMMENDATION OF QUALITY ASSURANCE COMMITTEE:**

Recommended  Not Recommended  Sent to How To Best Meet Need

**REASON FOR RECOMMENDATION:**

(Continue on Page 2 of this application form)

**DRAFT****Proposed Idea**

**THIS PAGE IS FOR THE PRIORITY AND ALLOCATIONS COMMITTEE**  
 (See Criteria and Principles to Guide Decision Making)

THIS BOX TO BE COMPLETED BY RWPC SUPPORT STAFF ONLY AND INCLUDE A BRIEF HISTORY OF RELATED SERVICE CATEGORY, IF AVAILABLE.

CURRENTLY APPROVED RELATED SERVICE CATEGORY ALLOCATION/UTILIZATION:

Allocation: \$ 527,362

Expenditure: \$ 183,376 Year-to-Date as of 10/27/16

Utilization: 3,374 Unduplicated Clients Served Year-to-Date as of 06/08/16

N/A Units of Service Provided Year-to-Date

AMOUNT OF FUNDING REQUESTED:

\$ Unsure This will provide funding for the following purposes which will further the objectives in this service category: (describe how):

PLEASE STATE HOW THIS IDEA WILL MEET THE PRIORITY AND ALLOCATIONS CRITERIA AND PRINCIPLES TO GUIDE DECISION MAKING. SITE SPECIFIC STEPS AND ITEMS WITHIN THE STEPS:

Principles: A,C,D,

Criteria STEP 1: A,F

Criteria Step 2: D,E,F

RECOMMENDATION OF PRIORITY AND ALLOCATIONS COMMITTEE:

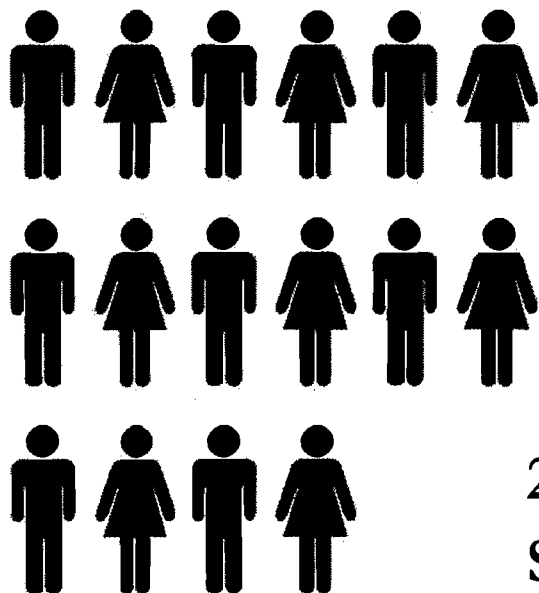
Recommended for Funding in the Amount of: \$ \_\_\_\_\_

Not Recommended for Funding

Other:

REASON FOR RECOMMENDATION:





## 2016 Houston HIV Care Services Needs Assessment

*A collaboration of:*

Houston Area HIV Services Ryan White Planning Council  
Houston HIV Prevention Community Planning Group  
Harris County Public Health, Ryan White Grant Administration  
Houston Health Department, Bureau of HIV/STD and Viral Hepatitis  
Prevention  
Houston Regional HIV/AIDS Resource Group, Inc.  
Harris Health System  
People Living with HIV in the Houston Area and Ryan White HIV/AIDS  
Program Consumers

Approved: December 8, 2016



## **Chapter 2: Service Needs and Barriers**

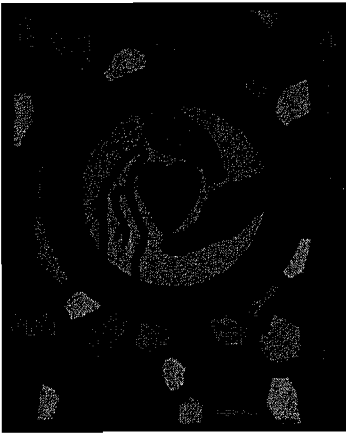
### Descriptions of Barriers Encountered

All funded services were reported to have barriers, with an average of 33 reports of barriers per service. Participants reported the least barriers for Hospice (two barriers) and the most barriers for Oral Health Care (86 barriers). In total, 525 reports of barriers across all services were indicated in the sample.

**(Table 1)** Within education and awareness, knowledge of the availability of the service and where to go to access the service accounted for 82% barriers reported. Being put on a waitlist accounted for a majority (66%) of wait-related issues barriers. Poor communication and/or follow up from staff members when contacting participants comprised a majority (51%) of barriers related to staff interactions. Almost all (86%) of eligibility barriers related to participants being told they did not meet eligibility requirements to receive the service or difficulty obtaining the required documentation to establish eligibility. Among administrative issues, long or complex processes required to obtain services sufficient to create a burden to access comprised most (59%) the barriers reported.

Most (84%) of health insurance-related barriers occurred because the participant was uninsured or underinsured and experiencing coverage gaps for needed services or medications. The largest proportion (81%) of transportation-related barriers occurred when participants had no access to transportation. It is notable that multiple participants reported losing bus cards and the difficulty of replacing the cards presented a barrier to accessing other services. Inability to afford the service accounted for all barriers relating to participant financial resources. The service being offered at a distance that was inaccessible to participants or being recently released from incarceration accounted for most (77%) of accessibility-related barriers, though it is worth note that low or no literacy accounted for 14% of accessibility-related barriers. Receiving resources that were insufficient to meet participant needs accounted for most resource availability barriers. Homelessness accounted for virtually all housing-related barriers. Instances in which the participant's employer did not provide sufficient sick/wellness leave for attend appointments comprised most (60%) employment-related barriers.

TABLE 1-Barrier Proportions within Each Barrier Type, 2016					
Education & Awareness	%	Wait-Related Issues	%	Interactions with Staff	%
<b>Availability</b> (Didn't know the service was available)	50%	<b>Waitlist</b> (Put on a waitlist)	66%	<b>Communication</b> (Poor correspondence/ Follow up from staff)	51%
<b>Definition</b> (Didn't know what service entails)	7%	<b>Unavailable</b> (Waitlist full/not available resulting in client not being placed on waitlist)	15%	<b>Poor Treatment</b> (Staff insensitive to clients)	17%
<b>Location</b> (Didn't know where to go [location or location w/in agency])	32%	<b>Wait at Appointment</b> (Appointment visits take long)	7%	<b>Resistance</b> (Staff refusal/ resistance to assist clients)	13%
<b>Contact</b> (Didn't know who to contact for service)	11%	<b>Approval</b> (Long durations between application and approval)	12%	<b>Staff Knowledge</b> (Staff has no/ limited knowledge of service)	7%
				<b>Referral</b> (Received service referral to provider that did not meet client needs)	17%
Eligibility	%	Administrative Issues	%	Health Insurance	%
<b>Ineligible</b> (Did not meet eligibility requirements)	48%	<b>Staff Changes</b> (Change in staff w/o notice)	12%	<b>Uninsured</b> (Client has no insurance)	53%
<b>Eligibility Process</b> (Redundant process for renewing eligibility)	16%	<b>Understaffing</b> (Shortage of staff)	2%	<b>Coverage Gaps</b> (Certain services/medications not covered)	31%
<b>Documentation</b> (Problems obtaining documentation needed for eligibility)	38%	<b>Service Change</b> (Change in service w/o notice)	10%	<b>Locating Provider</b> (Difficulty locating provider that takes insurance)	13%
		<b>Complex Process</b> (Burden of long complex process for accessing services)	59%	<b>ACA</b> (Problems with ACA enrollment process)	17%
		<b>Dismissal</b> (Client dismissal from agency)	4%		
		<b>Hours</b> (Problem with agency hours of operation)	16%		
Transportation	%	Financial	%	Accessibility	%
<b>No Transportation</b> (No or limited transportation options)	81%	<b>Financial Resources</b> (Could not afford service)	100%	<b>Literacy</b> (Cannot read/difficulty reading)	14%
<b>Providers</b> (Problems with special transportation providers such as Metrolift or Medicaid transportation)	19%			<b>Spanish Services</b> (Services not made available in Spanish)	9%
				<b>Released from Incarceration</b> (Restricted from services due to probation, parole, or felon status)	32%
				<b>Distance</b> (Service not offered within accessible distance)	45%
Resource Availability	%	Housing	%	Employment	%
<b>Insufficient</b> (Resources offered insufficient for meeting need)	56%	<b>Homeless</b> (Client is without stable housing)	100%	<b>Unemployed</b> (Client is unemployed)	40%
<b>Quality</b> (Resource quality was poor)	44%	<b>IPV</b> (Interpersonal domestic issues make housing situation unsafe)	0%	<b>Leave</b> (Employer does not provide sick/wellness leave for appointments)	60%



**Houston Area Comprehensive  
HIV Prevention and Care  
Services Plan  
2017 - 2021**

*Capturing the community's vision for an ideal system of  
HIV prevention and care for the Houston Area*

monthly household income of at least \$6,000 or greater (n=349, 43.8%), and even more participants reported living in a house or apartment paid for by self (n=635, 79.7%).

Transportation has consistently been a known limitation to fluid mobility within the Houston Area given its significant geographic spread and limited public transportation system, often creating a barrier to accessing HIV care because of the difficulties in navigating this distance. For the sample population, the majority reported owning a vehicle (n=487, 61.1%) while 236 respondents reported relying on public transportation (29.6%). However, 12 participants in the sample reported having no transportation available to them (1.5%) (**Table 2**).

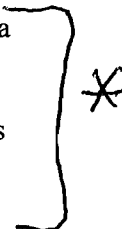


Table 2: Demographics of Needs Assessment Participants (N=797)

Description	No. (%)	Description	No. (%)
<b>Birth sex</b>		<b>Employment status</b>	
Male	498 (62.5%)	Full-time employment	302 (37.9%)
Female	245 (30.7%)	Part-time employment	192 (24.1%)
Intersex	13 (1.6%)	Temporary, contractual, or other work	162 (20.3%)
No response	41 (5.1%)	Student	26 (3.3%)
<b>Race/Ethnicity</b>		Retired	18 (2.3%)
Black or African American	396 (49.7%)	Disabled	48 (6.0%)
Hispanic	267 (33.5%)	Unemployed	16 (2.0%)
White	57 (7.2%)	No response	33 (4.1%)
Other/Multiracial	77 (9.7%)	<b>Household monthly income</b>	
<b>Age Group</b>		< \$1000	34 (4.3%)
<18	8 (1.0%)	\$1000-\$1999	15 (1.9%)
18-24	188 (23.6%)	\$2000-\$2999	72 (9.0%)
25-34	175 (22.0%)	\$3000-\$3999	89 (11.2%)
35-44	240 (30.1%)	\$4000-\$4999	45 (5.6%)
45-54	110 (13.8%)	\$5000-\$5999	135 (16.9%)
55+	76 (9.5%)	\$6000+	349 (43.8%)
<b>Education</b>		No response	58 (7.3%)
Post-secondary degree	437 (54.8%)	<b>Housing status</b>	
Technical/vocational degree	44 (5.5%)	House/apartment paid by self	635 (79.7%)
High school diploma	188 (23.6%)	House/apartment paid by other	87 (10.9%)
GED	63 (7.9%)	Subsidized housing	38 (4.8%)
Less than high school	59 (7.4%)	Stay with others	12 (1.5%)
No response	6 (0.8%)	No response	25 (3.1%)
<b>Health Insurance</b>		<b>Transportation</b>	
Private insurance	199 (25.0%)	Own vehicle	487 (61.1%)
Medicaid/Medicare	112 (14.1%)	Public transportation	236 (29.6%)
Harris Health System	60 (7.5%)	No transportation	12 (1.5%)
COBRA	67 (8.4%)	No response	62 (7.8%)
VA	11 (1.4%)		
Ryan White only	38 (4.8%)		
Self-pay	178 (22.3%)		
No response	340 (42.7%)		

Source: 2016 Houston HIV Prevention Services Needs Assessment

Of the total sample population, 493 identified as a man in their current gender identity or expression, with about 253 reporting woman and 5 reporting part-time as man and part-time as woman. Forty-six participants provided no response, total, for current gender identities or expression. About 473 participants reported a birth sex of male and a current gender identity of man (59.3%). Of those with a current gender identity or expression of man, 350 persons reported a sexual orientation of gay (43.9%), with the next highest percentage identifying as straight/heterosexual (n=121, 15.2%) followed by bisexual (n=20, 2.5%) and pansexual (n=1,

FY2017 Service Category Information Summary – Part A, MAI, Part B, SS

Last Updated: 2/13/17

Service	Allocation	Utilization	Outcomes	Needs Assessment	National, State, and Local Priorities																					
<b>Transportation (Untargeted &amp; Rural) (Van &amp; Bus Pass)</b>	<b>Part A:</b> FY98: \$488,405 FY99: \$580,909 FY00: \$838,460 FY01: \$912,947 FY02: \$1,015,666 FY03: \$945,743 FY04: \$598,816 FY05: \$570,000 FY06: \$570,000 FY07: \$512,000 FY08: \$654,539  <b>Part A/B:</b> FY09: \$654,539 FY10: \$595,366  <b>Part A:</b> FY11: \$625,366 FY12: \$543,459 FY13: \$543,459 FY14: \$527,361 FY15: \$527,362 FY16: \$527,362  Source: PROPOSED FY 2016 Allocations - Level Funding Scenario Based upon FY16 Actual Awards - as of 06/24/15	<table border="1"> <thead> <tr> <th></th> <th>CY10</th> <th>CY11</th> <th>CY12</th> <th>CY13</th> <th>CY14</th> <th>CY15</th> </tr> </thead> <tbody> <tr> <td>Van Based</td> <td>598</td> <td>394</td> <td>322</td> <td>478</td> <td>611</td> <td>754</td> </tr> <tr> <td>Bus Pass</td> <td>1,725</td> <td>2,406</td> <td>2,263</td> <td>2,628</td> <td>2,592</td> <td>2,342</td> </tr> </tbody> </table> <p>Source: RWGA and The Resource Group, 4/25/16</p>		CY10	CY11	CY12	CY13	CY14	CY15	Van Based	598	394	322	478	611	754	Bus Pass	1,725	2,406	2,263	2,628	2,592	2,342	<b>Van Based:</b> <ul style="list-style-type: none"> <li>Following van based transportation services:                             <ul style="list-style-type: none"> <li>69% of clients accessed HIV primary care at least once;</li> <li>72% accessed LPAP at least once; and</li> <li>74% accessed oral health services at least once.</li> </ul> </li> </ul> <b>Bus Pass:</b> <ul style="list-style-type: none"> <li>Following bus pass transportation services:                             <ul style="list-style-type: none"> <li>77% of clients accessed a RW service of some kind at least once;</li> <li>36% accessed HIV primary care at least once;</li> <li>20% accessed LPAP at least once; and</li> <li>25% accessed oral health services at least once.</li> </ul> </li> </ul> <p>Source: RWGA FY 2013 Final Year Outcomes Reports</p>	<b>Needs Assessment Rankings:<sup>a</sup></b> Transportation was defined as "Transportation to/from your HIV medical appointments on a van or with a Metro bus card" in the 2014 Needs Assessment. Results as defined are below: <ul style="list-style-type: none"> <li>55% of respondents reported a need for Transportation services, tying this service with Housing as the 5<sup>th</sup> highest ranked need.</li> <li>The most common barrier reported for Transportation Services was lack of transportation (18% of all reported barriers to this service).*</li> <li>Males, African American PLWHA, and PLWHA age 45+ reported the least difficulty accessing Transportation services</li> <li>Homeless PLWHA, out-of-care, and recently released had the most difficulty accessing Transportation services.</li> </ul> <p>*Anecdotally, the initial transportation gap in accessing Transportation services, and the ongoing gap of refilling bus cards was noticed during data collection for the 2011 and 2014 Needs Assessments, and the IRR and Transgender special studies. However, this particular issue has not been formally measured.</p> <p>Source: 2014 Houston Area HIV/AIDS Needs Assessment. Located at: <a href="http://www.rwpc-houston.org/Publications/2014%20Needs%20Assessment%20-%20FINAL%203-13-14.pdf">http://www.rwpc-houston.org/Publications/2014%20Needs%20Assessment%20-%20FINAL%203-13-14.pdf</a></p>	This service aligns with the following goals: <b>National HIV/AIDS Strategy (NHAS) Updated for 2020 (2015)</b> <ul style="list-style-type: none"> <li>Increase the percentage of persons with diagnosed HIV infection who are retained in HIV medical care to at least 90%.</li> <li>Increase the percentage of persons with diagnosed HIV infection who are virally suppressed to at least 80%.</li> </ul> <b>The Continuum of Care</b> <ul style="list-style-type: none"> <li>Increase the percentage of those aware of their HIV+ status retained in HIV care</li> <li>Increase the percentage of those aware of their HIV+ status with a suppressed viral load</li> </ul> <b>The Texas HIV Plan Update for 2014-2015 (2013)</b> <ul style="list-style-type: none"> <li>Ensure continuous participation in systems of care and treatment</li> <li>Increase viral suppression</li> </ul> <b>Comprehensive HIV Plan (2012-2014):</b> <ul style="list-style-type: none"> <li>Increase the percent of RW clients in continuous HIV care to 80%</li> <li>Reduce the proportion of diagnosed individuals who are not in HIV care by 0.8% each year</li> <li>Increase the proportion of RW clients with UVL by 10%</li> </ul> <b>Recommendations from the SIRR Study:</b> <ul style="list-style-type: none"> <li>Distribute bus passes through EIS at discharge for use as transportation to a community-based HIV care provider.</li> </ul> <b>Recommendations from the Transgender Special Study:</b> <ul style="list-style-type: none"> <li>Lack of transportation was cited most often (44%) by transgender consumers as a barrier to HIV care. It is recommended that the workgroup explore ways to reduce transportation barriers for this Special Population.</li> </ul>
		CY10	CY11	CY12	CY13	CY14	CY15																			
Van Based	598	394	322	478	611	754																				
Bus Pass	1,725	2,406	2,263	2,628	2,592	2,342																				



# **Access to HIV Care among Transgender and Gender Non-Conforming People in Houston**

A Special Study of the Houston Area Ryan White Planning Council  
Approved March 14, 2013

## BACKGROUND

The Houston Area Ryan White Planning Council is responsible for designing HIV care, treatment, and support services for people living with HIV/AIDS in the Houston Eligible Metropolitan Area (EMA). The Planning Council uses several sources of information in order to meet this mandate, including epidemiological profiles, service-utilization reports, and a community-wide needs assessment of HIV-positive individuals conducted every three years. When specific populations are underrepresented in current data sources, the Planning Council may also commission a special data collection effort, or *Special Study*, to fill data gaps.

In 2012, the Planning Council released its comprehensive HIV prevention and care services plan for the Houston Area. In it are the specific HIV-infected populations in the Houston EMA with insufficient data for assessing their current level of access to HIV services. In response, the Planning Council commissioned a series of Special Studies to gather data on each underrepresented group. This article presents the results of the Planning Council's first Special Study in the series, focused on transgender and gender non-conforming people living with HIV/AIDS in the Houston EMA.

## INTRODUCTION

Transgender individuals are among the highest risk for HIV infection in the U.S. today.<sup>1</sup> Moreover, the challenges often faced by transgender individuals in regards to discrimination, stigma, lack of resources, and other social determinants can make it difficult for them to access HIV services.<sup>1</sup> One study of transgender people living with HIV/AIDS showed a statistically lower rate of HIV treatment when compared to nontransgender people.<sup>2</sup> For these reasons and others, transgender communities are a high priority for HIV prevention, linkage, and retention in care efforts both nationally and in the Houston EMA.<sup>3</sup>

However, relatively little is known about the specific needs, gaps, and barriers to HIV care among transgender people in the Houston EMA. Transgender individuals are less than 1% of all Ryan White HIV/AIDS Program clients in the EMA,<sup>4</sup> and only 22 transgender-identified individuals participated in the EMA's most recent community-wide needs assessment of people living with HIV/AIDS.<sup>5</sup> This Special Study sought to describe the HIV service utilization patterns of transgender people living with HIV/AIDS in the Houston EMA, including socio-economic or behavioral factors that may be influencing their use of services, and to establish baselines for core HIV prevention and care indicators, including linkage to care and unmet need.

## METHODS

Participants were self-selected, self-identified transgender HIV-positive adult residents of the Houston EMA. Because many individuals may not identify with the term "transgender," inclusion screening questions used the broader terminology of "transgender or gender non-conforming" and offered both a definition of the term and examples along a broad continuum of gender expression. The text for the transgender inclusion screening question for the study was:<sup>6</sup>

**"Do you consider yourself to be transgender or gender non-conforming in any way?"**

Transgender/gender non-conforming refers to people whose gender identity or expression is different, at least part of the time, from the sex assigned to them at birth

## RESULTS

### HIV Testing, Diagnosis, and Linkage to Care

The first topic we wanted to address through this study was what motivates transgender people in the Houston EMA to test for HIV and where they test. In our sample, the most commonly-cited reason for testing was feeling sick (25%), followed by receiving an HIV test as part of a routine health check-up (21%). Three percent (3%) of the time the reason for testing was the recommendation of a medical provider, and another 3% was in response to community advertising. The most common location for HIV testing was a dedicated HIV clinic (34%), followed by an ER or hospital (17%). Thirteen percent (13%) said they were tested at a health department, and 9% were tested in jail or prison.

Because treatment for HIV can extend life expectancy and quality of life for those infected, length of time for linkage to care post-diagnosis and current care status are used as indicators of community health related to HIV both nationally and locally.<sup>3,9</sup> At the time of this study, baselines were missing for both of these measures for the transgender population in the Houston EMA. Therefore, the next topics we sought to address in the study were linkage to care and patterns of care. We asked respondents when they first saw a doctor for HIV following their diagnosis (either within three months or more than three months, per the federal benchmark<sup>9</sup>) and if they were currently meeting the national definition of being in care, which is defined as completing at least one of the following in the last 12 months: (1) seen a doctor for HIV, (2) taken HIV medications, (3) had an HIV viral load test, or (4) had a CD4 count test.<sup>10</sup>

(See Table 2) The majority of the transgender people in this study was linked to care within three months of their HIV diagnosis (76%). This percentage is comparable to current estimates for the Houston EMA as a whole (77%),<sup>11</sup> though lower than both local and national goals.<sup>3,9</sup> For those in the sample who did report delayed care, the most commonly-cited reason was denial about being HIV-positive (80%). However, 16% of the time the reasons were lack of knowledge about where to go for HIV services, fear about how the medical staff would react to their gender variance, and fear about how other clients would react. Twelve percent (12%) of the time the reason for delayed care was having to disclose their gender variant status to providers and staff.

**TABLE 2-Linkage to Care among Participating Transgender People Who Are HIV Positive (n=133) Compared to the General HIV-Positive Population in the Houston Area and Local and National Goals**

	Transgender Participants	General HIV+ Population <sup>a</sup>	Goal <sup>b</sup>
Linked to HIV Care within 3 Months of Diagnosis	75.9%	77.4%	85.0%

<sup>a</sup>Texas Department of State Health Services, 8/20/12

<sup>b</sup>National HIV/AIDS Strategy for the United States (July 2010); Houston Area Comprehensive HIV Prevention and Care Services Plan (2012 – 2014)

The majority of the people in this study was also currently in care (97%). This percentage far exceeds estimates for the general HIV-positive population in the Houston EMA (75%).<sup>12</sup> This is most likely a bias in our sample, rather than a true unmet need result, due to study recruitment taking place at HIV clinics and HIV group homes. Therefore, no additional analysis was performed on this data point.

### HIV Care Service Utilization, Barriers to Care, and Service Needs

(See Table 3) Another topic we wanted to explore in this study was the use of specific HIV care, treatment, and support services by transgender people in the Houston EMA. To do this, we

**TABLE 3-HIV Care Services Used and Barriers Reported by Participating Transgender People Who Are HIV Positive (n=132) in the Houston Area**

Service Category (in order)	Reporting Use of Service # (%)	Service Category (in order)	Reporting Barrier to Use # (%)
Primary HIV care	113 (85.6)	Oral health care	28 (21.2)
* Transportation	76 (57.6)	Primary HIV care	23 (17.4)
Case management	64 (48.5)	Case management	23 (17.4)
Oral health care	60 (45.5)	Transportation	18 (13.6) *
Mental health counseling	59 (44.7)	Medical nutritional therapy	15 (11.4)
Medical nutritional therapy	51 (38.6)	Mental health counseling	13 (9.8)
HIV medication assistance	46 (34.8)	Legal services	8 (6.1)
Substance abuse treatment	28 (21.2)	Health insurance assistance	7 (5.3)
Health insurance assistance	25 (18.9)	Hospice care	7 (5.3)
Legal services	21 (15.9)	HIV medication assistance	6 (4.5)
Day treatment	19 (14.4)	Day treatment	6 (4.5)
Language services	14 (10.6)	Substance abuse treatment	4 (3.0)
Hospice care	9 (6.8)	Language services	4 (3.0)

asked each respondent if, in the past 12 months, they had used each of the services that the Planning Council had prioritized for funding through the Ryan White HIV/AIDS Program and if they had experienced any difficulties accessing each of the services, regardless of recent use. Primary HIV care (86%), transportation (58%), and clinic-based case management (49%) were the most used services in past 12 months. The services cited most often as having difficulties to access were oral health care (21%), primary HIV care (17%), and clinic-based case management (17%). These findings are consistent with the general population of HIV-positive people in the Houston EMA.<sup>13</sup> \*

(See Table 4) Specific barriers faced by this population when seeking HIV services were also explored. When asked what barriers, if any, respondents had faced at any time since their diagnosis, the most commonly-cited was lack of transportation (44%). Also high on the list was being treated poorly by staff due to gender variance (29%), lack of funds to pay for services (28%), and denial about being HIV-positive (24%). In addition, 19% of respondents reported lack of provider familiarity with transgender needs as a barrier to care. Twenty-two percent (22%) reported no barriers. When compared to

**TABLE 4-Most Commonly-Cited Specific Barriers to HIV Care Reported by Participating Transgender People Who Are HIV Positive (n=105) Compared to the General HIV-Positive Population in the Houston Area**

Specific Barrier Experienced (in order)	# (%) Reporting	Rank among General HIV+ Population <sup>a</sup>
No transportation	46 (43.8)	6 *
Treated poorly by staff due to being transgender	30 (28.6)	--
No money, the services cost too much	29 (27.6)	11
Fear or denial about being HIV-positive	25 (23.8)	14
Wait times for services were too long	20 (19.0)	3
Hard to get an appointment for HIV services	20 (19.0)	5
Providers are not familiar with transgender needs	20 (19.0)	--
A problem with drugs or alcohol	18 (17.1)	--
Lack of housing	18 (17.1)	--
Felt fine, not sick, "didn't think I needed HIV care"	16 (15.2)	--
HIV care a low priority	16 (15.2)	--
No Barriers Experienced	30 (22.2)	--

<sup>a</sup>2011 Houston Area HIV/AIDS Needs Assessment, April 2011 (n=924). Ranking is for core and support services combined; no distinction between type of service was made in our study.

## Priority and Allocations

### FY 2017 Guiding Principles and Decision Making Criteria

(Priority and Allocations Committee approved 02-25-16)

Priority setting and allocations must be based on clearly stated and consistently applied principles and criteria. These principles are the basic ideals for action and are based on Health Resources and Services Administration (HRSA) and Department of State Health Services (DSHS) directives. All committee decisions will be made with the understanding that **the Ryan White Program is unable to completely meet all identified needs** and following legislative mandate **the Ryan White Program will be considered funding of last resort**. Priorities are just one of many factors which help determine allocations. All Part A and Part B service categories are considered to be important in the care of people living with HIV/AIDS. Decisions will address at least one or more of the following principles and criteria.

*Principles are the standards guiding the discussion of all service categories to be prioritized and to which resources are to be allocated. Documentation of these guiding principles in the form of printed materials such as needs assessments, focus group results, surveys, public reports, journals, legal documents, etc. will be used in highlighting and describing service categories (individual agencies are not to be considered). Therefore decisions will be based on service categories that address the following principles, in no particular order:*

#### Principles

- A. Ensuring ongoing client access to a comprehensive system of core services as defined by HRSA
- B. Eliminating barriers to core services among affected sub-populations (racial, ethnic and behavioral) and low income, unserved, underserved and severe need populations (rural and urban)
- C. Meeting the needs of diverse populations as addressed by the epidemiology of HIV
- D. Identify individuals unaware of their status and link them to care and address the needs of those that are aware of their status and not in care.
- E. Expressing the needs of the communities with HIV for whom the services are intended

#### Allocations only

- F. Documented or demonstrated cost-effectiveness of services and minimization of duplication
- G. Availability of other government and non-governmental resources, including Medicaid, Medicare, CHIP, private insurance and Affordable Care Act related insurance options, local foundations and non-governmental social service agencies

*Criteria are the standards on which the committee's decisions will be based. Positive decisions will only be made on service categories that satisfy at least one of the criteria in Step 1 and all criteria in Step 2. Satisfaction will be measured by printed information that address service categories such as needs assessments, focus group results, surveys, reports, public reports, journals, legal documents, etc.*

(Continued)

**DECISION MAKING CRITERIA STEP 1:**

- A. Documented service need with consumer perspectives as a primary consideration
- B. Documented effectiveness of services with a high level of benefit to people and families living with HIV infection, including quality, cost, and outcome measures when applicable
- C. Documented response to the epidemiology of HIV/AIDS in the EMA and HSDA
- D. Documented response to emerging needs reflecting the changing local epidemiology of HIV/AIDS while maintaining services to those who have relied upon Ryan White funded services.
- E. When allocating unspent and carryover funds, services are of documented sustainability across fiscal years in order to avoid a disruption/discontinuation of services
- F. Documented consistency with the current Houston Area Comprehensive HIV Prevention and Care Services Plan and the Continuum of Care and their underlying principles to the extent allowable under the Ryan White Program: to build public support for HIV services; to inform people of their serostatus and, if they test positive, get them into care; to help people maintain their negative status; to help people with HIV improve their health status and quality of life and prevent the progression to AIDS; to help reduce the risk of transmission; and to help people with AIDS improve their health status and quality of life and, if necessary, support the conditions that will allow for death with dignity

**DECISION MAKING CRITERIA STEP 2:**

- A. Services are effective with a high level of benefit to people and families living with HIV, including cost and outcome measures when applicable
- B. Services are accessible to all populations infected, affected, or at risk, allowing for differences in need between urban, suburban, and rural consumers as applicable under Part A and B guidelines
- C. The Council will minimize duplication of both service provision and administration and services will be coordinated with other systems, including but not limited to HIV prevention, substance use, mental health, and Sexually Transmitted Infections (STIs).
- D. Services emphasize access to and use of primary medical and other essential HRSA defined core services
- E. Services are appropriate for different cultural and socioeconomic populations, as well as care needs
- F. Services are available to meet the needs of all people and families living with or at risk for HIV infection as applicable under Part A and B guidelines
- G. Services meet or exceed standards of care
- H. Services reflect latest medical advances, when appropriate
- I. Services meet a documented need that is not fully supported through other funding streams

**PRIORITY SETTING AND ALLOCATIONS ARE SEPARATE DECISIONS.  
All decisions are expected to address needs of the overall community affected by the epidemic.**



**2016 Houston HIV Care  
Services Needs Assessment:  
Profile of Transgender and Gender  
Non-conforming Individuals**

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## PROFILE OF TRANSGENDER AND GENDER NON-CONFORMING INDIVIDUALS

A persistent challenge to designing HIV prevention and care services that meet the needs of all Houston area people living with HIV (**PLWH**) is the lack of epidemiological and surveillance data that accurately reflect the burden of HIV among transgender and gender non-conforming PLWH. A 2013 meta-analysis indicated a heavily disproportionate HIV burden among transgender women in the United States, estimating that 21.7% (1 in 5) of transgender women are living with HIV (Baral, et al., 2013). While included in most state and national surveillance datasets, transgender women living with HIV are categorized as male and men who have sex with men (**MSM**) by sex at birth and risk factor. Transgender MSM are often categorized as female with heterosexual risk factor. Gender non-conforming or non-binary individuals are included, but are only represented by sex at birth, not current gender identity. Data about service needs and barriers transgender and gender non-conforming PLWH in the Houston area encounter is of particular importance to local HIV planning as this information equips communities to provide prevention and care services that meet the unique needs of disproportionately affected gender minority groups.

Proactive efforts were made to gather a representative sample of all PLWH in the 2016 Houston HIV Care Services Needs Assessment as well as focus targeted

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## DEMOGRAPHICS AND SOCIO-ECONOMIC CHARACTERISTICS

(**Table 1**) In total, 20 participants in the 2016 Houston HIV Care Services Needs Assessment were identified as transgender or gender non-conforming, comprising 4% of the total sample.

All transgender and gender non-conforming participants were residing in Houston/Harris County at the time of data collection. Like the total sample of needs assessment participants, the majority of transgender and gender non-conforming participants were male at birth (90%) African American/Black (60%), between the ages of 25 and 49 (55%), resided in Harris County (100%), and were born in the U.S. (90%). Most transgender and gender non-conforming participants were categorized as transitioning or having transitioned from Male to Female (**MTF**) (50%) or were non-binary (40%). No transgender and gender non-conforming participants reported being out of

sampling among key populations (See: *Methodology*, full document), and results presented throughout the full document include participants who were transgender or gender non-conforming. This Profile highlights results *only* for participants who were transgender or gender non-conforming, as well as comparisons to the entire needs assessment sample.

*Notes:* “Transgender” and “gender non-conforming” are defined in this analysis as PLWH who indicated having a primary gender identity or gender expression at the time of survey that differed from the participant’s reported sex they were assigned at birth, including an option for “intersex”. As such, participants who self-identify as transgender or gender non-conforming but who did not meet this analysis criterion may be excluded. Care should be taken in applying the results presented in this profile to the Houston area transgender and gender non-conforming PLWH population as a whole due to small sample size. Data presented in this in the Demographics and Socio-Economic Characteristics section of this Profile represent the *actual* survey sample, rather than the *weighted* sample presented throughout the remainder of the Profile (See: *Methodology*, full document). Proportions are not calculated with a denominator of the total number of surveys for every variable due to missing or “check-all” responses.

care, and the majority had public health insurance coverage through Medicaid or Medicare. Compared to all needs assessment participants, greater proportions of transgender and gender non-conforming participants identified as gay or lesbian (60% v. 34%). Transgender and gender non-conforming participants also displayed wider variety in sexual orientation with “other” or write-in responses (25% vs. 5%), including pansexual, undecided, “transsexual”, and “demi-gray asexual”. Though representing a very small overall number, the proportion of participants recently released from incarceration was 85% higher among transgender and gender non-conforming participants was greater than among the total sample (15% vs 8%). Several socio-economic characteristics of transgender and gender non-conforming participants were also different from the total sample. The average annual



income among transgender and gender non-conforming participants who reported income was just over two-thirds the amount the total sample reported, or 71 cents per dollar (\$6,688 vs. \$9,380). A greater proportion of transgender and gender non-conforming participants reported experiencing current housing instability compared to the total sample (70% v. 28%; *not shown*).

Characteristics of transgender and gender non-conforming participants (as compared to all participants in general) can be summarized as follows:

- Residing in Houston/Harris County
- Male at birth
- MTF or non-binary at time of survey
- African American/Black
- Adults between the ages of 25 and 49
- Self-identified as gay or lesbian
- With higher occurrences of recent release from incarceration, lower average annual income, and a greater proportion unstably housed.

**TABLE 1-Select Characteristics among Transgender and Gender Non-Conforming Participants, Houston Area HIV Needs Assessment, 2016**

		TG / GN	Total			TG / GN	Total			TG / GN	Total
No.		%	%	No.		%	%	No.		%	%
<b>County of residence</b>				<b>Age range (median: 35-49)</b>				<b>Sex at birth</b>			
Harris	20	100%	93.4%	13 to 17	0	-	0.2%	Male	18	90.0%	67.3%
Fort Bend	0	-	4.2%	18 to 24	1	5.0%	3.4%	Female	2	10.0%	37.7%
Liberty	0	-	0.2%	25 to 49	11	55.0%	43.2%	Intersex	0	-	-
Montgomery	0	-	1.2%	50 to 54	2	10.0%	24.3%	MTF	10	50.0%	-
Other	0	-	1.0%	55 to 64	4	20.0%	26.2%	FTM	2	10.0%	-
				≥65	2	10.0%	2.8%	Other	8	40.0%	-
				Seniors (≥50)	8	40.0%	53.3%	Currently pregnant	0	-	0.2%
<b>Primary race/ethnicity</b>				<b>Sexual orientation (self-reported)</b>				<b>Health insurance (multiple response)</b>			
White	1	5.0%	11.80%	Heterosexual	2	10.0%	54.0%	Private insurance	4	14.3%	8.6%
African American/Black	12	60.0%	62.7%	Gay/Lesbian	12	60.0%	33.7%	Medicaid/Medicare	14	50.0%	49.8%
Hispanic/Latino	7	35%	23.9%	Bisexual	1	5.0%	7.7%	Harris Health System	6	21.4%	23.7%
Asian American	0	-	1.00%	Other	5	25.0%	4.5%	Ryan White Only	4	14.3%	17.0%
Other/Multiracial	0	-	0.6%					None	0	-	1.0%
<b>Immigration status</b>				<b>Yearly income (average: \$6,688)</b>							
Born in the U.S.	18	90.0%	84.6%	<b>Federal Poverty Level (FPL)</b>							
Citizen > 5 years	0	-	6.5%	Below 100%	9	45.0%	78.80%				
Citizen < 5 years	0	-	0.8%	100%	3	15.0%	12.70%				
Undocumented	0	-	2.0%	150%	0	-	3.70%				
Prefer not to answer	2	10.0%	4.4%	200%	0	-	2.80%				
Other	0	-	1.8%	250%	0	-	0.60%				
				≥300%	0	-	1.40%				

## BARRIERS TO RETENTION IN CARE

As in the methodology for all needs assessment participants, results presented in the remaining sections of this Profile were statistically weighted using current HIV prevalence for the Houston EMA (2014) in order to produce proportional results (See: *Methodology*, full document).

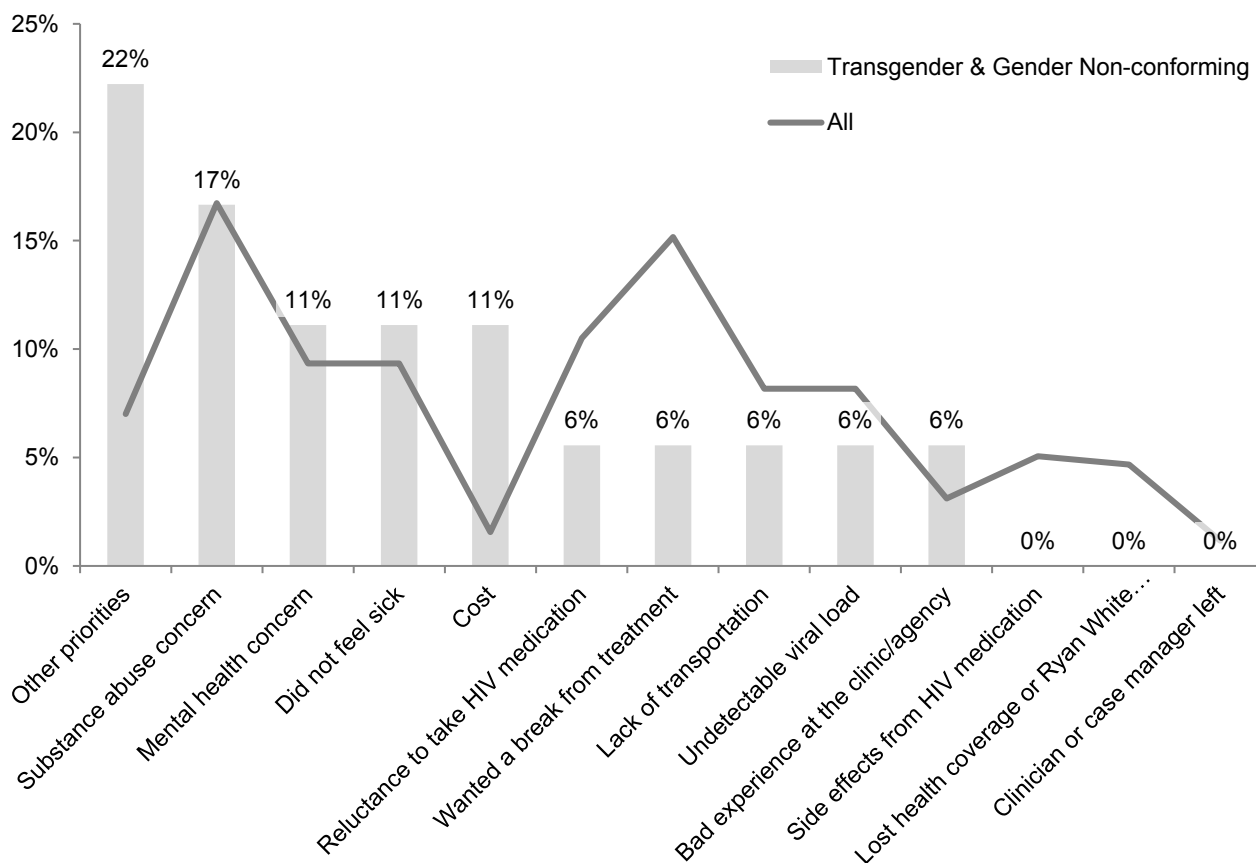
While 71% of all needs assessment participants needs assessment participants reported no interruption in their HIV care for 12 months or more since their diagnosis, only 59% of transgender and gender non-conforming participants reported no interruption in care. Those who reported a break in HIV care for 12 months or more since first entering care were asked to identify the reasons for falling out of care. Thirteen commonly reported reasons were included as options in the consumer survey, and participants could select

multiple reasons. Participants could also write-in their reasons.

(**Graph 1**) Among transgender and gender non-conforming participants, having other priorities at the time was cited most often as the reason for interruption in HIV medical care at 22% of reported reasons, followed by experience substance abuse or mental health concerns (17% and 11%, respectively), not feeling sick (11%), and difficulty paying for medical care (11%). The greatest differences between transgender and gender non-conforming participants and the total sample were in the proportions of reports of having other priorities at the time (22% vs. 7%), difficulty paying for medical care (11% vs. 2%), and wanting to take a break from treatment (6% to 15%). There were no write-in responses for this question.

**GRAPH 1-Reasons for Falling Out of HIV Care among Transgender and Gender Non-conforming PLWH in the Houston Area, 2016**

*Definition: Percent of times each item was reported by transgender and gender non-conforming needs assessment participants as the reason they stopped their HIV care for 12 months or more since first entering care.*



**OVERALL RANKING OF FUNDED SERVICES, BY NEED**

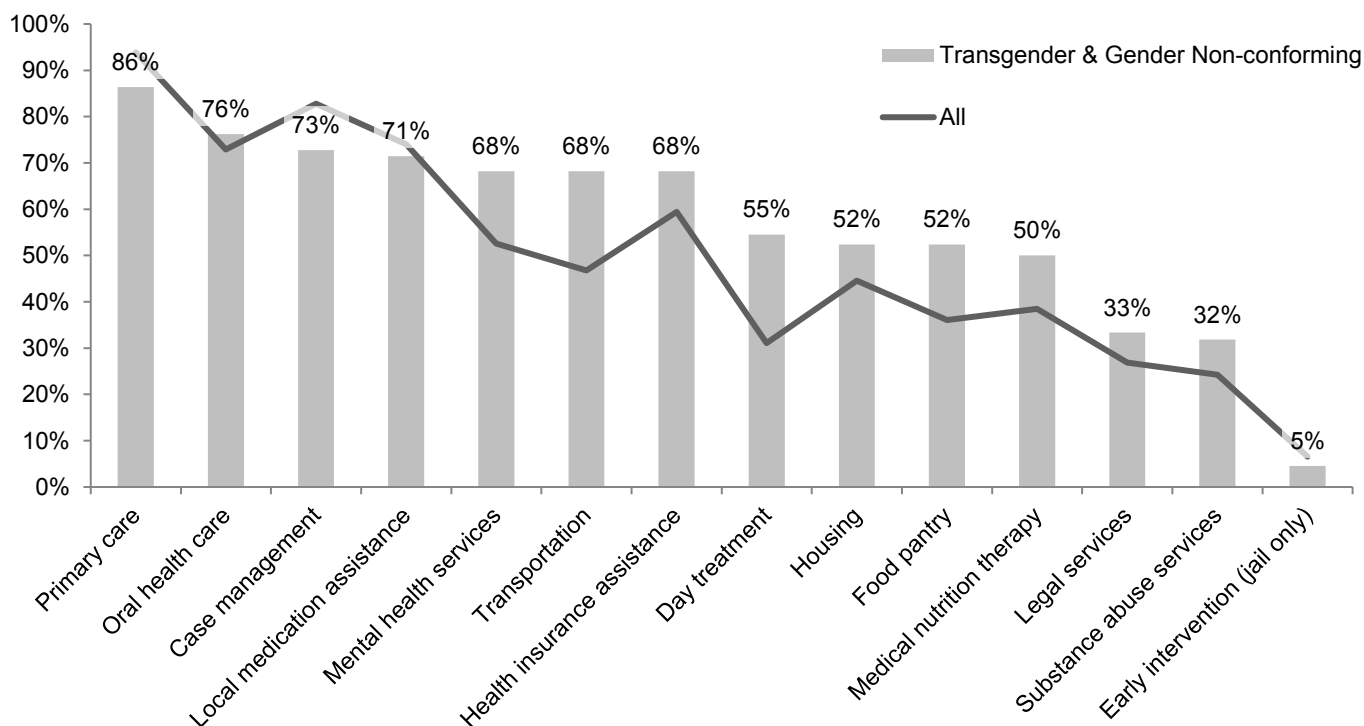
In 2016, 15 HIV core medical and support services were funded through the Houston Area Ryan White HIV/AIDS Program, and housing services were provided through the local HOPWA program. Though no longer funded through the Ryan White HIV/AIDS Program, Food Pantry was also assessed. Participants of the 2016 Houston HIV Care Services Needs Assessment were asked to indicate which of these funded services they needed in the past 12 months.

needed funded service at 86% of transgender and gender non-conforming participants reporting need, followed by oral health care (76%), case management (73%), local medication assistance (71%), and mental health services (68%). The greatest differences between transgender and gender non-conforming participants and the total sample were in the proportions reporting need for day treatment (55% vs. 31%), transportation (68% vs. 49%), mental health services (68% vs. 53%), and food pantry (52% vs. 36%).

(Graph 2) Among transgender and gender non-conforming participants, primary care was the most

**GRAPH 2-Ranking of HIV Services among Transgender and Gender Non-conforming PLWH in the Houston Area, By Need, 2016**

*Definition: Percent of transgender and gender non-conforming needs assessment participants stating they needed the service in the past 12 months, regardless of ease or difficulty accessing the service.*



**Other Identified Needs**

Twelve other/non-Ryan White funded HIV-related services were assessed to determine emerging needs for Houston Area PLWH. Participants were also encouraged to write-in other types of needed services.

(Graph 3) In general, transgender and gender non-conforming participants reported fewer currently unfunded needs and in lower proportions than the general sample. Additionally, needs for “other” services skewed toward services to meet physiological and safety needs like food bank and housing-related services. Of the 12 services options provided, the

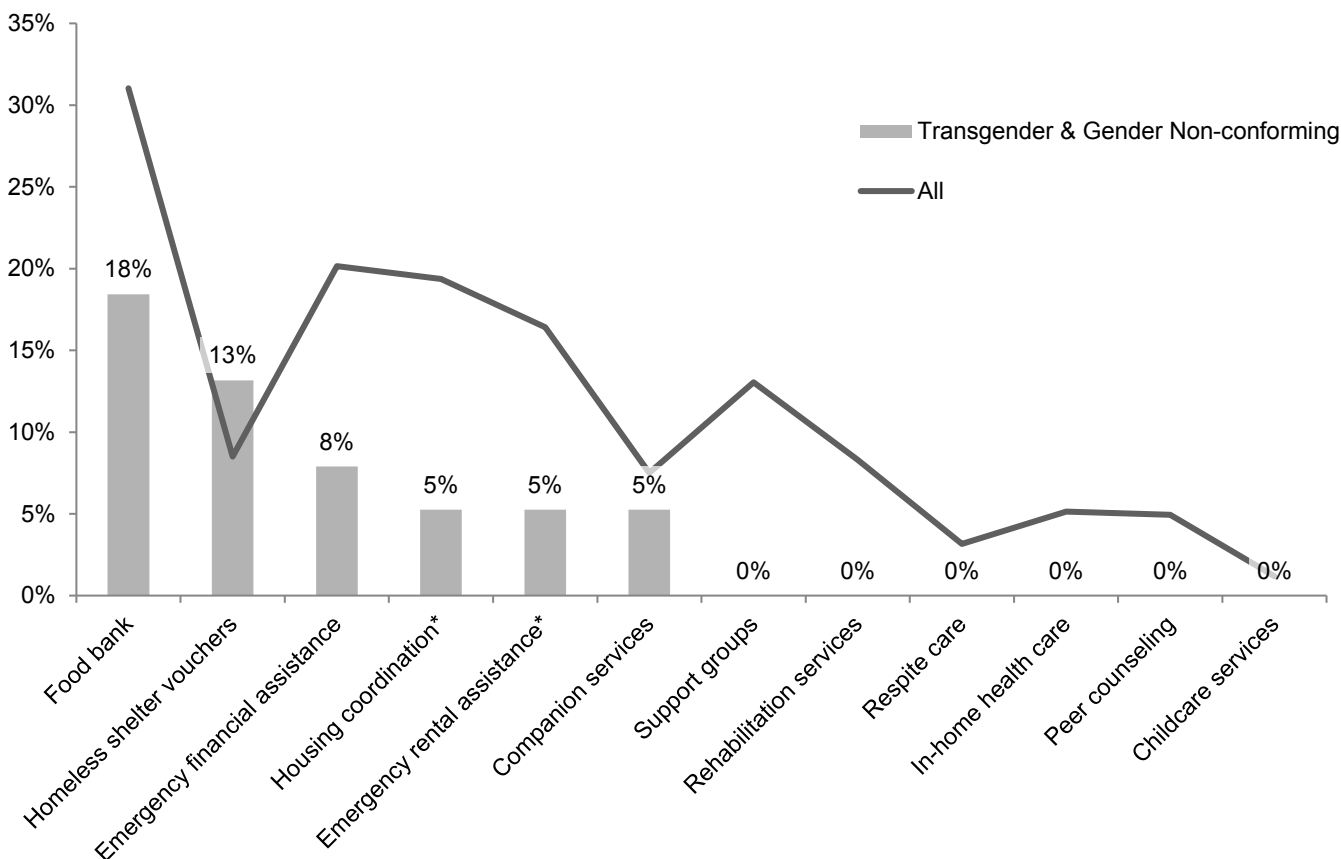
greatest proportion of transgender and gender non-conforming participants reported also needing food bank services (18%), followed by homeless shelter vouchers (13%), and emergency financial assistance (8%). Compared to the total sample, a greater proportion of transgender and gender non-conforming participants reported needing homeless shelter vouchers (13% vs. 8%), while smaller proportions reported needing housing coordination (5% vs. 19%) and food bank (18% vs. 31%).

Transgender and gender non-conforming participants provided no write-in services.

**GRAPH 3-Other Needs for HIV Services among Transgender and Gender Non-conforming PLWH in the Houston Area, 2016**

*Definition: Percent of transgender and gender non-conforming needs assessment participants, who selected each service in response to the survey question, “What other kinds of services do you need to help you get your HIV medical care?”*

\*These services are not currently funded by the Ryan White program; however, they are available through the Housing Opportunities for People with AIDS (HOPWA) program.



## OVERALL BARRIERS TO HIV CARE

For the first time in the Houston Area HIV Needs Assessment process, participants who reported *difficulty* accessing needed services were asked to provide a brief description of the barrier or barriers encountered, rather than select from a list of pre-selected barriers. Recursive abstraction was used to categorize participant descriptions into 39 distinct barriers. These barriers were then grouped together into 12 nodes, or barrier types.

(Graph 4) Only 7 transgender and gender non-conforming participants cited barriers to HIV care services. As this group comprises only 35% of all transgender and gender non-conforming participants and 1.4% of the total sample, great care should be taken in applying data and conclusions from Graph 4

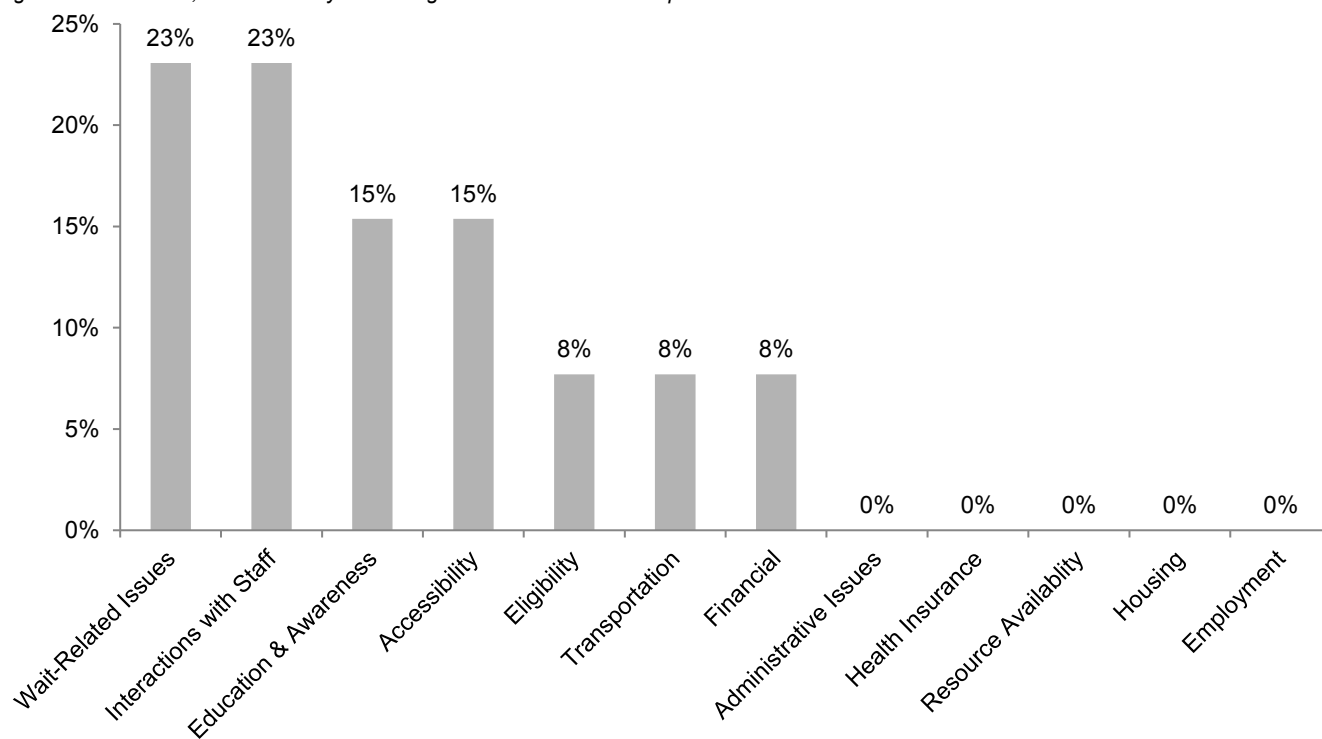
to the greater Houston area transgender and gender non-conforming PLWH population.

Overall, the barrier types reported most often among transgender and gender non-conforming participants related to wait-related issues (23% of all reported barriers); interactions with staff (23%), education and awareness (15%), and accessibility (15%).

Due to the small number of transgender and gender-nonconforming participants reporting barriers to HIV care services, comparison of barrier types between transgender and gender non-conforming participants and the total sample would not be generalizable and are not reported here.

**GRAPH 4-Ranking of Types of Barriers to HIV Services among Transgender and Gender Non-conforming PLWH in the Houston Area, 2016**

*Definition: Percent of times each barrier type was reported by transgender and gender non-conforming needs assessment participants, regardless of service, when difficulty accessing needed services was reported.*



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# **Access to HIV Care among Transgender and Gender Non-Conforming People in Houston**

A Special Study of the Houston Area Ryan White Planning Council  
Approved March 14, 2013

## BACKGROUND

The [Houston Area Ryan White Planning Council](#) is responsible for designing HIV care, treatment, and support services for people living with HIV/AIDS in the Houston Eligible Metropolitan Area (EMA). The Planning Council uses several sources of information in order to meet this mandate, including epidemiological profiles, service-utilization reports, and a community-wide [needs assessment](#) of HIV-positive individuals conducted every three years. When specific populations are underrepresented in current data sources, the Planning Council may also commission a special data collection effort, or *Special Study*, to fill data gaps.

In 2012, the Planning Council released its [comprehensive HIV prevention and care services plan](#) for the Houston Area. In it are the specific HIV-infected populations in the Houston EMA with insufficient data for assessing their current level of access to HIV services. In response, the Planning Council commissioned a series of Special Studies to gather data on each underrepresented group. This article presents the results of the Planning Council's first Special Study in the series, focused on transgender and gender non-conforming people living with HIV/AIDS in the Houston EMA.

## INTRODUCTION

Transgender individuals are among the highest risk for HIV infection in the U.S. today.<sup>1</sup> Moreover, the challenges often faced by transgender individuals in regards to discrimination, stigma, lack of resources, and other social determinants can make it difficult for them to access HIV services.<sup>1</sup> One study of transgender people living with HIV/AIDS showed a statistically lower rate of HIV treatment when compared to nontransgender people.<sup>2</sup> For these reasons and others, transgender communities are a high priority for HIV prevention, linkage, and retention in care efforts both nationally and in the Houston EMA.<sup>3</sup>

However, relatively little is known about the specific needs, gaps, and barriers to HIV care among transgender people in the Houston EMA. Transgender individuals are less than 1% of all Ryan White HIV/AIDS Program clients in the EMA,<sup>4</sup> and only 22 transgender-identified individuals participated in the EMA's most recent community-wide needs assessment of people living with HIV/AIDS.<sup>5</sup> This Special Study sought to describe the HIV service utilization patterns of transgender people living with HIV/AIDS in the Houston EMA, including socio-economic or behavioral factors that may be influencing their use of services, and to establish baselines for core HIV prevention and care indicators, including linkage to care and unmet need.

## METHODS

Participants were self-selected, self-identified transgender HIV-positive adult residents of the Houston EMA. Because many individuals may not identify with the term "transgender," inclusion screening questions used the broader terminology of "transgender or gender non-conforming" and offered both a definition of the term and examples along a broad continuum of gender expression. The text for the transgender inclusion screening question for the study was:<sup>6</sup>

**“Do you consider yourself to be transgender or gender non-conforming in any way?”**

Transgender/gender non-conforming refers to people whose gender identity or expression is different, at least part of the time, from the sex assigned to them at birth

on their birth certificate. Below are some examples of people who might consider themselves transgender:

MTF (male to female)	Drag performer (queen or king)
FTM (female to male)	Genderqueer
Part time as one gender/part time as another	Genderfluid
Transgendering	Feminine male
Transsexual	Masculine female
Cross dresser	Third gender
Androgynous	Two spirit

Please check one:

- Yes, I consider myself to be transgender or gender non-conforming in some way
- No. If no, please do NOT continue with the survey”

In addition, following national recommendations,<sup>1</sup> the two-step data collection method of asking sex assigned at birth and current gender expression was also used. Sexual orientation identification was also asked separately.

Our primary data collection method was a survey that addressed three overall topics: HIV diagnosis and linkage to care; HIV service needs, gaps, and barriers; and social determinants. Demographics were also collected. To participate, individuals could self-administer surveys online, in hard-copy by mail, or in hard-copy in-person at designated survey sites; they could also complete surveys via staff interview by telephone or in-person. Two trained interviewers conducted the surveys. Recruitment occurred through social promotion (i.e., flyers and postcards at bars, clubs, community centers, clinics, community-based organizations, and housing complexes), social media, staff promotion, and word of mouth. Surveys were voluntary and anonymous, and all participants were offered a \$20 gift card. Surveys were collected from August 27, 2012 through December 13, 2012.

This study was intended to be descriptive in nature; therefore, no sampling methods or control groups were used. Participation was non-identifying, and the results are self-reported. Data collection methods and survey questions were reviewed and approved by an advisory committee of transgender-identified community members, leaders, and gatekeepers as well as researchers with experience studying transgender populations (See Acknowledgments). Survey Monkey was used for data storage; and analysis was conducted in Microsoft Excel. Consistent with a descriptive study, no statistical tests were performed, and it is unknown if the comparisons presented here are significant.

## **SAMPLE**

([See Table 1](#)) A sample of 135 transgender or gender non-conforming people living with HIV/AIDS in the Houston EMA is included in this analysis.<sup>7</sup> Forty percent (40%) of the sample was natal males with a primary full-time current gender expression and/or identity of female (MtF), and 8% was natal females with a primary full-time current gender expression and/or identity of male (FtM) (a ratio of 5:1). An additional 37% had part-time discordant natal sex and current gender expression and/or identity, and 14% had concordant natal sex and current gender

expression and/or identity, though still identified as transgender or gender non-conforming. The average age of the sample was 40 years (standard deviation = 10.8; range = 19 - 63).

The sample was comprised of 77% African Americans, 17% White, non-Hispanics, 8% Hispanics, and 4% other, which is an overrepresentation of African Americans (and an underrepresentation of other racial/ethnic groups) when compared to current HIV/AIDS prevalence in the Houston EMA.<sup>8</sup>

The majority of the sample had at least a high school diploma or GED (69%), while 31% reported less than a high school education, which is 1.6 times higher than the percent reported by the general population of people living with HIV/AIDS in the Houston EMA (19%). At 47%, the sample reported more disability than the general HIV-positive population (39%) and only slightly less full- or part-time employment (16% vs. 18%). The percent of respondents living in their own home or apartment (38%) was 2.0 times less than the general HIV-positive population (77%), and the percent living in a group home for people who are HIV-positive (30%) was 2.3 times higher (13%). No-one in the sample reported living in a shelter, car, or on the street.

Twenty percent (20%) of the sample reported being released from a correctional facility in the last 12 months, which is comparable to the general HIV-positive population in the Houston EMA (19%).

The average length of HIV diagnosis in the sample was 12 years (standard deviation = 8.2; range = 0 - 30) with 8% diagnosed for one year or less.

**TABLE 1-**Demographic Comparison of Participating Transgender People Who Are HIV Positive (n=135) and the General HIV-Positive Population in the Houston Area

	Transgender Participants	General HIV+ Population
Transgender Identification		
Natal male/female expression (MtF)	40%	--
Natal female/male expression (FtM)	8%	--
Part-time male/female	37%	--
Non-variant	14%	--
Age, mean (sd)	40.2 (10.8)	44.7 (10.0) <sup>a</sup>
18-24	9%	3%
25-44	47%	44%
45+	44%	54%
Race/Ethnicity		
		<sup>b</sup>
White, non-Hispanic	17%	25%
African American	77%	50%
Hispanic	8%	23%
Other	4%	2%
Education		
		<sup>a</sup>
Less than high school	31%	19%
High school diploma/GED	58%	38%
Technical degree or above	11%	42%
Employment Status		
		<sup>a</sup>
Employed FT/PT	16%	18%
Temporary/seasonal/contract	5%	5%
Student	8%	--
Retired	4%	3%
Unemployed	28%	35%
Disabled/not working	47%	39%
Housing Status		
		<sup>a</sup>
Own house/apartment	38%	77%
With friends/family	25%	--
Group home	30%	13%
Shelter, car, street	0%	11%
Combination/changes often	7%	--
Incarceration History	20%	19% <sup>a</sup>
Years of HIV Diagnosis (sd)	12.2 (8.2)	11.2 (7.3) <sup>a</sup>

<sup>a</sup>2011 Houston Area HIV/AIDS Needs Assessment, April 2011 (n=924). Conducted in the Houston Eligible Metropolitan Area (EMA) of Chambers, Fort Bend, Harris (including the City of Houston), Liberty, Montgomery, and Waller Counties

<sup>b</sup>Texas eHARS (as of 12/31/2011). Jurisdiction is Houston EMA

## RESULTS

### HIV Testing, Diagnosis, and Linkage to Care

The first topic we wanted to address through this study was what motivates transgender people in the Houston EMA to test for HIV and where they test. In our sample, the most commonly-cited reason for testing was feeling sick (25%), followed by receiving an HIV test as part of a routine health check-up (21%). Three percent (3%) of the time the reason for testing was the recommendation of a medical provider, and another 3% was in response to community advertising. The most common location for HIV testing was a dedicated HIV clinic (34%), followed by an ER or hospital (17%). Thirteen percent (13%) said they were tested at a health department, and 9% were tested in jail or prison.

Because treatment for HIV can extend life expectancy and quality of life for those infected, length of time for linkage to care post-diagnosis and current care status are used as indicators of community health related to HIV both nationally and locally.<sup>3,9</sup> At the time of this study, baselines were missing for both of these measures for the transgender population in the Houston EMA. Therefore, the next topics we sought to address in the study were linkage to care and patterns of care. We asked respondents when they first saw a doctor for HIV following their diagnosis (either within three months or more than three months, per the federal benchmark<sup>9</sup>) and if they were currently meeting the national definition of being in care, which is defined as completing at least one of the following in the last 12 months: (1) seen a doctor for HIV, (2) taken HIV medications, (3) had an HIV viral load test, or (4) had a CD4 count test.<sup>10</sup>

(See Table 2) The majority of the transgender people in this study was linked to care within three months of their HIV diagnosis (76%). This percentage is comparable to current estimates for the Houston EMA as a whole (77%),<sup>11</sup> though lower than both local and national goals.<sup>3,9</sup> For those in the sample who did report delayed care, the most commonly-cited reason was denial about being HIV-positive (80%). However, 16% of the time the reasons were lack of knowledge about where to go for HIV services, fear about how the medical staff would react to their gender variance, and fear about how other clients would react. Twelve percent (12%) of the time the reason for delayed care was having to disclose their gender variant status to providers and staff.

**TABLE 2-Linkage to Care among Participating Transgender People Who Are HIV Positive (n=133) Compared to the General HIV-Positive Population in the Houston Area and Local and National Goals**

	Transgender Participants	General HIV+ Population <sup>a</sup>	Goal <sup>b</sup>
Linked to HIV Care within 3 Months of Diagnosis	75.9%	77.4%	85.0%

<sup>a</sup>Texas Department of State Health Services, 8/20/12

<sup>b</sup>National HIV/AIDS Strategy for the United States (July 2010); Houston Area Comprehensive HIV Prevention and Care Services Plan (2012 – 2014)

The majority of the people in this study was also currently in care (97%). This percentage far exceeds estimates for the general HIV-positive population in the Houston EMA (75%).<sup>12</sup> This is most likely a bias in our sample, rather than a true unmet need result, due to study recruitment taking place at HIV clinics and HIV group homes. Therefore, no additional analysis was performed on this data point.

### HIV Care Service Utilization, Barriers to Care, and Service Needs

(See Table 3) Another topic we wanted to explore in this study was the use of specific HIV care, treatment, and support services by transgender people in the Houston EMA. To do this, we

**TABLE 3-HIV Care Services Used and Barriers Reported by Participating Transgender People Who Are HIV Positive (n=132) in the Houston Area**

Service Category (in order)	Reporting Use	Service Category (in order)	Reporting
	# (%)		Barrier to Use
Primary HIV care	113 (85.6)	Oral health care	28 (21.2)
Transportation	76 (57.6)	Primary HIV care	23 (17.4)
Case management	64 (48.5)	Case management	23 (17.4)
Oral health care	60 (45.5)	Transportation	18 (13.6)
Mental health counseling	59 (44.7)	Medical nutritional therapy	15 (11.4)
Medical nutritional therapy	51 (38.6)	Mental health counseling	13 (9.8)
HIV medication assistance	46 (34.8)	Legal services	8 (6.1)
Substance abuse treatment	28 (21.2)	Health insurance assistance	7 (5.3)
Health insurance assistance	25 (18.9)	Hospice care	7 (5.3)
Legal services	21 (15.9)	HIV medication assistance	6 (4.5)
Day treatment	19 (14.4)	Day treatment	6 (4.5)
Language services	14 (10.6)	Substance abuse treatment	4 (3.0)
Hospice care	9 (6.8)	Language services	4 (3.0)

asked each respondent if, in the past 12 months, they had used each of the services that the Planning Council had prioritized for funding through the Ryan White HIV/AIDS Program and if they had experienced any difficulties accessing each of the services, regardless of recent use. Primary HIV care (86%), transportation (58%), and clinic-based case management (49%) were the most used services in past 12 months. The services cited most often as having difficulties to access were oral health care (21%), primary HIV care (17%), and clinic-based case management (17%). These findings are consistent with the general population of HIV-positive people in the Houston EMA.<sup>13</sup>

(See Table 4) Specific barriers faced by this population when seeking HIV services were also explored. When asked what barriers, if any, respondents had faced at any time since their diagnosis, the most commonly-cited was lack of transportation (44%). Also high on the list was being treated poorly by staff due to gender variance (29%), lack of funds to pay for services (28%), and denial about being HIV-positive (24%). In addition, 19% of respondents reported lack of provider familiarity with transgender needs as a barrier to care. Twenty-two percent (22%) reported no barriers. When compared to

**TABLE 4-Most Commonly-Cited Specific Barriers to HIV Care Reported by Participating Transgender People Who Are HIV Positive (n=105) Compared to the General HIV-Positive Population in the Houston Area**

Specific Barrier Experienced (in order)	# (%)	Rank among
	Reporting	General HIV+ Population <sup>a</sup>
No transportation	46 (43.8)	6
Treated poorly by staff due to being transgender	30 (28.6)	--
No money, the services cost too much	29 (27.6)	11
Fear or denial about being HIV-positive	25 (23.8)	14
Wait times for services were too long	20 (19.0)	3
Hard to get an appointment for HIV services	20 (19.0)	5
Providers are not familiar with transgender needs	20 (19.0)	--
A problem with drugs or alcohol	18 (17.1)	--
Lack of housing	18 (17.1)	--
Felt fine, not sick, "didn't think I needed HIV care"	16 (15.2)	--
HIV care a low priority	16 (15.2)	--
No Barriers Experienced	30 (22.2)	--

<sup>a</sup>2011 Houston Area HIV/AIDS Needs Assessment, April 2011 (n=924). Ranking is for core and support services combined; no distinction between type of service was made in our study.

the general population of HIV-positive people in the Houston EMA, some differences emerged.<sup>14</sup> For example, while lack of transportation is the highest ranking barrier to HIV care among our sample (when barriers existed), it ranked sixth among the HIV-positive population as a whole. Similarly, lack of funds ranked third in our sample (when barriers existed) yet eleventh among all HIV-positive persons in the Houston EMA.

This section of our survey also asked respondents if more or different services are needed by transgender people living with HIV/AIDS in the Houston EMA to more effectively manage HIV disease. The top five categories of responses were: (1) more housing, including rental assistance and shelters for transgender persons, (2) more transportation services, (3) assistance with basic needs such as food and clothing, (4) support groups for transgender persons, and (5) employment assistance for transgender persons.

### **Risk Activities, Co-Morbidities, and Discrimination History**

Multiple national studies of transgender people and two studies conducted in the Houston community<sup>15, 16</sup> have suggested that risk behaviors for HIV transmission are common in the transgender population as are other health concerns such as depression or substance abuse that can hinder the ability to access and maintain HIV care. We wanted to assess the frequency of these types of behaviors among HIV-positive transgender persons in the Houston EMA as well ([See Table 5](#)).

In our sample, sexual activities known to increase HIV transmission risk were reported more often than in the general HIV-positive population in the Houston EMA,<sup>13</sup> with one exception. In our sample, a slightly lower percentage of respondents reported no condom during their last

**TABLE 5-Comparison of Risk Behaviors and Co-Morbidities among Participating Transgender People Who Are HIV Positive and the General HIV-Positive Population in the Houston Area**

	Transgender Participants	General HIV+ Population <sup>a</sup>
Risk Activities, last 6 mo.		
Sex with someone known to be HIV+	39%	30%
Anonymous sex partner	30%	16%
Sex bartering	15%	6%
Shared needles/injection equipment	3%	1%
Had sex with known needle-sharer	5%	--
Condom Use		
No condom at last sexual activity	26%	30%
Does not <i>always</i> use condoms	60%	50%
Diagnosed with STD, last 6 mo.	13%	--
Mental Health Concern, last 30 days		
Anger management	26%	24%
Anxiety	54%	52%
Depression	62%	--
Fear of leaving the home	6%	--
Wanting to harm themselves	17%	9%
Attempt at self-harm	6%	--
PTSD	6%	--
Mental health concern requiring medication	44%	27%
Experience with Discrimination		
Been treated differently	84%	--
Been denied services	17%	--
Been asked to leave a public place	16%	--
Experience with Violence		
Verbal harassment/taunts	60%	--
Threats of violence	36%	--
Physical assault	30%	--
Sexual assault	23%	--
Rape	16%	--

<sup>a</sup>2011 Houston Area HIV/AIDS Needs Assessment, April 2011 (n=924)

sexual activity (26%) than did the population as a whole (30%). However, a higher percentage of our respondents (60%) reported not *always* using condoms during sexual activity than did the general population (50%). Also of note, 13% of our sample reporting being diagnosed with an STD other than HIV in the last six months.

Results related to co-occurring concerns were varied. A higher percentage of the respondents in our sample (70%) than in the general HIV-positive population in the Houston EMA<sup>13</sup> reported having a least one mental health concern in the past 30 days; however, comparable and lower percentages reported a concern with alcohol use or drug use, respectively. Of note, however, is the difference in frequency of *type* of mental health concern reported. Among the HIV-positive transgender persons in our sample, 17% reported wanting to harm themselves compared to 9% of the general HIV-positive population. Moreover, 44% of our sample reported having a mental or emotional problem severe enough to require prescription medication compared to 27% of the general HIV-positive group.

Lastly, our study also sought to describe the local transgender HIV-positive population's experience with gender variant-related stigma, discrimination, and violence. The results were high, with 84% of respondents reporting receiving differential treatment in public due to gender variance, including 16% who reported being asked to leave a public place. In addition, 60% of respondents reported being harassed or taunted due to their gender variant status, 36% reported being threatened with violence, and 30%, 23%, and 16% reported being the victims of physical assault, sexual assault, and rape, respectively, at some time in their lives.

## LIMITATIONS

There are limitations to this study. Respondents were self-identified and self-selected according to provided definitions of inclusion criteria. Though the broad scope terminology utilized at screening may have produced a more inclusive sample of respondents, the lack of a random sample, sampling frame, control group, and statistical testing lessens the study's generalizability, and results may not be fully representative of the study population as a whole. To mitigate this limitation, comparisons have been provided between study results and those found in larger samples. Respondent self-selection can also result in duplication as do some of the recruitment methods used in the study, such as incentives and word of mouth promotion. A data matching protocol was applied post-data collection in order to reduce potential duplication. Another limitation is the use of mixed-methods for data collection, which resulted in both self- and interviewer-administration of the survey tool. While this approach may have reduced barriers to participation in the study, it may also have lessened the accuracy of the survey instrument and produced variability between respondents. Data collected by the tool were also self-reported, and confirmation was not possible due to study design. As a result, there is no way to validate the individual experiences described by respondents, and the results presented here should not be interpreted or used as verification of service delivery or health outcomes.



## DATA SUPPLEMENT—FOCUS GROUP RESULTS

Three focus groups were held in October 2012 to complement the quantitative results of this Special Study. The goal of the focus groups was to better understand the perspectives of HIV-positive transgender clients in the Houston EMA in regards to their HIV status and to hear directly from clients about opportunities for improving the HIV system of care. A total of 14 self-identified and self-disclosed transgender HIV-positive individuals participated in the series. Key themes from their discussions are described below.

**Gender variance is perceived as having greater stigma than HIV.** Focus group participants were asked to describe what daily life is like as a transgender identified person living with HIV. For most participants, being gender variant was a greater source of concern than being HIV-positive. Said one participant, “that’s a worse stigma, [being] gay or transgender, than the disease itself.” According to focus group participants, this often results in transgender people isolating themselves from the public and from needed HIV services out to fear of others knowing they are transgender. Explained a participant, “A lot of transgender people are afraid to come out. A lot of them feel fear [about] how they’re going to be received.”

**The HIV medical home is an effective model for transgender clients.** Because many transgender identified persons may be fearful of public reaction, an HIV medical home or “one-stop-shop” was cited as a preferred model for HIV care for this population, and a dedicated HIV clinic was identified as the preferred type of provider. According to focus group participants, fear about disclosure of and/or differential treatment due to being gender variant or HIV-positive is a main reason why transgender people are out of care. Explained a participant, “They say, if they go to the doctor and see someone they know, they will tell their business. At [an HIV clinic], everybody is the same. They already know.” Said another participant, “They [the HIV clinic] deal with one situation, HIV...you walk in, and everyone’s going through the same thing.” A third participant noted, “When you go to an [HIV clinic], they give you the same treatment. They are going to treat you with respect.” In addition, HIV clinics that “cater to” transgender clients were also praised, with one participant describing them as “wonderful.”

**Increased capacity for serving gender variant clients remains a system wide need.** Participants in all three groups described repeated interactions with HIV providers who were “insensitive” to their transgender status, particularly in regards to pronoun usage and name. Explained one participant, “You know [your client] is a male, but she’s dressed as a female. But, the first thing that comes out of your mouth is ‘excuse me, *sir*, can I help you.’ That makes the client uncomfortable. There’s no way I can discuss my problems, concerns, needs, frustrations when you’ve just disrespected me.” Participants had the overall impression that staff at HIV clinics are hired without regard to their experience working with transgender clients.

Discrimination appeared to be more pronounced in the broader social service community than in the HIV services arena. Said one participant, “It is easier for [non-transgender people] to walk up and get services, like shelter. Even going to certain clothing closets. They said you can only get male clothes. I don’t dress as a man, so why should I get male clothing?” Training on client-centered pronoun usage, name usage, and improving the gender variant sensitivity of policies and procedures were all identified as potential solutions. When describing a positive experience regarding pronoun usage following a change in policy, one participant said, “It’s not something you’re already used to. It’s something that somebody had to tell you [to do].”

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8. Living HIV/AIDS cases in the Houston EMA as of December 31, 2011. Source: Texas eHARS.
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13. Respondents in the community wide needs assessment of the general HIV-positive population in the Houston EMA were asked to indicate if they "had difficulty" accessing core medical and support services funded by the Ryan White HIV/AIDS Program. Core medical services that respondents reported most often as having "some difficulty getting" were oral health care (29%), HIV medication assistance (20%), clinic-based case management (18%), and primary HIV care (17%). Source: Houston Area Ryan White Planning Council, 2011 Houston Area HIV/AIDS Needs Assessment, April 2011.
14. When respondents in the community wide needs assessment of the general HIV-positive population in the Houston EMA indicated difficulty accessing core medical or support services funded by the Ryan White HIV/AIDS Program, they were subsequently asked what specific barrier they encountered. Most commonly cited barriers were (1) lack of knowledge about where services are offered, (2) lack of knowledge about how to access services, (3) wait times, (4) ineligibility for services, (5) difficulty making or keeping appointments, (6) transportation, (7) paperwork, (8) inconvenient location, (9) poor treatment by agency staff, (10) perception of ineligibility for services, (11) inability to pay for services, (12) fear of disclosure of status, (13) language barriers, and (14) denial about being HIV-positive. Source: Houston Area Ryan White Planning Council, 2011 Houston Area HIV/AIDS Needs Assessment, April 2011.
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# BLOG.AIDS.GOV - Changing to HIV.gov in Spring 2017

## 250 Sites Participated In Listening Session With The Transgender Community

December 21, 2016 • By [Caroline Talev, MPA, Public Health Analyst, Office of HIV/AIDS and Infectious Disease Policy, U.S. Department of Health and Human Services](#)



The HHS Office of HIV/AIDS and Infectious Disease Policy (OHAIDP) recently convened a community listening session to hear about the ways that the [Secretary's Minority AIDS Initiative Fund \(SMAIF\)](#) might help to further improve HIV prevention and care for transgender women of color. Transgender women of color have extremely high rates of HIV that are driven and compounded by other health issues, socioeconomic barriers,

transphobia, discrimination, and other challenges. Too often, the community's needs are overlooked or addressed in ways that are not optimal.

The SMAIF promotes innovation, addresses critical emerging issues, and has established new collaborations across federal agencies to improve the national response to HIV and to create lasting changes in programs that improve the quality, efficiency, and impact of HIV programs that serve racial and ethnic minorities. The listening session provided an important opportunity to hear from community members about their recommendations for how they believe SMAIF might leverage existing resources to improve the response to HIV and AIDS among transgender women of color. Leaders from a variety of organizations from across the nation volunteered on a first-come, first-served basis to answer the following questions:

1. What are the most important barriers to improving HIV prevention and care for transgender women of color that you think the SMAIF might help address?
2. What are your recommendations for activities to address these barriers?

The community speakers included:

1. JoAnne Keatley, MSW, Director, Center of Excellence for Transgender Health, University of California, San Francisco (UCSF)
2. Kim Watson, Co-Founder/Vice-President, Community Kinship Life
3. Leo Rennie, Senior Legislative and Federal Affairs Officer, American Psychological Association
4. Cecilia Chung, Senior Strategist, Transgender Law Center
5. Tonia Poteat, PhD, MPH, PA-C, Assistant Professor, Center for AIDS Research, Johns Hopkins University Bloomberg School of Public Health
6. Luis Freddy Molano, MD, Vice President of Infectious Diseases and LGBTQ Programs, Community Healthcare Network
7. Octavia Lewis, MPA, Project Manager, Bronx-Lebanon Hospital
8. Sean Coleman, Executive Director, Destination Tomorrow
9. Danielle Castro, MA, Project Director, Center of Excellence for Transgender Health, UCSF
10. Bamby Salcedo, President and CEO, TransLatin@Coalition

These speakers shared their knowledge, passion, and recommendations during the session. Several themes emerged, including:

- Ensure that HIV providers and staff provide gender-affirming and nondiscriminatory health care and service environments.
- Capture accurate data for the transgender community in CDC surveillance and other data systems.
- Support efforts to address social determinants of health, including mental health services.
- Address disparities of transgender youth, including the risk of bullying and its consequences.
- Increase evidence-based interventions for community-based projects.
- Actively recruit in the transgender community and provide leadership opportunities and training so that transgender people can lead efforts to design and implement programs and policies that serve the transgender community.

Dr. Richard Wolitski, Director of the HHS Office of HIV/AIDS and Infectious Disease Policy (OHAIDP), moderated the session and provided opening remarks. He was followed by Dr. Amy Lansky, Director of the White House Office of

National AIDS Policy (ONAP) who spoke about the [NHAS](#) and the transgender community, as well as highlighting the three new developmental indicators that the White House released on [World AIDS Day 2016](#). One of the developmental indicators is to “increase the percentage of transgender women in HIV medical care who are virally suppressed to 90%.” Following Dr. Lansky, Dr. Timothy Harrison, Senior Policy Advisor in OHAIDP, discussed the purpose of [SMAIF](#), its unique role, and the types of projects that have been funded.

The listening session was recorded and the recommendations will be shared with HHS partners, along with written submissions. I encourage you to listen to the session and review the presentation because the data clearly show very high rates of HIV infection among transgender women of color, poorer health care outcomes among women living with HIV, and other disparities. We have the knowledge and effective tools to create a future in which transgender women do not experience these disparities and we can end new HIV infections. The time to act is now.

Download the listening session [recording](#). [MP3 12 MB]

Download the [speakers' slide-presentations-and-other-recommendations-received](#) [PDF 4,331 KB]

[Sign up to receive email updates of AIDS.gov blog posts \(and more!\)](#)

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## Bureau of HIV/STD and Viral Hepatitis Prevention

### Summary of TransHealth Luncheon

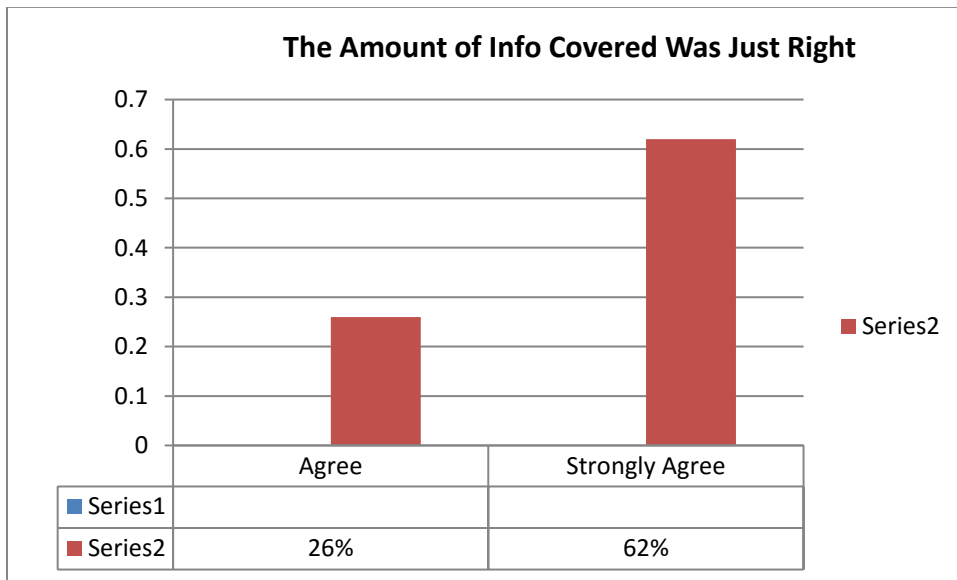
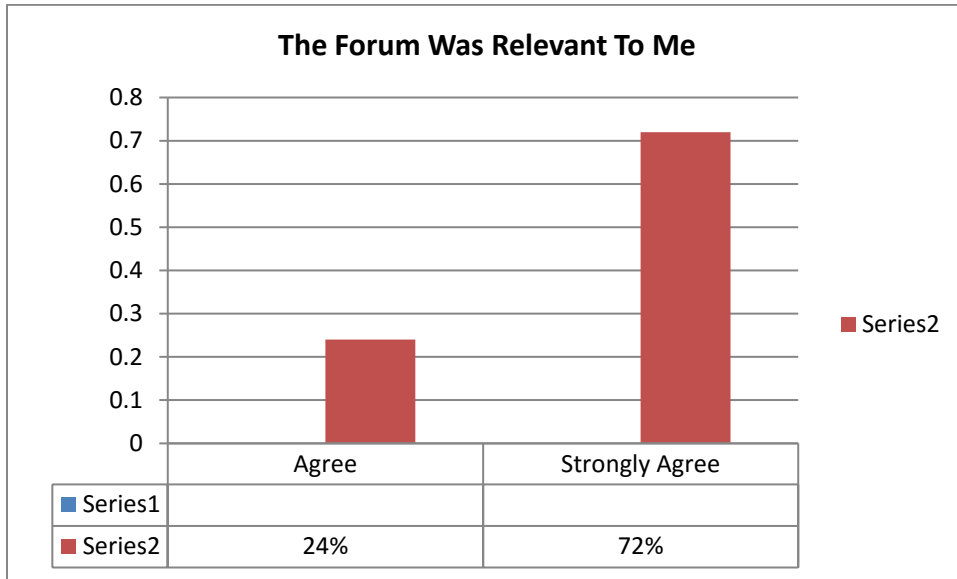
Due to the increase in HIV infection among the transgender population and many attempting to access services, the need for more cultural awareness is great. While attempting to assist the transgender population with accessing services, many barriers were identified, such as lack of housing, access to health care, cultural awareness, etc.

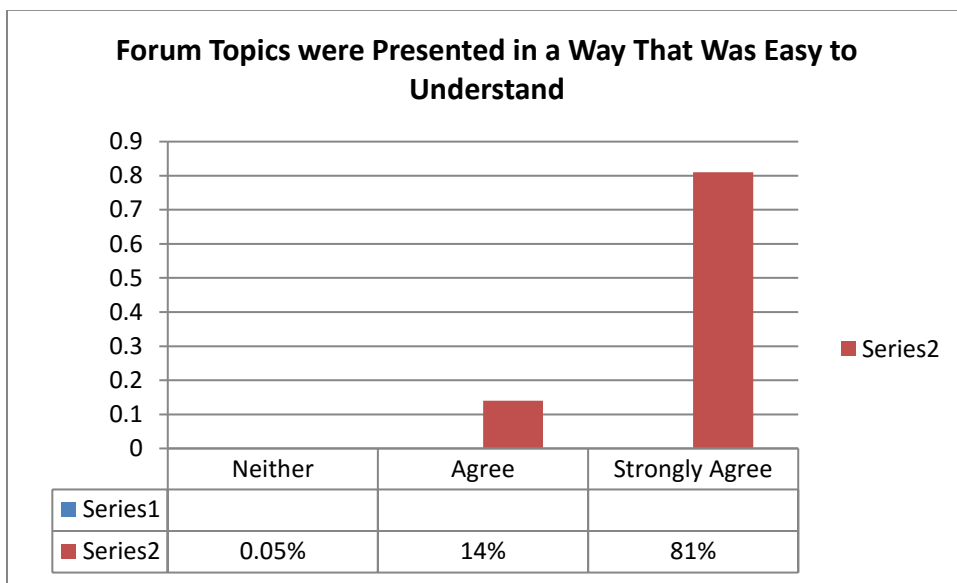
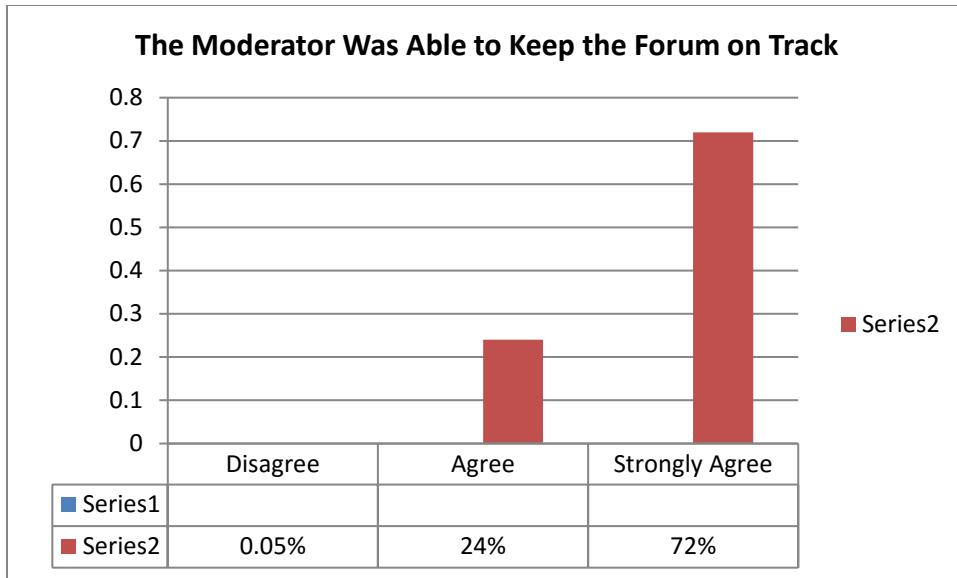
On January 25, 2017, the Houston Health Department – Bureau of HIV/STD and Viral Hepatitis Prevention held a luncheon at The Montrose Center to engage the transgender community as a first step in creating a dialogue to better understand the needs and concerns of this community and how the Bureau of HIV/STD and Viral Hepatitis Prevention can address the identified needs. The luncheon consisted of three round-table discussions, i.e., Emerging Concerns, Barriers to Healthcare, and Cultural Awareness. There were sixty-six participants of which twenty-one or 32% completed the evaluation.

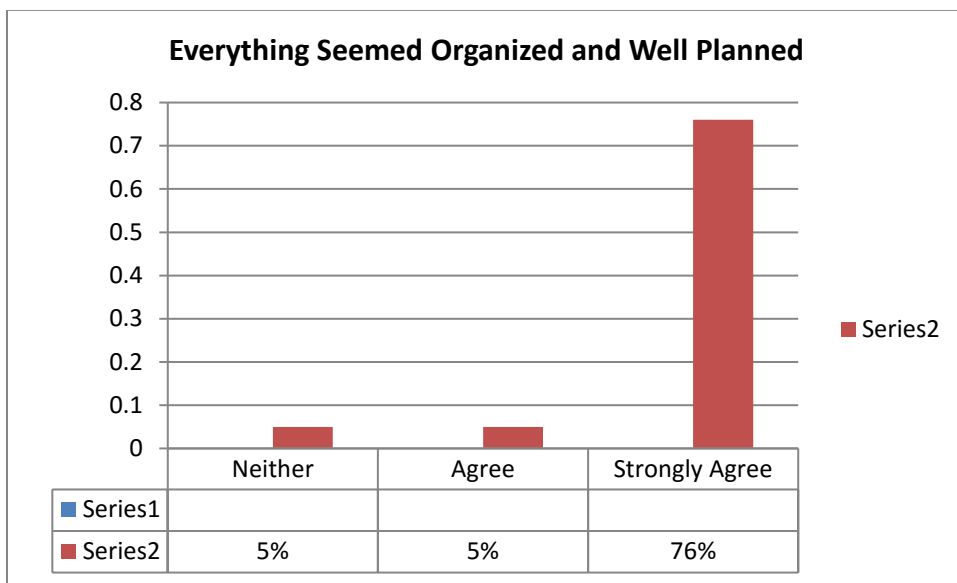
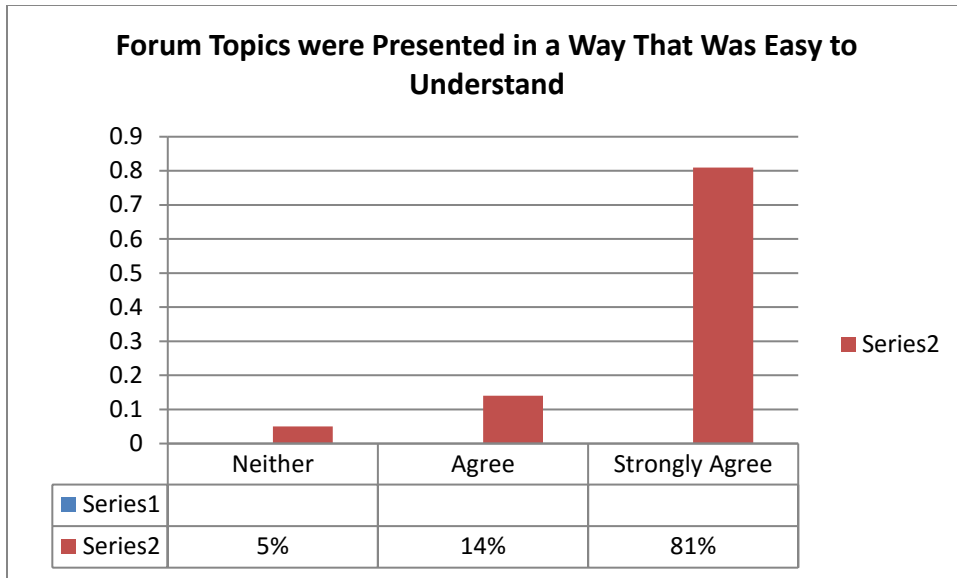
#### Summary of the Luncheon Discussion:

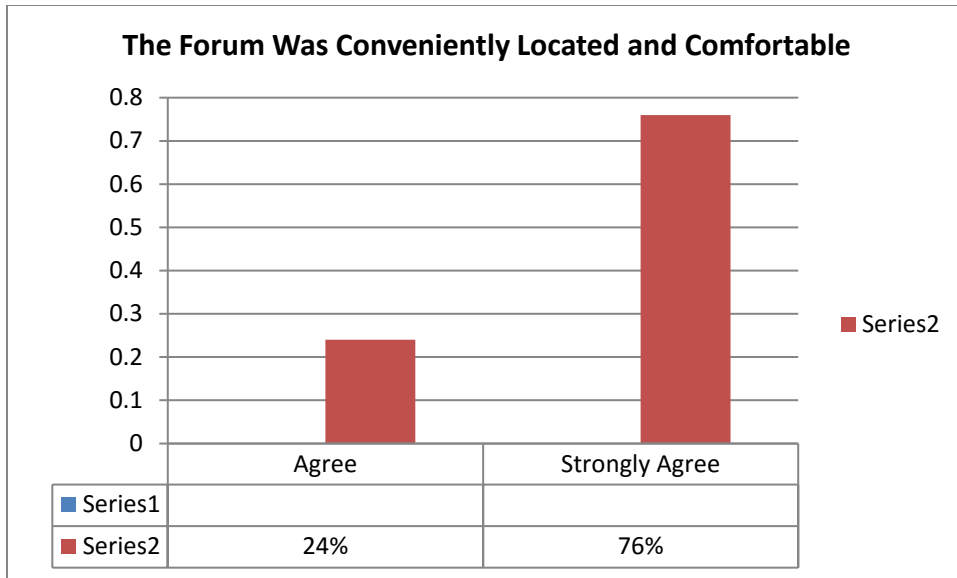
1. Although the Transgender Community has decided to no longer remain silent to ensure their presence throughout the Houston community in order for their voice to be heard, it appears the transgender community lacks a leader to facilitate the movement; and as a result, there appears to be a lack of trust within the transgender community.
2. Needs of the transgender community vary along gender/transgender as well as racial lines
3. It appears Male-Female transgender persons receive less services and attention as opposed to Female-Male transgender persons.
3. Lack of housing is a major barrier for the population
4. The term “Transgender” varies widely impacting how Trans seek and receive services

Evaluation Results









## Results of the TransHealth Questionnaire

### How do you define Transgender?

*A person who identifies as the opposite of their sex of birth*

*Male to female; female to male*

*A person who feels and believe in being a female or fem 24/7*

*Someone may be defined as Trans when their gender identity does not correspond with their genetic sex traits*

*I describe transgender as being my true self. I don't think about it. It just is.*

*Individual transitioning and complete transition to sex status different than what was born*

*A person that made or makes a change to make themselves happy*

*Someone who defines its gender as different as his/her sex at birth*

*Transmale and transfemale; some in-between; cisgender*

*There is no one definition – it's a multiple level*

*One who unfortunately is born with the opposite genitals*

*Birth gender and mental state aren't representative*

*Someone gets body transformation in life. Mentally*

*...Seriously?!?*

*I define we are persons like other person human. We feel the same*

*A person/human being that heart and mind is of the opposite gender that he/she was born to be!!!*

*As a person who may define themselves as someone who identifies differently from their birth sex*

*Gender identity*

*Male to female; female to male; a person that lives 2 years as a woman*

*Human – male to female; female to male*

*Human being as a female trapped in a male's body*

*Person that feel like that is what they are*

*Gender identity doesn't match biological sex*

*A person who identifies with a sex other than how they were biologically born*

*Identifying with a different gender other than the gender assigned at birth*

*An individual who doesn't identify as the gender born as*

*Individual who self identifies as the opposite sex*

*Aligning – cisgender identity*

*A transition of who I really am from the inside*

*When a person's self- image does not match their assigned gender*

*A person that feel more comfortable living as the opposite sex; also, one that's in transmission to the opposite sex*

*Transgender is who you go to bed as; what your brain is; sex is who you go to bed with*

*Identifying different from the sex the doctor said you were at birth*

*A person born in the wrong body*

*A person*

## What is Health Care to you?

*Being able to seek medical care services at one's chose of medical provider*

*There is not enough for people that is living as a Transgender*

*Its something that will be a help to me in my access choices*

*All encompassing access to comprehensive physical, mental, and social support in an environment that is supportive and knowledgeable for all*

*A facility that I can go and get treated*

*Access a system for reason of medical care for well being*

*The care of the whole body and mind*

*The system that is responsible for your healthcare including your mental health*

*Helping everyone, every disease, and every circumstances*

*Care for the body, mind, and spirit*

*Whole care, physical, mental, and emotional care*

*Medical aid*

*Taking care of myself; medical provider; doctor's visit*

*Equal access to regular healthcare as well as trans-specific care*

*It is good*

*It's the most important issue to me or all of us supposedly*

*Total well-being*

*Getting medical needs taken care of regardless of identity or sexual orientation*

*So complicated and don't understand our needs as a transgender woman*

*The opportunity to be able to get while sick or any other circumstances*

*To be able to have the proper hormones and doctors*

*Take care of yourself with meds*

*HRT-GP-STI*

*Treatment for wellness and prevention as well as sickness*

*Care that includes the physical and mental aspects of an individual*

*Coverage of care for health*

*Very important*

*Comprehensive mental, medical well-being services*

*A facilitator*

*Regular visits with a health care professional, i.e., doctor, PA, nurse, etc*

*Its very important to me!! Not only for myself, family, and friends so that we can get all the treatments that we need*

*Ability to get all necessary medical and mental care and follow-up*

*Affirming the human experience through medical service*

*Getting the best heath care possible*

*A system that does no work appropriate for everyone*

## How Do You Feel Society Views You and Why

*Society doesn't accept our community due to ignorance*

*I think that as a caregiver, we need to be more educated to service the Trans community. I am a caregiver and I enjoyed and learned a lot*

*I feel society has its picks good and bad*

*Society views me as a cis-gendered woman because of my display – culture of HEIFRO-NORMATIVITY*

*Society I think views me as a fetish, a taboo for the most part. If I don't pass society has a problem*

*For the Trans population, society views from stigmatism, generalizations, and misunderstanding*

*Confused-not happy with yourself and trying something out*

*As a gay man, I feel society views me as a minority fighting for rights, but from the outside they consider me as "other"*

*Society views me for me. It's really if I want to let society view myself because of fear of acceptance*

*They view me as a gay man, which I am*

*I am mixed, straight, and male. I suspect there are some who view my badly*

*An outsider...not gay, not straight*

*I feel good. Never have issues*

*I am viewed as a threat and a preck and as an undesirable. If you need to ask why, you can start by looking in the mirror*

*Stereotyped due to our history in society*

*I think society fears what they don't know and as long as they don't know or seek to understand, stigma will continue*

*As a gay male, I feel validated because I refuse any less*

*Too much judgment and poor services. Also the society looks as a different person.*

*People don't accept us because of our sexual appearances and likes*

*They view us very badly; some people just don't understand us physical and emotional*

*Do us bad*

*I do not feel that society is well equipped to interact with the transgender population in any accepting way*

*A transgender is viewed as an oddity and on the fringes of society*

*As a gay femme man, I feel that society sees me as someone that less than*

*As a friendly gay man!*

*Less than because of lack of education an open mindedness*

*N/A – not a transgender person*

*In a big 1 with discrimination*

*Society views us negatively, either as a joke or subject to ridicule. Why? Because that's the way people are taught at school, home and church*

*In a very distant way because as us being human, we tend to avoid people, places, and things that we don't understand*

*I come from a very discriminatory time. I feel many people are uneducated to the Trans community nd rely on what they were told growing up!*

*As less than because there are no Trans protections*

*DNA*

*I think society need to get more educating about respecting people's life style*



**Have You Ever Access Services at one of the Health Department's clinic (Sunnyside, Northside, Sharpstown)**

No – 100%

**Are you willing to participate in a focus group?**

No (3)

*Need more information*

*Would love to be an advocate member!*

*If it was needed*

*Maybe*

Yes (29)

No answer (2)

**What parts of today's forum were most memorable?**

*Learning more about transwomen*

*Breakout discussions*

*Table discussions*

*The pain that each individual carries*

*The conversation*

*Ice Breaker*

*I especially liked the set-up of the rotation of the tables*

*The table sessions with the facilitators*

*I loved it - thanks for the information-:)*

*The fact that you could hear about the transgender community*

*The topics sessions*

*Small group discussions*

*Cultural*

*Table discussions*

*The focus discussions*

**What did you learn that you did not know before today's forum?**

*All*

*Needs of other parts of the transgender people*

*I am pretty active in society*

*The lack of cultural awareness from medical professionals and CBOs when interacting with members of the transgender community*

*Some of the barriers the Trans community faces*

*Cultural Awareness*

*Internal "family" organization of trans-women*

*Trans groups*

*The worries and concerns of the transgender women of color*

*Discussing the "cultural awareness" issues as these are issues that move us forward*

*Cultural awareness, Health care awareness*

**What would you have liked to learn in today's forum but was not covered?**

*Plans to implement suggestions*

*Where does Harris County Health Services and on Senate Bill 6*

*Gender fluid/non-pinar*

*What does competent education for transgender cultural awareness look like; where do we start?*

*Everything was excellent!!*

*Health series that transmen and transwomen find the most competent and accessible*

*The housing opportunities for Transgender who do not have a social security number*

*The level of support from HHD*

*Everything was great*

**What part of today's forum should have been changed or done differently?**

*Inclusion of available resources*

*What's the current situation for the community*

*Nothing Great Job!*

*Nothing; everything flowed nicely*

*The sound system*

*There was more focus on societal discrimination than focus on health care and health specific information*

*Everything was perfect - the setting and the topics presented*

*Everything was fantastic*

**What other thoughts or suggestions you have regarding today's forum**

*Want more*

*Keep it up!*

*Everything was just perfect*

*To have more of these conferences for the transgender community*

*What's the next step?*

*The luncheon was an amazing educational opportunity*

*More seating and tables. That's a good thing-:)*

*All the gift bags are towards women. My suggestion would be to have gender neutral "gift bags"*

**Prioritizing Identified Needs**

On February 17<sup>th</sup>, the Manager of the Service Linkage Program met with two members of the transgender community to prioritize the identified needs. *(It must be noted that seven members of the community were invited to participate)*

**Emerging Concerns**

Lack of rural representation

Mental health

Lack of provider education

Lack of visibility of Trans people of color

Lack of funding

Affordable Care Act

SB6 – Restroom Bill

Education

Inequality in the workplace

Domestic Violence

Language/Translation barriers changes within race

Lack of leadership and unification

Sex work/police harassment

Addiction

Murder/Suicide

Lack of diversity training

Immigration barriers

Identification barriers

Stigma

Negative representation in the media

Housing

Incarceration/Rehabilitation

### Barriers to Healthcare

STI Testing/Routine testing (normalize)  
Access to PrEP (Education, demonstration, effects)  
Stigma  
Education – Silicon injections  
Wellness exams (prostate & pap smears)  
Transportation  
Insurance coverage  
Hormone therapy  
Marketing – active promotion of services for transgender, correct terminology (trans and not drag queen)  
Sensitivity to when one is in transit  
Resource guide for trans  
DIY-HRT (Do it yourself hormones)

### Cultural Awareness

Isolation  
Building relationships  
Increasing tolerance  
Diverse language (pronouns)  
No true trans representatives  
Discrimination within one's race  
Internal/external transphobia  
Body image  
Family support  
More venues for the transgender community (their own center)  
Competency to provide education (use trans people)  
Accountability – do what you say you are going to do  
Acknowledging your fears

# **Positively Trans**

Initial report of a national needs assessment of transgender and gender non-conforming people living with HIV.



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  - 6 Advocacy priorities
  - 7 Barriers to Health Care and Well Being
- 10 Future Reports**
- 11 Recommendations**
- 12 Acknowledgments**



Chung, Cecilia; Kalra, Anand; Sprague, Laurel; and Bré Campbell. (2016). Positively Trans: Initial report of a national needs assessment of transgender and gender non-conforming people living with HIV. Oakland, California: Transgender Law Center.



## About Transgender Law Center

Founded in 2002, Transgender Law Center has grown into the largest trans-specific, trans-led organization in the U.S. changing law, policy and attitudes so that all people can live safely, authentically, and free from discrimination regardless of their gender identity or expression. As a multidisciplinary national organization, Transgender Law Center advances the movement for transgender and gender nonconforming people using an integrated set of approaches, including strategic litigation, policy advocacy, educational efforts, movement building, and the creation of programs that meet the needs of transgender and gender nonconforming people and communities.

[www.transgenderlawcenter.org](http://www.transgenderlawcenter.org)

## Positively Trans

### About Positively Trans

Positively Trans (T+), developed and directed by Transgender Law Center Senior Strategist Cecilia Chung, is a constituent-led project grounded in the principle that we are all capable of forming our own network, telling our own stories, and developing our own advocacy strategies in response to inequities, stigma, and discrimination over punitive laws and lack of legal protections in our local communities.

With the support of Elton John AIDS Foundation, TLC launched T+ as a response to the structural inequalities that drive the high rate of HIV/AIDS and poor health outcomes. By partnering with a National Advisory Board of community leaders, T+ seeks to mobilize and promote resilience of trans people most impacted by or living with HIV/AIDS, particularly trans women of color, through research, policy advocacy, legal advocacy, and leadership strengthening.

# Introduction + Background

In 2015, Transgender Law Center launched Positively Trans as a project to develop self-empowerment and advocacy by and for transgender people living with HIV. Positively Trans operates under the guidance of a National Advisory Board (NAB) of transgender people living with HIV from across the United States; the NAB is primarily composed of trans women of color who are already engaged in advocacy or leadership roles in their local communities.

Recent studies indicate that transgender people, especially transgender women of color (TWOC), experience disproportionate economic marginalization<sup>i</sup>, homelessness, and stigma and discrimination in healthcare access and provision<sup>ii</sup>; harassment and violence at school<sup>iii</sup>; and police abuse<sup>iv</sup>, as well as physical, sexual and physical violence<sup>v</sup>. In the face of these systemic threats and barriers to autonomy and wellbeing, the impact of HIV on the transgender community cannot simply be addressed by programs that

work to affect individual behaviors; we must address the systemic barriers our community members face—and the complex interactions of these systems—to reduce HIV risk and increase access to care and other resources for trans people living with HIV (TPLHIV). We believe that effective HIV responses for transgender people must include a combination of leadership development, community mobilization and strengthening, access to quality health care and services, and policy and legal advocacy aimed to advance the human rights of the community. Furthermore, we believe that an effective HIV response for trans people must center the leadership, voices, and experience of TPLHIV particularly trans women of color.

In order to identify community needs and advocacy priorities, we conducted a needs assessment in the summer of 2015. The needs assessment was released online and made available across the U.S. Key questions

focused on barriers to health and well-being for transgender people living with HIV and on their legal and health priorities. This report describes the responses to a small subset of those questions. We made the survey available online in English and Spanish; 80% of complete responses came from the English language instrument and the remaining 20% came from the Spanish language instrument. Recruitment took place through existing networks of transgender people and people living with HIV, and through clinics serving transgender people living with HIV. Responses were limited to people living with HIV in the U.S. whose sex at birth is different from their current gender identity. The project was reviewed and given exempt status by the Eastern Michigan University Institutional Review Board.

## Respondent Demographics

More than 400 people responded at least in part to the survey, with complete responses coming from 157 respondents. The analysis we provide in this report contains data only from the set of complete responses. The majority were female-identified U.S. citizens making less than \$23,000 per year. More than 40% had been incarcerated in their lifetime and 42% currently live in the South. The median length of time since identifying as transgender/gender non-conforming was 5 years greater than the median

Based on responses to several items on the survey instrument, we expect that the survey mostly attracted respondents who already have access to medical care. As a result, the responses may underrepresent the experiences of those who are more isolated. Because respondents were recruited through existing networks and not randomly selected, the results cannot be interpreted as representative of all transgender people living with HIV in the U.S. Instead, these results should be understood as illustrating the experiences and priorities of transgender people living with HIV and as providing a starting point for further engagement.

length of time living with HIV, suggesting that transgender and gender non-conforming people face unique risk and vulnerability to the HIV/AIDS epidemic. Table 1 contains a summary of demographic information for respondents who submitted complete surveys. Descriptive statistics of respondent demographics suggest that the survey oversampled whites and undersampled young people and people living in the Northeast.



# Table 1.

Summary of Respondent Demographics (N=157)

Item	%	Item	%		
Gender Identity	MTF/transfeminine spectrum	84%	Metropolitan Area	Urban	70%
	FTM/transmasculine spectrum	12%		Suburban	14%
	Other identity	4%		Rural	16%
Survey Language	English response	80%	Education	Less than HS diploma	15%
	Spanish response	20%		HS diploma or GED	22%
Race/Ethnicity	African American	26%		Some College	36%
	Latina/o	33%		College Graduate	20%
	White	32%		Graduate school	8%
	Asian	6%	Incarceration	Any incarceration history (Prison, Jail, Immigration detention)	41%
	Native	4%		None	59%
	Arab	3%		Current Annual Income	\$12,000 or less
	Native Hawaiian/Pacific Islander	3%	\$12,000 to \$23,000		22%
Race/Ethnicity	One race only	91%	\$23,000 to \$47,000		20%
	Multiracial	9%	\$47,000 to \$75,000		8%
Citizenship	U.S.	88%	More than \$75,000		8%
	Not U.S.	12%	Age	25 and under	9%
Region	Northeast	14%		26 to 40	39%
	South	42%		41 to 55	41%
	Midwest	13%		56 and over	11%
	West	29%			
	Alaska, Hawaii, Puerto Rico	2%			

Numbers rounded off to nearest percentage

**Median length of time since identifying as transgender/gender non-conforming** **17 years**

**Median length of time living with HIV** **12 years**

# Findings

This initial report focuses on findings related to two key areas:

## ADVOCACY PRIORITIES & BARRIERS TO HEALTH CARE

Subsequent reports will include findings on stigma, violence, substance abuse, law enforcement interaction, identity documents, and priorities for youth and elders.

# Advocacy Priorities

Creating gender affirming and non-discriminatory healthcare facilities and addressing HIV-related discrimination were the top health and legal priorities for respondents. Many respondents expressed concerns about hormone replacement and antiretroviral therapies and their side effects for transgender people. Ensuring support for mental health and recovery from trauma and for personal (self) care were selected as top critical priorities for transgender people living with HIV.

Participants were asked to select their top five health concerns. Figure 1, shows the

items ranked by percentage of respondents who indicated each item was among their top 5 concerns. Not listed are: dental care (35%), interaction between hormone therapy and anti-retroviral therapy (35%), complications from silicone injections (26%), pre-exposure prophylaxis and post-exposure prophylaxis (16%), substance abuse (9%), and reproductive health (8%).

Respondents overwhelmingly selected discrimination as priorities for legal advocacy work. Addressing HIV-related discrimination and discrimination in employment, public accommodations, and housing made up four of the top five priorities. The other top five priority focused on the critical need to access gender appropriate ID documents.

Not listed in Figure 2 are: dealing with law enforcement, including addressing a past criminal record (38%); immigration (17%); and family law, including parental rights (14%). We hypothesize that immigration issues rank higher among Asian/Pacific Islander and Latina/o respondents; further analysis will determine this.

The concerns about discrimination were coupled with the belief of many respondents that they were not knowledgeable enough about their legal rights. Together, these two sets of responses highlight a critical need for rights-based trainings and advocacy work specifically for transgender people living with HIV.

# Barriers to Health Care and Well Being

To better understand the healthcare barriers that transgender people living with HIV face, respondents were asked if they had ever gone six months or longer without medical care since their HIV diagnosis. 41% of respondents (n=65) indicated that they had.

Respondents who had been incarcerated or detained were significantly more likely to have gone without medical care for more than 6 months (51% of those detained versus 35% of those never detained, p<0.03).

## TOP 5 HEALTH CONCERNS

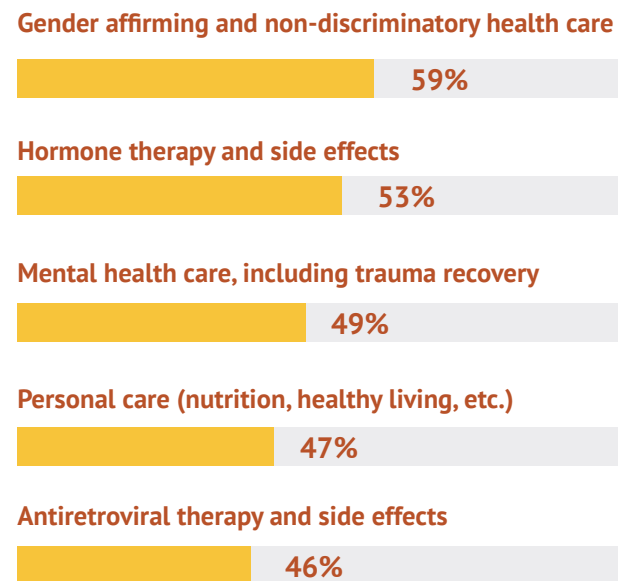


Figure 1 respondent-identified legal priorities

## TOP 5 LEGAL PRIORITIES

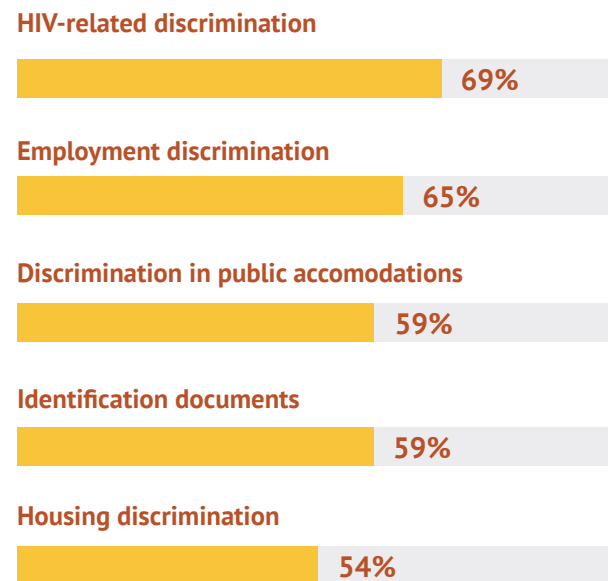


Figure 2: respondent-identified health concerns

## How confident are you that you know your rights...

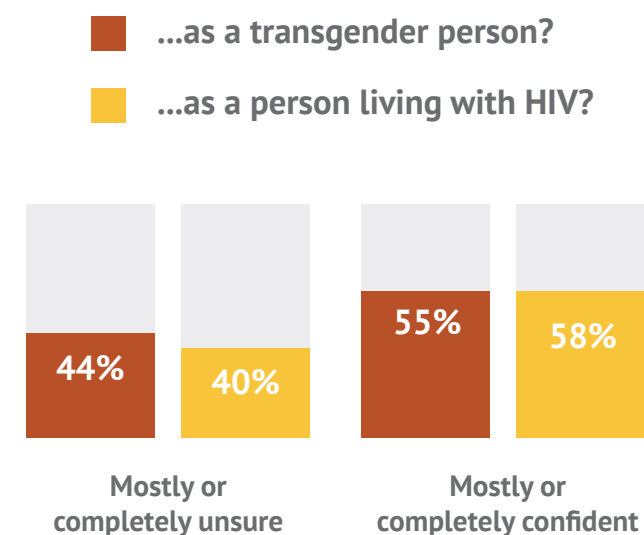


Figure 3: respondent confidence with legal rights

## Have you ever gone more than six months without medical care since your HIV diagnosis?

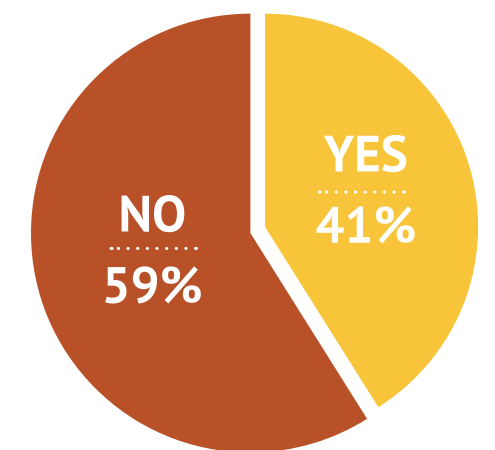


Figure 4: respondents with long gaps in health care since HIV diagnosis (N=157)

The respondents who had gone without care for more than six months were asked a further question about why this happened. The most common reason respondents reported for going without healthcare for more than 6 months was previous or anticipated discrimination by a healthcare provider (29%). Other reasons included having too many other things to deal with (20%), economic barriers such as health care costs and transportation (17%), not having a health care provider (12%), and fear that someone they knew would see them (8%),

Respondents who had gone without healthcare for more than six months highlighted costs as a barrier to health coverage. All respondents were asked about health insurance and only 80% of respondents indicated that they had health coverage. The percentage of respondents with

insurance coverage dropped dramatically for Hispanic and Latino/a respondents (67%) and African American respondents (75%) when compared with White respondents (94%). Differences for Latina/o and White respondents were significant at the  $p < 0.02$  level. When stratified by income, insured rates also showed expected disparity – 100% of respondents earning more than \$75,000 annually reported having health insurance, while only 70% of those earning less than \$12,000 did. As a group, 87% of those earning more than \$12,000 overall reported being insured, underscoring the particular vulnerability low-income people face in attaining health coverage as well as the increased likelihood that people of color experience extreme poverty.

Many respondents indicated the previous experience or expectation of mistreatment by providers. The distance that can occur between many transgender people living with HIV and their providers is at least partially demonstrated by the low number of respondents (9% to 17%) who indicated that they had providers who shared their experiences as transgender or gender non-conforming people. The clearest barrier to health and well-being reported in the survey was the outright denial of health services. Respondents indicated that they had been denied health care because they were transgender or gender non-conforming (31% had this experience) and because they were HIV-positive (20% had this experience). These high numbers reflect violations of respondents' human right to health care.

### Transphobic provider discrimination as predictor of gap in care

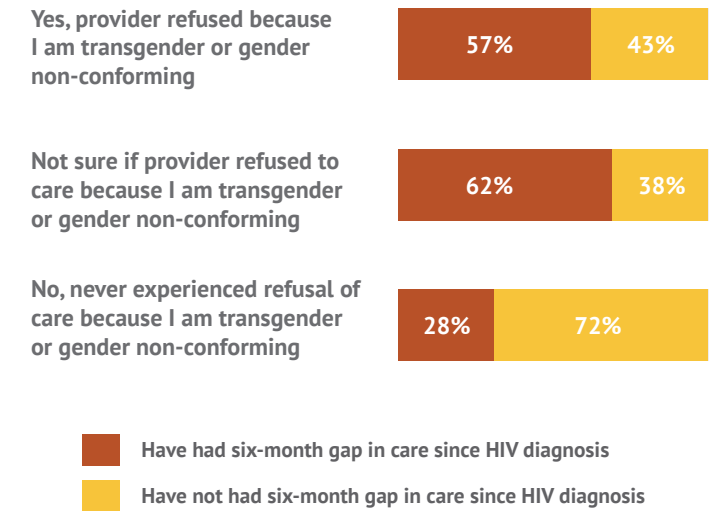


Figure 8: transphobic provider discrimination associated with gap in health care access ( $p < 0.0001$ ,  $N = 156$ )

### Are any of your health providers transgender or gender non-conforming?

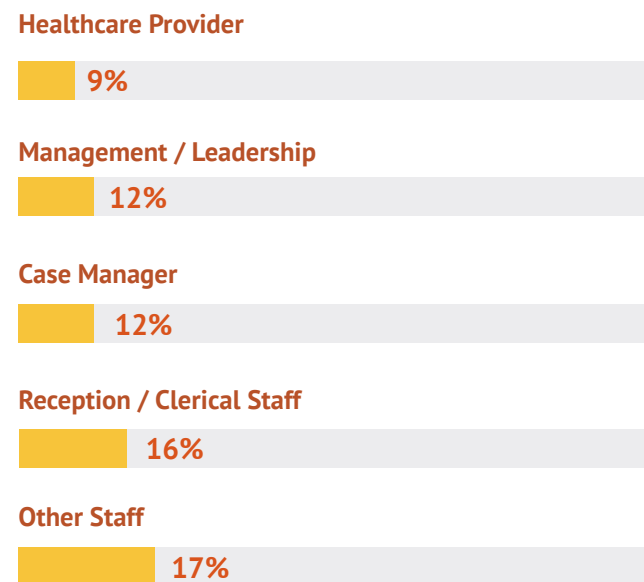


Figure 5: Percentage of respondents answering "yes" for each type of provider

### Has a health care provider ever refused you care because you are...

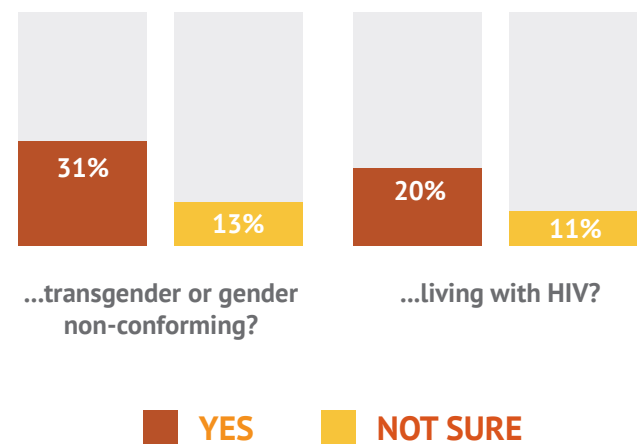


Figure 6: Respondents reporting provider refusal to treatment ( $N = 157$ )

### Has a health care provider ever refused you care because you are...

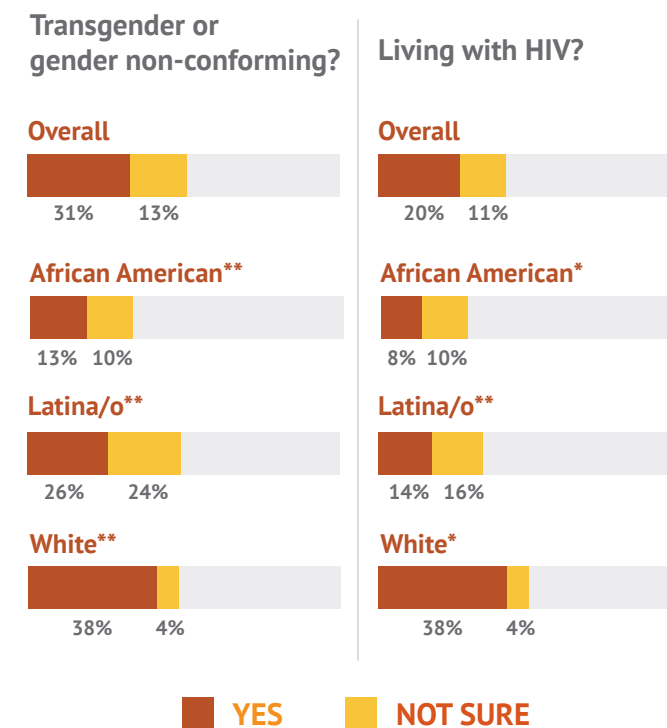


Figure 7: provider refusals broken down by race; \* $p < 0.10$ , \*\* $p < 0.01$

### Serophobic provider discrimination as predictor of gap in care

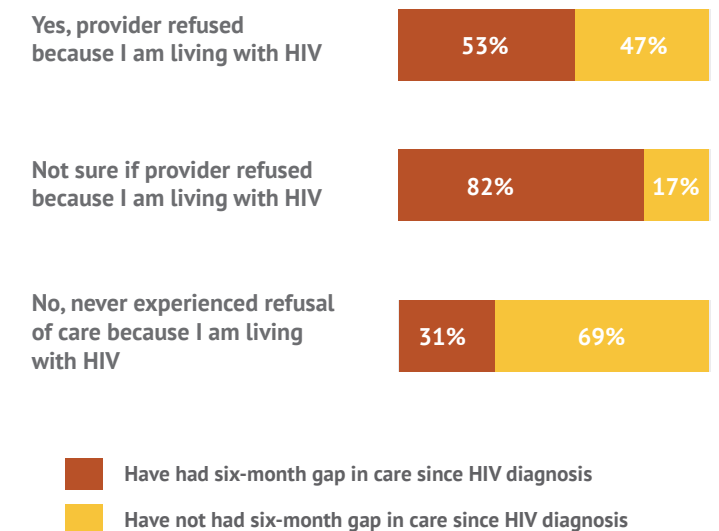


Figure 9: Serophobic provider discrimination associated with gap in health care access ( $p < 0.0001$ ,  $N = 155$ )

# Future Reports

In addition to descriptive statistics of areas of the needs assessment not covered in this initial report, future reports will include statistical inference to determine what, if any, relationships exist between variables measuring health outcomes, stigma, experiences of violence, viral load suppression, immigration, and participation in social change activism.

## Recommendations

The work of the National Advisory Board of Positively Trans and the responses to the survey by transgender people living with HIV across the U.S. demonstrate immediate and critical needs to protect transgender health and access to legal rights.

**The following recommendations are not listed in priority order as each will be required if ending barriers to care and access to legal rights are to be a reality for transgender people living with HIV.**

**The following programs and initiatives are required:**

Legal and rights-based advocacy training programs designed specifically by and for transgender people living with HIV

.....

Support systems for transgender people living with HIV who have experienced discrimination, and for those who anticipate discrimination, to be able to access care and services without fear of mistreatment

.....

Identification and development of economic initiatives to relieve the financial barriers and stresses that limit access to care, for all transgender people living with HIV with particular attention to the needs of transgender people of color

.....

Focused anti-discrimination interventions and training in gender-affirming care in healthcare facilities, combined with ongoing accountability processes to correct discriminatory actions

.....

Healthcare and service provider education and support to address the mental health needs, including the effects of trauma, of transgender people living with HIV

## Contact Us

For more information, visit [www.transgenderlawcenter.org](http://www.transgenderlawcenter.org)

# Acknowledgments

Transgender Law Center is grateful to the many people who have contributed their time and energy to Positively Trans. Without them, this work would not be possible.

## POSITIVELY TRANS TRANSGENDER LAW CENTER STAFF



**Cecilia Chung**  
Senior Strategist, Transgender Law Center

Cecilia Chung is nationally recognized as an advocate for human rights, social justice, health equity, and LGBT equality. She was the former Chair of the San Francisco Human Rights Commission and is currently serving on the Health Commission. Cecilia has been working tirelessly on the local, national and international levels to improve access to treatment for transgender people and people living with HIV, and to erase stigma and discrimination through education, policy, advocacy, and visibility.



**Anand Kalra**  
Health Programs Manager, Transgender Law Center

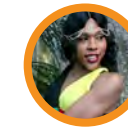
As Health Programs Manager at Transgender Law Center, Anand Kalra translates wins in law and policy into practice at the level of user experience. Coming from a background in library & information science, Anand applies systems analysis to identify breakdowns in the administration of health care in the private and public sectors, and uses this knowledge to create understandable educational materials and trainings for transgender community members and service providers. Prior to joining Transgender Law Center, Anand worked in public schools, private museums, academic libraries, and a pediatric clinic. He has ten years' experience as an activist in trans and LGB communities and holds a master's degree in Information Science from the University of Michigan.

## POSITIVELY TRANS NATIONAL ADVISORY BOARD



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Arianna Lint is a "refugee" Latina Transgender Woman who started her own organization, Translatina Florida Chapter. Previously, she served as the Director of Transgender Advocacy at SunServe, a South Florida not-for-profit social service and mental health agency serving the Lesbian, Gay, Bisexual, Transgender, and Questioning Community.



**Milan Sherry**  
New Orleans, LA

Milan Nicole Sherry is a Black Trans Revolutionist from New Orleans, Louisiana, and co-director of her own organization, Trans Dignity And Pride. As a Founding Member of the organization BreakOUT, she has been integral to her community development and campaign victories since 2010. Milan graduated from the Center for Third World Organizing's Movement Activist Apprenticeship Program in 2013, received the 2013 NOLA Unity Award for her work in the New Orleans LGBTQ community, received the POC Leader award in 2014 and the 2015 Equality Louisiana Rising Star Award.



**Channing-Celeste Wayne**  
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Channing-Celeste is a transgender woman who tirelessly advocates for improved health outcomes among people living with HIV/AIDS, especially trans women of color. Diagnosed with HIV in 1989, her first advocacy was for herself, which naturally branched outwards. She is Assistant Program Manager at Larkin Street Youth Services.



**Octavia Lewis**  
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Octavia Y. Lewis, MPA leads all transgender-related programming and services at The Hetrick-Martin Institute. She provides youth with transferrable skills needed to navigate the systems which are in place to assist them while teaching them to find their voices to advocate for themselves, educating allies on what it means to be an ally, and leading through exemplary leadership skills on living one's authentic life unapologetically.



**Dee Dee Chamblee**  
Eastpoint, GA

Dee Dee Chamblee has over 25 years of grassroots organizing experience, and is Executive Director of LaGender Inc and Co-Director of SnapCo Solutions Not Punishment Coalition. As Founder of LaGender Inc, she helps transform the environment in Atlanta, GA around trans issues such as HIV/AIDS, homelessness, mental health, incarceration, and police profiling.



**Ruby Corado**  
Washington, DC

Ruby was born in San Salvador, El Salvador. She fled a civil war when she was 16 years old. Now 43 years old, she has lived in Washington, D.C. for the past 27 years where she has devoted the last 20 years as an advocate for the inclusion of transgender, genderqueer and gender non conforming gay, lesbian, and bisexual people in mainstream society. Ruby is the founder of Casa Ruby, the only Bilingual Multicultural LGBT Organization providing life-saving services and programs to the most vulnerable in the LGBT community.

## POSITIVELY TRANS NATIONAL ADVISORY BOARD (CONTINUED)



**Tela Love**  
New Orleans, LA

Tela LaRaine Love is a trans advocate from New Orleans, Louisiana. She is co-founder of New Legacy Ministries, a grassroots organization striving to raise the voices of marginalized communities, including transgender women of color.



**Tiommi J. Lockett**  
Little Rock, AR

Tiommi J. Lockett is an African-American Trans\*woman, born and raised in Helena, Arkansas. She advocates for those living with HIV/AIDS, and has attended the 53rd annual Presidential Advisory Council on HIV/AIDS meeting, participated in a five-speaker panel discussing Medicaid expansion and the private option, and served as the Arkansas State Coordinator for AIDSWatch 2014.



**Teo Drake**  
Greenfield, MA

Teo Drake is a spiritual activist, an educator, a practicing Buddhist and yogi, and an artisan who works in wood and steel. When this blue collar, queer-identified trans man living with AIDS isn't helping spiritual spaces be more welcoming and inclusive of queer and transgender people or helping queer and trans folks find authentic spiritual paths, he can be found teaching martial arts, yoga, and woodworking to children or blogging at [www.rootsgrowthetree.com](http://www.rootsgrowthetree.com)

## In Addition

We would like to express our thanks to Laurel Sprague, Bré Campbell, Jenna Rapues, Chris Roebuck, Erin Armstrong, Collette Carter, *Poz Magazine*, *thebody.com*, *HIV Plus Magazine*, Positive Women's Network USA, the SERO Project, AIDS United, and AIDS Foundation of Chicago.

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## Endnotes

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<sup>Y</sup> Bradford, J., Reisner, S.L., Honnold, J.A. and Xavier, J., 2013. Experiences of transgender-related discrimination and implications for health: results from the Virginia Transgender Health Initiative Study. *American Journal of Public Health*, 103(10), pp.1820-1829.



## Why Transgender Women Have the Country's Highest HIV Rates

**There are a lot of factors behind this invisible epidemic, none of them good.**

By [Sunnivie Brydum](#)

April 02 2015 4:57 PM EDT

Transgender women are the fastest-growing population of HIV-positive people in the country, according to Miss Major, a 70-year-old transgender woman of color and the executive director of TGI Justice Project, a San Francisco-based advocacy organization that fights for the rights of transgender, intersex, and gender-variant people who are in prison or have served jail time.

Most experts agree with Major's assertion, but hard data backing up that reality is hard to come by since HIV data collection methods often either mistakenly categorize transgender women as men who have sex with men, or don't distinguish between transgender and nontransgender women.

This kind of systematic mislabeling and ignorance is a grim reality for many trans women, says Major. Medical professionals, police officers, and even gay and lesbian communities "go out of their way to crush us so that we feel ignored and rejected, and that our wishes and desires don't count," Major says. "There is no care for who we are and what we do."

The data validates Major's concerns. A 2009 report from the National Institutes of Health found that nearly a third of transgender Americans are HIV-positive. The study also indicated that many transgender women may not know their HIV status, due to a series of cultural, social, and economic barriers.

Transgender women of color are at an even greater risk for HIV infection than their white peers. The NIH study noted that African-American and Latina transgender women had the highest infection rates; among those transgender women of color surveyed, more than 56% of black trans women were HIV-positive, and Latina trans women had an HIV infection rate of 16%.

Transgender women often require regular hormone therapy, and many of those who can afford the out-of-pocket expense undergo various forms of gender-reassignment surgery. But with multiple medications necessary already (such as estrogen, which must be taken weekly), HIV-positive trans women are less likely to regularly use antiretroviral medication than are their nontransgender peers. The NIH study, which focused on a clinic in New York City, reported that transgender women were often concerned that HIV medication would interfere with their hormone therapy. One woman told NIH researchers that many of her fellow HIV-positive trans women prioritized hormone therapy over HIV medication: "They feel that the HIV meds would mess with the hormones, and by them being transgender, they want the hormones to work OK."

A great deal of the medication and treatment these women need is not covered by insurance, and is often



costly and difficult to obtain. To make matters worse, antidiscrimination laws rarely cover transgender women.

“In the majority of the states in the U.S., it’s legal to discriminate on the basis of gender identity,” says JoAnne Keatley, director of the Center of Excellence for Transgender Health at the University of California, San Francisco. “You can deny a person employment or you can terminate someone who is transitioning on the job merely because they are transgender.”

That kind of discrimination has a devastating effect on the economic well-being of transgender people. According to a 2011 report from the National Center for Transgender Equality, transgender people were four times more likely than the general population to live in extreme poverty, with a household income less than \$10,000 a year, and more than twice as likely as the general population to be homeless. A staggering 90% of the 6,450 transgender people surveyed nationwide reported being the target of harassment, mistreatment, or discrimination at work.

This complex web of intertwining oppression and discrimination leaves many transgender women with no option to support themselves but to turn to underground employment—most frequently by engaging in sex work.

“We have to scrounge for housing, and it puts us in the street at night to cover what we need to cover during the day,” explains Major. “It’s kind of like a merry-go-round that we’re on, and it’s difficult to stay [HIV-] negative.”

Cyd Nova, the harm reduction coordinator at San Francisco’s St. James Infirmary, a clinic for current and former sex workers, agrees that trans women are often forced to turn to sex work to support themselves.

“Sex work is a form of labor available to people who may not have many other options,” says Nova. “Sex work is also a means of empowerment for a community that often has high financial needs.”

But the effort to meet those needs runs into problems with the criminalization of sex work, which hits transgender women particularly hard. Police officers sometimes target trans women, and in several major U.S. cities, use the presence of multiple unused condoms as evidence of prostitution.

“Trans women are disproportionately profiled and targeted by law enforcement for harassment and arrest,” says Nova. “And because of policies like [using] condoms as evidence, trans women often face a choice between protecting themselves and their partners from HIV and risking arrest.”

Incarceration also plays a role in the high HIV rates. When a trans woman is arrested and jailed for prostitution—or any other crime—many prisons will house her with male inmates. Other jails keep trans prisoners in solitary confinement, often only releasing the inmate from her cell for an hour or so each day,





presumably for her protection.

“Once a trans person becomes part of that cycle of criminal injustice, it’s hard to break out of that,” says Keatley.

While sex workers in general are more likely to be HIV-positive than those who do not engage in sex work, transgender female sex workers are at four times greater risk for contracting HIV than other female sex workers, according to an international analysis published in 2008 in the Journal of Acquired Immune Deficiency Syndromes.

Further complicating efforts to combat HIV among transgender people is that population’s basic lack of access to medical care. The 2009 NIH study examined one community-based health clinic in New York City and identified a number of reasons that transgender women aren’t seeking preventive health care, including limited access to low-cost care and safe, trans-inclusive medical environments, along with the incompetence of many doctors about basic transgender health care, which results in trans women feeling unsafe to disclose their HIV status.

The combination of social stigma, institutional discrimination, economic hardship, and distrust of medical professionals creates a major barrier to connecting transgender women with HIV-related care.

“Not much HIV-prevention messaging is aimed toward or accessible to trans people,” says Nova. Noting that most HIV-prevention programming is for gay and bisexual men, Nova argues that current prevention efforts don’t meet the needs of HIV-positive trans women.

When this reality is layered with the medical profession’s lack of understanding around transgender health care, the result is an identity that is stigmatized and often treated as psychiatric illness. Given that, Nova says, “it is no wonder that trans people are hesitant to come into contact with HIV care, which in turn multiplies the risk of transmission.”

Tags: [Stigma](#)



# HIV Specialist



## Transgender Health

Excellence in  
the Care of  
Trans Patients

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Women & PrEP

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Hormone  
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A TIP FROM A  
**FORMER  
SMOKER**

**HIV alone  
didn't cause the  
clogged artery  
in my neck.  
Smoking with  
HIV did.**

*Brian, age 45, California*

*Brian had his HIV under control with medication. But smoking with HIV caused him to have serious health problems, including a stroke, a blood clot in his lungs and surgery on an artery in his neck. Smoking makes living with HIV much worse. You can quit.*

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BY JAMES M. FRIEDMAN, MHA  
EXECUTIVE DIRECTOR, AAHIVM

The Academy will greatly miss Ken's leadership, insight and passion for advancing the care and treatment of HIV patients.

## Making a Change for Good

**MET KEN SOUTH** on my first day as executive director of the Academy in September, 2007. When I joined AAHIVM, Ken had been with the organization for only six weeks as director of membership. Ken did an excellent job building and managing the AAHIVM membership until he transitioned over as head of credentialing following the untimely passing of Director Peter Fox in 2012.

Under Ken's leadership, the Credentialing Program doubled in size, the credential for HIV Pharmacists (AAHIVP) was introduced, and the credentials were extended to three years. The Academy will greatly miss Ken's leadership, insight and passion for advancing the care and treatment of HIV patients.

But on a personal level, it will be me who will miss him the most. He was the only one on staff that I could talk to about black and white TV, the Studebaker, the Kingston Trio, or Vice President Nixon. Thankfully, he will be staying on for one day per week to direct and manage our HIV and Aging project—which he developed.

We have been fortunate to find and hire Dan Ebeling, who held a management position at the Registry of Interpreters for the Deaf (RID), where he was responsible for the management and growth of their credentialing program. The RID program is both larger and more complicated than our credentialing program in that it included over 1,800 individual exams per year, including management of a network of over 40 remote test sites. Dan will provide a fresh perspective and new insight into strategically growing our credentialing program. I have no doubt he is the right person to accept the baton from Ken as we continue to run the race to end this epidemic.

Besides providing a forum for me to thank Ken and welcome Dan, this is an important *HIV Specialist* because it explores a topic many of our providers have asked us to cover, transgender health.

While the transgender community has been in the news as a topic of societal debate, one fact is not debatable: the provider community wants and needs to learn more about the unique health challenges facing transgender individuals.

As it relates to HIV, studies reveal high HIV prevalence rates among transgender women in the United States, with African-American transgender women being more likely to have HIV than transgender women

of other races/ethnicities. We know that many social and structural factors pose challenges to preventing HIV among transgender people. This edition explores many of those issues, along with clinical insight into treatment and prevention.

I would like to extend my sincerest gratitude to Dr. Asa Radix and Dr. Peter Meacher of Callen-Lorde Community Health Center in New York, NY, for serving as our guest editors for this issue. The pages that follow provide the valuable insight into transgender health that our providers requested, thanks to their contribution and their collaboration with top experts in the field. **HIV**



James M. Friedman

*James M. Friedman*

## HIV Workforce Crisis

**THANK YOU** for writing that important piece in the March *HIV Specialist* about the HIV workforce crisis.

I wanted to let you know that there is another FM-based HIV fellowship, now in its second year, that I started at UMass in July of 2014, in response to the need you outline in your article and the NHAS.

Here is a link to our homepage: <http://www.umassmed.edu/fmch/fellowships/hiv/>, which is listed on both the AAHIVM and HIVMA websites.

I was the lead author on the most recent AAFP HIV/AIDS Curriculum Guideline you mentioned, and Jeff Kirchner was a contributing editor.

Later this month the *FP Essentials Monograph Care of the HIV Patient* will be published, written by myself and three of my colleagues at UMass/Worcester. <http://www.aafp.org/cme/subscriptions/fp-essentials/editions/443-ed.html>, and here is the link to the AAFP Curriculum Guideline: [http://www.aafp.org/dam/AAFP/documents/medical\\_education\\_residency\\_program\\_directors/Reprint273\\_HIV.pdf](http://www.aafp.org/dam/AAFP/documents/medical_education_residency_program_directors/Reprint273_HIV.pdf)

Along with Chris Bositis, of Lawrence, MA, I am also the STFM HIV Working Group Co-Chair. Chris runs an HIV AOC in Lawrence, and we are both committed to addressing the HIV workforce shortage.

I thought that I should put Chris's and my name on your radar given our similar professional passions in this area.

Thank you,

**Phil Bolduc**

HIV Program and Fellowship Director  
Assistant Professor of Family Medicine and Community Health  
University of Massachusetts Medical School  
Family Health Center of Worcester

**THE ISSUE** of primary care physician shortages is very concerning for the healthcare delivery in our nation. I was pleased to read that one solution to this shortage is to engage more nurse practitioners into providing HIV care in the article titled "One solution to looming physician shortage" in the March 2016 issue of *HIV Specialist*.

It is a fact that as of March 2016, only 21 states and the District of Columbia, allow nurse practitioners full scope authority/practice; however, the three states mentioned as having the highest prevalence of HIV (New York, California, and Florida) ALL have restricted scope of practice. The article

states California has full scope authority/practice, which it does not.

Thank you for your time and for addressing that nurse practitioners are an integral solution to the overall transformation of healthcare delivery.

Sincerely,

Aimee Castellon-Maestri,  
RN, BSN, DNP student **HIV**





## Dan Ebeling Joins AAHIVM as Credentialing Director

**AAHIVM** WELCOMES DAN EBELING as our new Credentialing Program director. Ebeling was chosen from over 100 applicants to replace the retiring Ken South as director.

South's last day at the Academy was June 30, marking the ninth anniversary of what he describes as the pinnacle of his impressive 45 year-long career.

"I absolutely feel that the Academy has been the perfect fit for me because I have been able to apply my knowledge of my life experiences with the epidemic with the autonomy and creativity I crave," said South. "Best of all, are the countless fond memories of the relationships with AAHIVM staff, board and members. My life has truly been enriched because I was lucky enough to be a part of the team!"

South joined AAHIVM nine years ago as the membership director, then transitioned to head the credentialing department. Following his retirement, South will consult for AAHIVM, continuing to oversee the organization's HIV and Aging Consensus Project, developed to assess how the presence of both HIV and common age-associated diseases alter the optimal treatment of HIV as well as other co-morbidities.

After earning his Masters of Divinity degree in 1972, South founded the GLBT Coalition of the Connecticut Conference of the United Church of Christ and was co-founder of the Hartford Gay & Lesbian Health Collective. He began his HIV career at the height of the epidemic with AID Atlanta and has worked with the AIDS National Interfaith Network, AIDS Action, the AIDS Institute of KOBAs Associates, and the President's Commission on the AIDS Epidemic.

"There is no doubt that Ken has made a significant contribution to the fight against HIV and AIDS throughout his career," said AAHIVM Executive Director James Friedman. "Just as the HIV community has benefited from Ken's passion for the cause, so too has the Academy. I consider it an honor to have worked with him and wish Ken all the best in this next chapter of his life."

New Credentialing Director Dan Ebeling most recently held the Certification Management position at the Registry of Interpreters for the Deaf (RID), where he was responsible for the management and growth of their credentialing program. Ebeling oversaw the administration of over 1,800 individual exams per year including management of a network of over 40 remote test sites. He excels in working directly with subject matter experts, volunteer committees and association leadership.

"We are confident that Dan will be an asset to our organization because of his extensive experience in leading a successful certification program," added Friedman. "I welcome his new perspective, fresh ideas and passion for strategically growing the AAHIVM credentialing program."

The AAHIVM three-year professional certifications are the first and only credentials offered to physicians, nurse practitioners, physician assistants and pharmacist specializing in advanced level HIV care. The HIV Specialist (AAHIVS) credential is available to practicing frontline care clinical providers, while the HIV Expert (AAHIVE) designation can be earned by non-practicing practitioners. The HIV Pharmacist (AAHIVP) certification is available to HIV-specialized pharmacists.

"AAHIVM has an established credential that promotes a high quality standard of care for HIV patients, and I'm excited to be joining a team that is focused on such an important mission," said Ebeling. "I'm looking forward to continuing the growth of a reliable and relevant credentialing system to ensure that HIV patients receive the best of care."

Ebeling began this new chapter with the Academy on June 1 in order to have the opportunity to work in conjunction with South prior to his retirement.



HIV



# In the NEWS

## CDC Offers New Materials Featuring Transgender Women Living with HIV

**T**HE U.S. CENTERS for Disease Control and Prevention (CDC) is expanding its Act Against AIDS portfolio to bring more visibility to transgender women. The most recent addition brings three new digital story videos, posters, web banners, and palm cards to the HIV Treatment Works campaign, which encourages people living with HIV to stay in care.

CDC and its partners are pursuing a high-impact prevention approach to achieve the goals of the *National HIV/AIDS Strategy: Updated to 2020*, which includes goals and recommendations specific to transgender persons. Activities associated with these endeavors include funding and supporting community-based organizations in their efforts to improve services for transgender persons with a particular focus on transgender women of color, on the HIV care continuum.

Although many transgender people have difficulty finding health care providers who understand their unique challenges, there are positive stories that demonstrate excellent patient/provider relationships. One of these stories comes from Jamie, who describes her HIV care provider in her own digital story. “I can’t say anything negative about [my doctor]. She’s very positive and she has a lot of resources. She’s been helpful in getting me to feel comfortable with this process and not feel like I’m completely lost.”

To view Jamie’s and other digital stories like hers, or share them with your patients, visit [www.cdc.gov/hivtreatmentworks](http://www.cdc.gov/hivtreatmentworks). In addition to *HIV Treatment Works*, transgender women are also featured in the *Doing It* and *Let’s Stop HIV Together* campaigns. Other materials regarding HIV prevention and treatment in the transgender community, as well as resources for HIV care providers who are working to address transgender needs, will be added in the future. All of these materials are available at no cost and can be ordered directly from CDC-INFO at [www.cdc.gov/cdc-info](http://www.cdc.gov/cdc-info).

“HIV, you have no power here. And if it's between you and me, I guarantee I'll win.”

Jamie – Atlanta, GA  
Living with HIV since 2015.

**HIV TREATMENT WORKS**

When I was first diagnosed with HIV, I felt like I would never have a strong quality of life again. But life does not end with an HIV diagnosis. I formed a strong, honest relationship with my medical provider and together we created a plan to keep me healthy. I want to encourage other transwomen living with HIV to take care of themselves by taking their medication, and taking time to do what makes them happy. There is light at the end of the tunnel, and you can live a full and amazing life as long as you stay in care and prioritize your health.

Get in care. Stay in care. Live well.  
[cdc.gov/HIVtreatmentWorks](http://cdc.gov/HIVtreatmentWorks)

## ‘DO ASK, DO TELL’ TOOLKIT Provides Pathway to LGBT Data Collection for Providers

THE FENWAY INSTITUTE and the CENTER FOR AMERICAN PROGRESS have launched a project to help health care providers and other health system stakeholders collect sexual orientation and gender identify (SOGI) information in clinical settings. The project’s goal is to promote better understanding of the specific health issues facing lesbian, gay, bisexual, and transgender (LGBT) individuals and improve health outcomes for this population.

At the heart of the campaign is the “Do Ask, Do Tell” toolkit ([www.doaskdotell.org](http://www.doaskdotell.org)), which provides tested sexual orientation and gender identity questions that are recommended by national LGBT organizations and which have been shown to work with diverse patient populations served by community health centers in the U.S. The toolkit focuses particularly on electronic health records (EHRs), which are at the heart of the multi-year federal “Meaningful Use” initiative that promotes a transition from paper to electronic records in clinical settings. In fall 2015, the federal Department of Health and Human Services released a final rule for the third and final stage of the Meaningful Use program that requires certified EHR systems to have the capacity to collect structured data on sexual orientation and gender identity.

The toolkit describes how to collect SOGI data in EHRs, how to use these data to support clinical processes such as ensuring that transgender individuals receive anatomically appropriate screenings and care, and how to train clinical staff to interact with LGBT patients in ways that are affirming and welcoming. As part of a partnership with the National LGBT Health Education Center ([www.lgbthealtheducation.org](http://www.lgbthealtheducation.org)), the toolkit also highlights other resources that health care providers can use to offer culturally and clinically competent care reflective of their LGBT patients’ unique needs.

# In the NEWS

## Biomarker Tracks Accelerated HIV-Associated Aging

**B**Y MEASURING A MOLECULAR SIGNATURE OF AGING, researchers have found that HIV infection accelerates aging, adding an average of five years to an individual's biological age.

The more rapid aging is occurring in people receiving antiretroviral treatment, so that even though treatment enables them to live for many decades, they remain at higher risk of aging-related chronic disease.

The National Institute of Mental Health, in an AIDS.gov blog, said that studies of people with HIV infection have noted a higher risk of diseases associated with aging, such as liver and kidney failure, cancer, and heart disease.

While the observations have suggested that HIV infection causes accelerated aging, there hasn't been a biologically based marker of aging with which scientists could clarify and quantify the impact of HIV on aging.

In search of such a marker, scientists at the University of Nebraska Medical Center, led by Howard Fox, M.D., Ph.D., in collaboration with scientists at the University of California, San Diego School of Medicine, led by Trey Ideker, Ph.D., turned to epigenetics, a term for changes to DNA that affect its function without altering the sequence of bases that make up DNA. Through epigenetic processes, experience can alter the genome, silencing or activating genes.

Building on information from previous research on methylation and aging, the team found that methylation tracked well with chronological age in those without HIV. In HIV-positive individuals, however, the changes in methylation were accelerated, adding an average of five years to "epigenetic" age. This fast forward occurred even in those who had had HIV for short duration, less than five years. Previous models found that aging-related changes in methylation parallel increases in mortality; the changes found here in HIV positive patients suggest a 19% increase in mortality.

The team also found that one region of the genome was particularly rich in HIV-associated changes in methylation: this region, the human leukocyte antigen locus, encompasses genes that encode molecules that are central to immune responses. The authors suggest that epigenetic processes may contribute to the changes in regulation of this region of the genome and thus the progression, or control, of HIV.

The work provides an objective method of assessing the impact in individuals of HIV on biological age. It provides insight into the mechanisms behind the accelerated aging, and may offer a means of identifying individuals vulnerable to aging-related chronic disease, and who may benefit from more careful attention to monitoring and preventive treatments. Given epigenetic changes observed in the HLA region, it may provide clues to future approaches to controlling infection.

To read the complete blog, please visit <https://blog.aids.gov/2016/04/biomarker-tracks-accelerated-hiv-associated-aging.html>



## President Obama Reflects on 35th Anniversary of HIV/AIDS in America

**N**OTING THAT FIVE YEARS AGO HE SAID that an AIDS-free generation was within reach, President Obama recounted advances that have been made and said "the global community" is committed to ending the epidemic by 2030.

"This will take American leadership, smart investments, and a commitment to ensure that all communities are heard and included as we move forward," the President said.

Over these 35 years, he said, "We've learned that stigma and silence don't just fuel ignorance, they foster transmission and give life to a plague." But, he added, "We've seen that testing, treatment, education, and acceptance can not only save and extend lives, but fight the discrimination that halted progress for too long."

"We've invested in research and evidence-based practices that have given us revolutionary tools like treatment as prevention and pre-exposure prophylaxis," Obama said. "We've made critical investments to help eliminate waiting lists for the AIDS Drug Assistance Program. We've continued efforts to support the promise of a vaccine. And the Affordable Care Act has resulted in millions of individuals gaining affordable, high-quality health coverage—all without denial for pre-existing conditions like HIV."

There is more work to do, said the President. "The economically disadvantaged; gay and bisexual men, especially those who are young and Black; women of color; and transgender women all continue to face huge disparities—I'm confident that if we build upon the steps we've taken, we can finish the job," he said.

## Johns Hopkins Performs First Transplants Between HIV+ Donors and Recipients

**I**N MARCH, Johns Hopkins Medicine in Baltimore, MD performed the first liver and kidney transplants from an HIV-positive donor to recipients who are also HIV-positive.

The transplants were made possible by the bipartisan HIV Organ Policy Equity (HOPE)

Act passed by Congress and signed by President Obama in 2013. In February, Hopkins became the first U.S. hospital to be approved for the transplants from the United Network for Organ Sharing, which had banned transplantation of organs from HIV+ patients since 1984.

In the surgeries, one donor provided a liver to one recipient and a kidney to another.

The new law was drafted with the help of Dorry L. Segev, MD, a Johns Hopkins associate professor of surgery, who had watched organs from HIV-positive donors being wasted while HIV-positive patients awaiting transplants died. Dr. Segev led the team that performed the transplants.

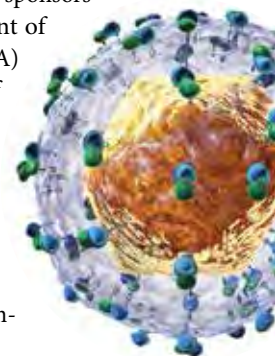


Dr. Dorry Segev (right), of Johns Hopkins Medicine, led the team of doctors who transplanted organs from an HIV+ patient into two different HIV+ patients in March.

## Chronic Hep C Virus Infection: Developing Direct-Acting Antiviral Drugs *Industry Guidance*

The Food and Drug Administration (FDA) has issued guidance to assist sponsors in the clinical development of direct-acting antiviral (DAA) drugs for the treatment of chronic hepatitis C. The guidance is intended to serve as a focus for continued discussions among the Division of Antiviral Products pharmaceutical sponsors, the academic community, and the public.

The guidance is available at [http://www.fda.gov/downloads/Drugs/GuidanceComplianceRegulatoryInformation/Guidances/UCM225333.pdf?source=govdelivery&utm\\_medium=email&utm\\_source=govdelivery](http://www.fda.gov/downloads/Drugs/GuidanceComplianceRegulatoryInformation/Guidances/UCM225333.pdf?source=govdelivery&utm_medium=email&utm_source=govdelivery)



## Pentagon to End Transgender Troops Ban

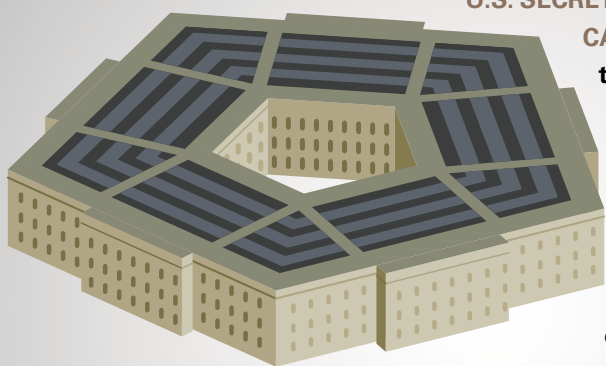
U.S. SECRETARY OF DEFENSE ASHTON B.

CARTER ANNOUNCED JUNE 30 that the armed services' ban on transgender members is being repealed.

The decision comes as the military has undergone major changes in the role of women and the inclusion of gays, lesbians and bisexual service members.

Defense Secretary Ashton B. Carter said last July he was establishing a working group to research transgender military service and set a six month deadline for completion of its work. However, the process has taken nearly a year.

Under the Pentagon's previous policy, transgender people could be discharged, although last year that policy was modified to move the discharge authority to higher levels in the military, making it harder to force out transgender troops. But the lack of a new, clear policy created complications for transgender soldiers as well as their commanders, including questions about gender-specific uniforms, grooming requirements and bathroom usage.



## Feds Launch HIV Health Improvement Group for Medicaid Programs

**T**he Centers for Medicaid Services (CMS), the Centers for Disease Control and Prevention (CDC) and the Health Resources and Services Administration (HRSA) announced June 24 the launch of new joint initiative, the HIV Health Improvement Affinity Group.

The new entity will bring together state public health and Medicaid and Children's Health Insurance Program CHIP agencies to collaboratively improve health outcomes for enrollees living with HIV by identifying opportunities to strengthen the HIV care continuum among those populations.

An AIDS.gov blog said participating state public health and Medicaid/CHIP programs can learn about, and share, best and promising approaches with their state peers to improve viral load suppression among people living with HIV who are enrolled in Medicaid and CHIP.

Read more at <https://blog.aids.gov/wp-content/uploads/HIV-Health-Improvement-Affinity-Group.pdf>.

HIV

# FROM THE MARGINS TO THE

## Challenges Remain for Transgender Health, Best Practices Needed for Proper Care

ASA RADIX, MD, MPH, AAHIVS and PETER MEACHER, MD, AAHIVS

**O**VER THE LAST FEW YEARS transgender individuals have gained greater visibility in the mainstream media, appearing on the cover of *Time* magazine and *Vanity Fair* and prominently featured on both the small and big screen. What is missing however are transgender narratives that accurately portray day-to-day life experiences faced by the majority of transgender people.

Transgender individuals, especially transwomen of color, encounter extremely high rates of stigma and discrimination, including social rejection, verbal, physical and sexual assault, exclusion from employment opportunities and housing, and yes, even access to public restrooms<sup>1,2</sup>. It is no surprise that transgender persons experience higher rates of psychological distress, including anxiety, depression and suicidality<sup>3,4</sup>.

Although research in this population is limited, it has been evident for some time that transgender women have disproportionately high rates of HIV infection, with estimates that about one in five transwomen are HIV-positive<sup>5,6</sup>. HIV risk factors include higher rates of sex work<sup>7</sup>, lower rates of condom use<sup>8</sup>, sexually transmitted infections<sup>9,10</sup>, co-occurring mental health issues and substance use<sup>4,11,12</sup>. Studies have shown that transgender people avoid necessary medical care due to healthcare discrimination, including denial of care, facing harassment and abuse, and encountering providers who are uninformed about their health

care needs<sup>13</sup>. This avoidance of health services leads to poorer health outcomes, including lower rates of viral suppression for those who are HIV-infected<sup>14,15</sup>.

This issue of *HIV Specialist* highlights both unmet needs and best practices for the care of transgender individuals. This is extremely timely considering the recent statements from experts in the field that “the majority of health-care needs can be delivered by a primary care practitioner.”<sup>16</sup>

Dr. Steven R. Klemow (Influence of Integrated Transgender Healthcare on ART Adherence and Outcomes) provides a first-hand perspective from his decades’ long experience working with transgender persons, including an overview of HIV care continuum and the importance of integrating gender affirming care in a medical practice.

Linda Wesp and colleagues (Excellence in the Care of Trans Patients; expanding the base of gender affirming healthcare professionals) discuss

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# MAINSTREAM

gaps in medical education that result in many health professionals lacking knowledge to care for sexual and gender minorities. The authors provide concrete recommendations to improve curricula and institutional culture to enhance the delivery of culturally competent and appropriate care to transgender clients. This article also provides links to clinical practice guidelines and online educational resources in transgender health.

What does it mean to provide gender affirming services in your practice setting? Andrew Goodman (Culturally Sensitive In-Office Care for the TGNC Patient) gives a step-by-step guide to creating a safe environment, and best practice tips for history taking and physical examination.

Some transgender clients may opt to initiate hormone therapy. Dr. Meera Shah (Transgender Hormone Therapy; Practical guidelines for the HIV care provider) provides an overview of the feminizing and masculinizing hormone protocols as well as recommendations about laboratory monitoring.

Finally, Elena Cyrus, et al, discuss the current status of PrEP use and the need to scale up prevention services to transgender women. She outlines some of the barriers to PrEP use and provides an agenda to address educational, research and funding gaps.

This issue provides a unique look at some of the HIV-related health concerns affecting transgender people, predominantly transgender women. Many issues are not fully addressed here, such as the health needs of transgender men and those of non-binary people, who have largely been excluded from HIV-related research. Although greater visibility has been achieved for transgender people, there is still much more to do to ensure health equity for this population. **HIV**

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#### ABOUT THE AUTHORS

**Asa Radix, MD, MPH, AAHIVS**, is the Director of Research and Education and an

infectious disease physician at the Callen-Lorde Community Health Center in New York City. Asa has 20 years experience working with transgender clients and is the clinical associate editor of *Transgender Health*.



**Peter Meacher MD, AAHIVS**, is a Board Certified Family Physician and has been Chief Medical Officer

of Callen-Lorde Community Health Center since 2013. He was Chief Resident and then a Faculty Development Fellow at Montefiore's Department of Family Medicine from 1995-1999. In the South Bronx he worked for 14 years as an HIV and Primary Care Provider, becoming the Medical Director of a federal qualified health center and developed programs in HIV & transgender care. A founder of what became the Bronx Community Pride Center, he was active in Bronx LGBT community organizing from 1995-2005.





# EXCELLENCE IN THE **Care** OF TRANS PATIENTS

## Expanding the Base of Gender-Affirming Healthcare Professionals

BY LINDA WESP, RN, MSN, NP-C, AAHIVS, OSCAR E. DIMANT, MD CANDIDATE and TIFFANY E. COOK, BGS

**T**HE WORD “TRANSGENDER” IS AN UMBRELLA TERM used to describe individuals who have a gender identity different than the sex they were assigned at birth. Transgender people face health disparities that research suggests are linked to societal stigma, discrimination, and denial of civil and human rights<sup>1,2</sup>.

According to the National Transgender Discrimination Survey<sup>3</sup>, over 19% of transgender respondents were refused medical care and 28% postponed medical care when sick or injured due to discrimination or inability to pay.

When presenting for care, 50% of transgender people reported having to teach their medical providers about transgender-related healthcare needs. Of the patients who had a health care provider deny them care, 60% attempted suicide, in stark comparison to the 4.6% rate of the general U.S. population who report a lifetime suicide attempt.

It is imperative and urgent that we address these health disparities. This article reviews some background and gaps in practice and education, and advances a recommendation for a three-pronged approach to improve the healthcare climate for transgender patients: improved education, community-based action, and commit to ongoing assessment and sharing knowledge.

### Background

Healthcare professionals currently do not receive consistent or comprehensive training regarding transgender patients. In a 2011 survey of allopathic and osteopathic medical school deans in the United States and Canada, the median number of hours spent on sexual and gender minority populations in medical school education was approximately five<sup>4</sup>.

The authors also found that although 97% of schools reported education about sexual orientation to include questions about a history of sex with “men, women, or both,” only 30.3% taught about gender transitioning. A survey of nursing faculty in baccalaureate nursing programs found that the median time devoted to sexual and gender minority health was about two hours, and that the knowledge, experience, and readiness for teaching LGBT health topics was limited among baccalaureate faculty<sup>5</sup>.

Faculty members and healthcare professionals can choose to seek out continuing

education to improve knowledge and competence in caring for transgender populations; numerous educational opportunities exist and are outlined in the online resources box below. However, evaluation of the impact of continuing education on patient care outcomes has been limited.

Knowledge cannot be assumed to lead to behavior change, improved quality of care, or improved patient outcomes. Therefore, assessing learning regarding clinical behavior changes through knowledge-based questions alone is considered insufficient.

### Recommendations

To transform the healthcare experiences of transgender patients, we suggest a three-pronged approach: improved institutions, education, and climate; community-based action; and a commitment to ongoing assessment and information sharing.

These are iterative, rather than sequential steps that are core aspects of expanding our capability to care for transgender communities. All three are necessary and serve to support each other.

**Key components for developing gender-affirming providers include openness to learning, honesty about what is not known, and self-reflexivity when mistakes are made.**

**Understanding the difference between cultural humility and cultural competence is also crucial.**

At the center of this recommendation is the concept of cultural humility. Cultural humility is defined as openness, self-awareness, egolessness, supportive interactions, and self-reflection/critique<sup>6</sup>. Entrenched norms of gender binary, lack of exposure to transgender identities, and/or biased cultural narratives about transgender people contribute to a situation in which the majority of healthcare providers, educators, and support staff within healthcare institutions are not ready to care for transgender patients.

Key components for developing gender-affirming providers include openness to learning, honesty about what is not known, and self-reflexivity when mistakes are made. Understanding the difference between cultural humility and cultural competence is also crucial, with the latter being a “detached mastery of a theoretically finite body of knowledge”<sup>7</sup>.

Therefore, all efforts should continually seek to encourage a lifelong commitment to self-evaluation in order to redress power imbalances, as opposed to solely memorizing information. With this foundation, healthcare providers will be well on their way to becoming professionals the transgender community can trust and collaborate with.

**Improve Institutions, Education, and Climate:** A crucial step in expanding the base of gender-affirming healthcare professionals is to prepare future graduates to care for transgender patients and to ally themselves with the community. Learning

objectives in mandatory curriculum for health professions students should cover information about emergency and routine healthcare needs that may be the same or different for cisgender and transgender patients. It should also include information about social determinants of health and disparities. Resources for health professions faculty regarding education and collaboration can be found in the online resources box.

Students should be encouraged to participate in skill-building opportunities to learn appropriate clinical interactions with transgender patients in situations both related and unrelated to gender transition. One recommended modality is simulation and the use of transgender standardized patients or teaching associates<sup>8</sup>. In addition to assisting students in developing new skills and achieving authentic interactions, standardized patient employment opportunities for transgender individuals, an oft underemployed population, provide compensation and shift the power dynamic between the cisgender professional and the transgender patient. In addition to focusing on student trainees, training the current healthcare workforce is crucial. Several new studies explore large-scale educational interventions. One training covered basic terminology, transgender identity, common stressors, health disparities, transitioning (social, medical, and surgical), allyship, primary care and transition related care, intake/registration concerns, and billing concerns in two-hour training sessions for 35 administrators and providers across four months<sup>9</sup>.

Embedded within these topics are important sub-topics, including barriers to care, HIV prevention, gathering sexual orientation and gender identity data formally and regularly, caring for partners and families, gathering a sensitive and comprehensive sexual health history, and making appropriate referrals to social work and mental health providers.

Findings included improved post-training scores on attitudes towards transgender individuals, increased awareness of transphobic practices, and increased readiness to serve transgender populations. Another training covering similar content provided a six-week modular health education curriculum focused on health care for LGBT elders to over 800 nurses over a three-year period. They found post-test knowledge gains across all modules, but were unable to measure long-term outcomes<sup>10</sup>.

A theory-based strategic plan for implementing institutional and educational change can enhance didactic trainings. Often underutilized in bio-medicine, paradigm and theoretical approaches are intrinsic to the development of effective curricula.

We recommend utilizing a transformative paradigm that helps learners identify their own assumptions about gender and reframe them through interactive discourse<sup>11</sup>. When seeking to train the local current workforce, a needs-assessment (discussed further below in *Community-based action*) can establish goals.

Within the strategic plan, structural needs (policies, procedures, etc.) along with professional development needs are



considered for every student, staff member, and volunteer who comes in contact with patients. When there is sufficient momentum to move forward with training, delivery methods and content should be considered.

Identify potential educators and internal champions for both trainee- and professional-level education. A committee that is dedicated to the longitudinal outcomes of transgender experience within the institution should be developed and provided with the tools to move forward. Consider that some learners benefit more from a problem-based learning environment in which they are challenged to solve a problem without guidance from an instructor, while others learn best in web-based courses which allow time to critically reflect and work through definitions and information without group process.

**Community-based action:** When seeking to develop change within a system, it is critical that we do not postpone immediate action while working towards development of the best possible care system.

Healthcare providers who are interested and able to provide care for transgender people can begin to do so immediately, following established practice guidelines provided in Online Resources for Healthcare Professionals sidebar. While this may increase capacity in the short-term, further steps must be taken to establish partnerships with the local community to assess needs and plan longer-term actions.

Transgender people may be of any age, race, ethnicity, ability, or socioeconomic status, and they present with a wide variety of healthcare needs. Lack of training for healthcare providers leads to provider ambivalence and uncertainty during the healthcare encounter and anticipation by transgender people that their needs will not be met<sup>12</sup>.

This process cannot be ignored, especially considering that many patients have already had negative personal or communal experiences with healthcare professionals, as documented in the National Transgender Discrimination Survey<sup>3</sup>. Given this, it is essential to build trust and genuine collaboration between the healthcare system and the transgender community that is grounded in community-based action.

Establishing partnerships can occur through identifying initial leaders within the local community and reaching out to them. Community Advisory Boards or Community Participatory Action Research are powerful ways for institutions to receive feedback, engage in critical reflection, and enable community members to fully participate in their care.

These strategies will help provide the data necessary for a thorough needs-assessment that is necessary to train the workforce and create systems appropriate for the local communities. James et. al documents one formation of a Community Participatory Action Board, tracking its development into a rich resource that was effective in reaching their goals and building trust with the community<sup>13</sup> and this is consistent with previous research suggesting that



## GLOSSARY

The following terms may be used throughout the article and are important concepts in gender-affirming healthcare.

**GENDER IDENTITY:** One's sense of self as female, male, a blend of both, a third gender, or no gender.

**GENDER EXPRESSION:** How one presents one's gender to the world; may include expression through behavior, clothing, haircut or voice.

**TRANSGENDER:** An umbrella term used to describe individuals who have a gender identity different than the sex they were assigned at birth. May include individuals who identify as genderqueer, gender fluid, transsexual, gender nonconforming, or agender.

**GENDER NON-CONFORMING:** A term describing people who do not conform to societal expectations of how they should express their gender; may also include people who have a gender outside of the gender binary.

**GENDER BINARY:** A gender system that classifies sex and gender into two distinct and opposite categories of male/female and masculine/feminine.

**GENDER-AFFIRMING:** Positive attitudes, language, and behaviors that are consistent with someone's authentic gender identity. For example, using greetings, names, and pronouns that validate authentic identified gender as opposed to ignoring or negating it.

**GENDER TRANSITION:** The individualized process of modifying social gender expression and/or physical secondary sex characteristics to align with authentic gender. May include some, all, or none of the following: change in hairstyle, clothing, name, pronouns; masculinizing or feminizing hormone therapy; gender confirming surgeries.

**CULTURAL HUMILITY:** When someone is open, self-aware, egoless, supportive, and engaged in ongoing self-critique when dealing with others who are culturally different from themselves.



participatory research is a valuable tool with great potential to address health disparities<sup>14</sup>.

Commitment to ongoing re-assessment and sharing knowledge: Finally, building the capacity to care for transgender patients includes continually assessing progress and sharing knowledge to support future directions. As the scientific, political, economic, and cultural climates change along with the needs of the communities, it is essential that professionals be flexible in order to provide the best possible care to our patients.

To accomplish this, we must have systems in place to assure safety and quality improvement, track patient outcomes utilizing both quantitative and qualitative data, and share our data with other professionals and across disciplines.

One way to formally share data is to develop a shared data agreement and database with other practices. Another is to publish results in journals: the advantages to publishing include reaching more providers and having the opportunity to elucidate the framework/theory of our work, which is important in understanding work in the context of multiple viewpoints and

choices. When publishing results, it is again critical to partner with, and give recognition to, community members and leaders.

Recognizing the people in the community who have been invaluable to the work is an important aspect of remaining accountable to, and demonstrating genuine collaboration and respect for, the community.

Through this triad of professional education improvements, community-based action, and ongoing assessment and research base development, we can radically expand the base of gender-affirming healthcare professionals, establish healthier relationships with the transgender community, and achieve widespread excellence in the care of trans patients.

### Conclusion

Expanding the base of gender-affirming healthcare providers in the United States must begin with the adoption of cultural humility on the part of providers and educators as the foundational component to providing patient-centered care and building trust within transgender communities.

Each organization or institution may be at a different point in the process; therefore, include ongoing critical and honest assessment of your own needs as you implement structural and curricular change internally, take short-term and long-term community-based action, and commit to ongoing reassessment.

Doing this will ensure a program has taken the essential first steps in transforming transgender healthcare and together we will continue to build institutional and organizational capacity to meet the needs of our transgender patients. **HIV**

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# Online Resources for Healthcare Professionals

## Practice Guidelines:

- Center of Excellence for Transgender Health Primary Care Protocols
- WPATH Standards of Care Version 7
- Transgender HIV/AIDS Health Services Best Practices Document

## Educational Opportunities:

- World Professional Association for Transgender Health (WPATH) Global Education Initiative
- National LGBT Health Education Center Webinars
- Services and Advocacy for GLBT Elders (SAGE) Publications
- AETC National Resource Center
- Callen-Lorde Community Health Center
- Health Professional Advancing LGBT Equality (GLMA) Publications
- National Resource Center on LGBT Aging

## Support and Collaboration:

- Transgender Medical Consultation Service (TransLine)
- AAMC MedPORTAL LGBT and DSD Patient Care Collection

Fellow at the University of Wisconsin-Milwaukee College of Nursing PhD program, where she is conducting her dissertation research on access to care for trans youth.



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“Permit me to give feedback.”

inclusive signage  
discrimination

“you are going to give yourself a blood clot”

respectful, sensitive sta

gender-neutral language hormone

welcoming and accepting barriers to care

treatment goals

non-prescribed “I am you

“I’d like to continue your hormones

“what you’re doing is really

building rapport

open-ended

street/

manage chronic conditions

# Culturally Sensitive IN-OFFICE Care FOR THE TGNC Patient

BY ANDREW GOODMAN, MD

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therapy regimen

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**T**RANSGENDER AND GENDER NON-CONFORMING (TGNC) people face a unique challenge when accessing medical care. For many, basic expression of identity necessitates accessing feminizing or masculinizing hormone therapy, or surgical care from a system that is untrained and unprepared to offer these services in a sensitive and supportive manner.

A recent survey of a sample of endocrinologists showed that over one-third refused to provide transgender patients hormone care and two-thirds reported no formal training in transgender care<sup>1</sup>. TGNC patient care is not part of the curriculum in most U.S. medical schools<sup>2</sup>. Many insurance payors still carry specific exclusions for coverage of hormone therapy or gender-affirming surgeries and fail to cover necessary screenings based on gender (pap testing in transgender men, for instance.)<sup>3</sup>

Many transgender patients also experience discrimination in health care. A 2010 survey of LGBT people found that 70% of TGNC patients reported experiencing health care professionals refusing to touch them or using excessive precautions, using harsh or abusive language, being physically rough or abusive; blaming them for their health status or refusing needed health care. In almost every category in this survey, TGNC respondents reported experiencing the highest rates of discrimination and barriers to care. Caring for TGNC patients may seem intimidating to providers who are inexperienced. Although most primary care and HIV providers do not currently prescribe hormone therapy or perform gender affirming procedures, integrating sensitive and knowledgeable history and physical exam skills is very important in fostering rapport, facilitating trust, and improving patient health outcomes.

## History-taking Skills

In obtaining a medical history providers must understand that TGNC patients may *anticipate* discrimination based on prior experiences accessing health care. Providers should communicate in a sensitive and nonjudgmental way, understanding that, although grouped under the same umbrella of TGNC, each patient is unique.

Patients should be given the opportunity to describe their own identity and experiences, rather than providers making assumptions<sup>5</sup>. While many aspects of taking medical history for TGNC patients may be no different than for non-TGNC patients, providers should keep a few areas in mind.

## Fostering Rapport

Building rapport with TGNC patients starts well before the patient is in the exam room. Inclusive signage and brochures in the waiting areas, respectful and sensitive staff, and intake forms that include a broad range of sexual orientations and gender identities are all clues that patients may look for to judge a practice's sensitivity.

Additionally, TGNC patients should be invited to identify their preferred name and pronoun when registering. There

are many pronouns that patients may identify with, including masculine, feminine, and gender neutral pronouns. Practices should have systems and training in place so these patients' preferences are documented and used consistently with all staff. Titles, such as Ms., Mrs., or Mr., should be avoided<sup>5</sup>.

Some providers express concern that changing procedures to ask all patients about pronouns and gender identity may offend some cis-gender patients. Staff can be trained to teach patients about why this question is asked: "We ask every patient about their preferred name and pronoun, instead of assuming, to make sure our practice is welcoming and accepting of everyone."

### Asking About Hormone Therapy

While many providers may not be directly managing a patient's hormone therapy, it is still important to know details about a patient's regimen to provide comprehensive care. Questions about medications, dosaging, and route of administration, as with any other medication a patient may be taking, are appropriate. There are many guidelines for hormone therapy, dosing and monitoring, that are freely accessible online, including Callen-Lorde's own guidelines<sup>6</sup>.

For many TGNC patients, due to lack of providers or insurance coverage, obtaining hormone therapy from licensed providers who are following accepted care guidelines is not always possible, so obtaining hormones from friends, unlicensed providers, or internet pharmacies may be their only options to the medication they need.

This can result in unnecessary harms for patients from poor quality pharmaceuticals, inappropriate dosages, and unsafe injection techniques<sup>7</sup>. Patients may not readily disclose this due to concerns about stigma. Providers should avoid stigmatizing words, such as "street", "illegal", or "illicit" hormone therapy and ask instead about "non-prescribed" hormone therapy. Patients can be invited to describe their injection technique so the provider can assess for safety.

When assessing progress through hormone therapy, providers should use the patient's own individual treatment goals and appropriate lab monitoring as guides. It is inappropriate for providers to comment on a patient's physical appearance, masculinity or femininity, or body changes. If patients ask providers to comment on their physical appearance, providers should politely redirect the conversation back to the patient's individual treatment goals.

When concerns about a patient's hormone therapy regimen arise, it is important to provide counseling in a sensitive manner. Feedback should be based on medical science or expert opinion, and discussion of risk should recognize that many TGNC patients experience tremendous benefit from hormone therapy.

Statements like "you are going to give yourself a blood clot" or "what you're doing is really unsafe", are inappropriate. "I am concerned about your risks for blood clots" or "I'd like to help you continue your hormones more safely" are much

better phrases to begin conversations with patients. I prefer to ask for permission to give feedback, in order to increase the patient's openness to discussing risk.

### Sexual Health History-Taking

As is the case with all patients, taking a sexual health history from TGNC patients is crucial to gaining a comprehensive picture of their health. This may feel intimidating to providers who are unfamiliar with TGNC care.

Gender identity (one's own internal sense of maleness or femaleness) is often confused with sexual orientation (one's identity as it relates to the genders one feels attracted to.) Providers may mistakenly make assumptions about their TGNC patient's sexual orientations, rather than asking. TGNC people include a broad range of sexual orientations, including gay, straight, bisexual, queer, or pansexual (attracted to a broad range of genders.) Some TGNC patients experience difficulty in deciding on a sexual orientation. Although patients should be invited to identify with a sexual orientation that feels most correct, sexual orientation should generally be based on the affirmed, rather than natal, gender of the patient<sup>5</sup>.

When discussing specific body parts, especially genital or chest/breast, many TGNC patients may feel uncomfortable using traditional anatomy words that feel gendered. Many providers have learned to adopt more gender neutral language or to ask patients which words they are comfortable with using. Gender neutral language is also useful when discussing screenings, such as pap testing<sup>8</sup>.

Providers may also mistakenly assume that TGNC patients are not at risk for sexually transmitted infections or pregnancy. As with all patients, providers should collect information on sexual health and offer appropriate supportive counseling, screenings, and treatment in a non-judgmental manner. Providers should use open-ended questions to start a conversation, such as "What questions do you have about your sexual health?" or "What do you think about your risk for STI's (or pregnancy)?"

### Asking About Surgeries

Medically necessary gender affirming surgeries are pursued by many, but not all TGNC patients. Sometimes this is due to financial or insurance barriers. TGNC patients experience varying degrees of dysphoria with their bodies, and some do not desire surgery or only certain surgeries. Providers should approach asking patients about surgery without assuming a patient's desire to undergo surgery.

Due to these financial and insurance barriers, many patients choose to pursue medically necessary surgeries from unlicensed or inexperienced providers. Trans-feminine patients may have had silicone injections, for instance, from friends or other unlicensed providers, using unsafe injection practices or non-medical silicone<sup>9</sup>. Patients may not know what anatomic structures were removed during surgery<sup>8</sup>,



may not have been appropriately counseled on post-operative care, and may experience poor surgical outcomes. Providers should recognize that TGNC patients sometimes accept or are uninformed of increased risk in pursuing medically necessary procedures, and discuss this with patients sensitively and supportively.

“Top surgery” is the most common gender affirming surgery, and may include removal of breast tissue, chest reconstruction, or breast augmentation. “Lower surgery” may include hysterectomy and or oophorectomy, orchiectomy, or various genital reconstructive surgeries. As genital reconstructive surgeries involve complex surgeries with specific cosmetic, urologic, and sexual health outcomes, these procedures should only be performed by experienced surgeons<sup>8,10</sup>.

### Sensitivity During Physical Examination

Due to traumatic and stigmatizing experiences that many TGNC patients have had with medical providers, many may have boundaries with physical examination. This may be especially true with chest/breast, anal, and genital examinations. In general, providers should only examine these areas when absolutely necessary and assess a patient’s comfort with doing so before proceeding. If patients indicate discomfort with examination, providers should respect those boundaries and not withhold medical necessary treatment as a consequence. Providers should maximize opportunities for patients to maintain control, especially during sensitive examinations<sup>8</sup>.

Although use of medical staff as chaperones during sensitive exams may be a standard practice, many TGNC patients may not be comfortable with chaperones, experiencing this as voyeuristic. TGNC patients may wish to have friends or other support people present during sensitive exams. Some patients may also have specific requests during their exam, such as undressing only from the waist below. Providers should respect these requests as much as possible. Similar to history-taking, providers should also avoid the use of gendered language during examination or when describing physical exam findings to a patient<sup>8</sup>.

While office visits with a TGNC patient may become focused on support and care needs for a patient’s gender identity, providers should consider the patient’s general health needs. Providers should monitor their patient’s psychosocial well-being, perform routine health screenings, and manage

chronic conditions that may emerge<sup>11</sup>. Although office visits and examinations can be intimidating for TGNC patients, skilled providers providing sensitive and appropriate care can help to restore patient trust in medical care and improve patient health outcomes. **HIV**

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## Influence of Integrated Transgender Healthcare on ART Adherence and Outcomes

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# BE A HEALER

## [not simply a clinician]

BY STEVEN R. KLEMOW, MD

**T**HE BURDEN OF HIV INFECTION in the transgender population is significant, particularly among transgender women. The most recent 2015 World Health Organization (WHO) Technical Brief on Transgender People and HIV reported an estimated prevalence of 19%, based on meta-analyses accrued from pooled data of transgender women in 15 countries with laboratory-confirmed data.

The accuracy of these estimates is of course confounded by many factors, including potential reluctance of transgender individuals to seek testing and treatment, lack of identification documents and EMR systems that account for non-binary or patient-reported gender definitions, and the mercurial nature of how individuals self-report in matters pertaining to gender identity in healthcare settings. Isolated populations who have historically been excluded from traditional societal definitions are elusive targets for study.

The factors driving this crisis are equally complex, but seem to share a similar theme of isolation, lack of access to resources, and a struggle for acceptance or validation. Employment discrimination, lack of legal protections, exclusion from healthcare resources and gender-affirming care, homelessness, substance abuse, subsistence sex work and subsequent incarceration all contribute to increased risk of high-risk behavior.

Many transgender women who have sex with men have high risk partners, or may eschew condom use in an effort to achieve validation of their gender identity, or to avoid rejection. In the United States, we still offer few sanctuaries where transgender individuals can feel safe, and many healthcare settings unfortunately

remain particularly daunting to this population. Given the crucial link between adherence and outcomes in the HIV positive population, what measures can we take as providers to encourage transgender persons living with HIV to engage and remain in care?

### Encouraging adherence

Several studies have demonstrated that transgender women living with HIV are less likely to adhere to antiretroviral therapy, compared to their cisgender counterparts (Mizuno, Frazier, Huang, & Skarbinski, 2015; Sevelius, Carrico, & Johnson, 2010).

The reasons postulated for this are multifactorial and complex, and in many ways mirror those obstacles identified for all people living with HIV. These include low levels of social support, younger age, depression, financial obstacles, perceived medication side effects, substance use, and low adherence self-efficacy. However, for transgender individuals, adherence may be complicated by additional factors, such as poor provider engagement and trust, previous negative experiences in healthcare settings, and the lack of integration of their transgender health into their primary care.





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Previous population-based surveys have suggested that transgender individuals may prioritize hormonal therapy and other transition-related interventions over other aspects of their health, including HIV care and pharmacotherapy (Kammerer, Mason, Conners & Durkee, 2001).

This priority is understandable in the context of self-reported improvements in quality of life, psychological well-being, and self-confidence when transgender individuals achieve gender congruency and integrity, often via hormonal therapy (Murad, 2010). Although prescription hormonal therapy is not costly (for transgender women, standard regimens such

**The factors driving this healthcare crisis are equally complex, but seem to share a similar theme of isolation, lack of access to resources, and a struggle for acceptance or validation. Employment discrimination, lack of legal protections, exclusion from healthcare resources and gender-affirming care, homelessness, substance abuse, subsistence sex work and subsequent incarceration all contribute to increased risk of high-risk behavior.**

as estradiol, spironolactone, and finasteride are available via \$4 generic programs at commercial pharmacies), lack of access to providers willing to provide transgender care often forces these individuals to obtain agents at considerable cost via street markets without medical supervision or guidance.

A 2010 study of 314 transwomen in San Francisco found that 49.1% reported taking hormones not prescribed by a clinician (de Haan, Santos, Arayasirikul, and Raymond 2015). As a consequence, this relatively routine and safe intervention often becomes an emotionally-consuming ordeal, fraught with potential complications, both medical and psychosocial. Since there is consensus agreement that patients living with HIV are well-served by receiving both HIV and primary care from an integrated resource, it is logical to surmise that transgender health should be integrated into HIV management as well, since non-surgical transgender management is a primary care issue.

The New York State Department of Health AIDS Institute Guidelines for the Care of the HIV-Infected Transgender Patient recommend that clinicians providing services to HIV-infected transgender patients should integrate transgender treatment recommendations and standards of care into their practice. This recommendation is in part informed by evidence that ART adherence has been found to correlate with positive gender affirmation and adherence to hormones (Sevelius, Saberi, & Johnson, 2014). Additionally, informed consent models for transgender health are well-established, and have greatly simplified the process of managing hormonal therapy on practical and medicolegal terms.

Although cultural incompetence has been ascribed to the historical reluctance of many HIV clinicians to adopt transgender management into their practice, some have hesitated to pursue hormonal therapy due to concerns of inadequate expertise or time. However, the management of hormonal therapy in transgender individuals living with HIV is neither time-consuming nor complex, particularly with the advent of published algorithms.

Also, the emergence of newer antiretroviral regimens that portend significantly less drug interactions with feminizing agents has greatly ameliorated concerns of polypharmacy. For transgender men, androgen-based therapies are exceptionally straightforward and have no meaningful ART interactions at all.

Although previous studies have suggested that compared to cisgender women living with HIV, transwomen are less likely to receive ART (Melendez, 2005), and are less likely to be adherent (Sevelius, 2010), there is some evidence that these disparities may be improving.

In a ten-year retrospective analysis conducted in 2013 by the University of Pennsylvania, which evaluated 37,000 patients being treated for HIV among 13 clinics participating in the HIV Research Network, the percentages of transwomen who were retained in care, received ART, and achieved virological suppression were roughly equal to men (80 percent, 76 percent, and 68 percent vs. 81 percent, 77 percent and 69 percent respectively) (Yehia, 2013).

### Provider affirmation essential

Some progress may be explainable by general advances in HIV therapy and management, and an increased focus on overall LGBT health over the last decade. However, it is reasonable to postulate that heightened transgender activism and a paradigm shift in emphasis on cultural competency may be having a positive effect. Based on focus groups and surveys of transwomen conducted by the Tom Waddell Health Center and the Center for AIDS Prevention Studies Department of Medicine at UCSF, it is clear that transgender persons clearly associate gender affirmation from their healthcare resources with their likelihood of engaging and remaining in care. (Sevelius 2014).

As providers of HIV care, we are in a position to set an example for transgender-inclusive care, and changes must occur at all stages of patient engagement and interaction. In a population who has experienced such trauma and rejection, rapport and trust may be thwarted at the earliest steps in intervention.

In my experience working for many years at a large Ryan White-funded HIV clinic, I observed many patients identifying themselves as cis-gender during intake interviews, only to report otherwise once they had assessed their sense of safety during their encounters with providers. Many transgender women (we saw few transgender men) presented for their initial

**If we are to identify ourselves as healers, not simply clinicians, it is incumbent on us to provide one place where these human beings will unequivocally be safe, respected, and heard.**

encounters dressed in masculine attire, and remained closeted about their gender identity for several visits. Admittedly, this was at a county hospital setting, where patients were mainly underinsured and seeking subsidized healthcare—but it was clearly an LGBTQ-friendly environment, completely devoted to HIV care, and there was still a palpable fear of rejection.

There also remains a tendency to apply our own definitions of cultural competency. Gender-affirming care must account for individuals who don't conform to traditional binary definitions, and generalizations cannot be made regarding what "community" with whom these individuals align.

Among at least 50 transgender individuals for whom I provided combined HIV and transgender primary care over a decade, the majority had few to no transgender friends, and many reported minimal participation in LGBTQ circles. Even with the implementation of transgender-inclusive protocols, many members of staff still deferred to the LGBTQ community as a preferred haven for these women, despite sexual orientation and gender identity being distinct entities, united predominantly in activist terms, sequestered together as demographic groups perhaps only due to shared ostracism.

For some of these women, affiliation with the LGBTQ community came at the cost of discretion, and many I encountered were in pursuit of a means to be, and to live life as, women—not as transgender women. Some preferred not to identify with any gender at all. Every assumption I made afforded a new lesson in stereotypes and humility, and it quickly became apparent that the appropriate strategy was to eschew all definitions and simply mirror the language they used to describe themselves.

Arguably, the unifying factor leading to the elusiveness of this community to healthcare providers and advocates is a misconception that they are in fact a community, as opposed to a population of discrete individuals, with unique identities, who in the absence of gender-affirming treatment or care often live in isolation—driven by fear of being singled out, shunned, abused, or abandoned.

If we are to identify ourselves as healers, not simply clinicians, it is incumbent on us to provide one place where these human beings will unequivocally be safe, respected, and heard. And if we can relieve our patients from the chaotic ordeal of trying to manage their transgender health on their own, we may make room for them to focus on their HIV care, which we know is essential for survival.

I posed this question to Nell Gaither of the Transpride Initiative in Dallas, who has been a leader in obtaining healthcare resources for trans persons in our community, and she perhaps summarized what we can accomplish most eloquently:

"I think part of the phenomenon of better HIV medication adherence once transgender patients are relieved of the chaos of managing their own hormonal therapy is, that maybe for the first time in their lives, their identity is being respected. When someone else values them and validates their lives, they begin valuing their own lives as well. For so many trans persons, all we ever hear is that our most core sense of identity, our most fundamental concept about who we are, is illegitimate, is a fabrication, is a lie. Often that comes, directly or indirectly, just from standard cis-normative assumptions and interactions, from healthcare professionals basing identity on biology. So when a person who historically represents the most likely source of undermining our identity instead validates and even celebrates our identity, it's powerful. It changes lives. Or maybe you could say in a way it gives new life." **HIV**

**Arguably, the unifying factor leading to the elusiveness of this community to healthcare providers and advocates is a misconception that they are in fact a community, as opposed to a population of discrete individuals, with unique identities, who in the absence of gender-affirming treatment or care often live in isolation—driven by fear of being singled out, shunned, abused, or abandoned.**



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**PrEP as a  
viable option  
for HIV  
incidence  
reduction  
among  
transgender  
women**



# Transgender Women & PrEP

BY ELENA CYRUS and ASA RADIX, MD

**T**RANSGENDER WOMEN continue to be at the forefront of the HIV epidemic in the U.S. and globally. Pre exposure prophylaxis therapy (PrEP) is a biomedical treatment that can curtail the spread of HIV in at-risk populations. However, PrEP awareness and uptake have not reached levels needed to impact the concentrated epidemic among transgender women. This article briefly overviews PrEP for transgender women, examining potential barriers and providing recommendations for future research and programmatic efforts.

Transgender women who have sex with men are at increased risk for HIV transmission, surpassing odds of seroconversion among cis-gender, high-risk heterosexuals, and other sexual and gender minorities (e.g., men who have sex with men, transgender men, or transgender women who have sex with women).<sup>1-3</sup>

Pre exposure prophylaxis (PrEP), a biomedical therapy that combines the antiretroviral medications emtricitabine and tenofovir (Truvada®) received approval by the U.S. Food and Drug Administration (FDA) in 2012 for HIV prevention among high-risk heterosexual individuals and men who have sex with men (MSM). Despite the known efficacy of PrEP and potential impact on HIV incidence reduction, there has not been wide-spread acceptance as expected<sup>4</sup>.

A recent study demonstrated MSM and transgender women were willing to engage in PrEP therapy once they became aware of the drug as an option, suggesting that low PrEP uptake may be associated with low knowledge and self-efficacy.

In the extension phase of the landmark iPrEX efficacy study for Truvada®, researchers found no significant difference between MSM and transgender women in opting to initiate PrEP therapy once they were aware of that option. Thus, it's natural to ask why aren't more high-risk transgender women in our communities using PrEP?

## Epidemiology

There is limited surveillance data on HIV among transgender women. Data for transgender women often are conflated with data for cis-gender men who have sex with men, and existing studies have been conducted with populations outside of the U.S. or non-ethnic or racial minorities<sup>5</sup>. The studies that do focus on transgender women have consistently demonstrated that HIV prevalence is higher for transgender women, and by extension the risk of acquisition also is greater.

There is no reliable denominator to accurately estimate the prevalence of HIV among transgender women in the U.S. While estimates of the transgender population (men and women) in the U.S. range between .3%–1%<sup>6,7</sup>, reliable population level statistics for transgender women are not readily available.

Reasons for the lack of data are multifaceted, including non-self-identification as transgender for fear of harassment or discrimination, inappropriate methodology to capture changing gender status of individuals in census data, unstandardized research instruments and methodology for the transgender population, and limited funding for studies focusing specifically on transgender populations<sup>5,8</sup>.

Policy differences across the states can also influence transgender women's risks, as some states prohibit discrimination

and provide more legal protection for transgender populations than others<sup>9</sup>.

For example, in states where the Medicaid extension under the Affordable Care Act (ACA) has not been accepted, transgender women with an SES between the cut offs for Medicaid and ACA may fall into the insurance gap, rendering them ineligible for either type of insurance coverage<sup>10</sup>.

Policies of this type enforce institutionalized discrimination against transgender women and other underserved populations, increasing their vulnerability. One sequelae of this social isolation, discrimination, and prejudice is the engagement of transgender women in commercial sex work for economic survival. Commercial sex work alone is high-risk, but has compounded risk as it is also linked with more substance use, multiple sexual partners, and unprotected sexual acts<sup>11-22</sup>.

### PrEP efficacy among transgender women

PrEP therapy has the potential to curtail the concentrated epidemic of HIV in high-risk populations, but certain conditions must be satisfied to ensure efficacy.

For example, routine HIV testing is integral to achieving lower incidence in at-risk populations. High-risk individuals who are routinely screened and are aware of their HIV status diminish the risk of transmission to uninfected people, and, help inform medical providers on appropriate courses of treatment.

In 2013, the largest percentage of new HIV infections was among transgender women<sup>23</sup>. Meta-analysis studies estimated HIV prevalence among transgender women to be between 22%–28%, but in one study, only 12% of transgender women self-reported their positive HIV status, suggesting that 10%–16% were unaware of their status<sup>23</sup>.

## Transgender women face exacerbated experiences of discrimination, social isolation, and stigma, which may manifest into acute negative mental health outcomes such as depression and anxiety.

Adherence to PrEP is essential to reduce the odds of HIV seroconversion. Without adherence to the drug regimen, effective drug concentration will not be achieved and the protective effect against HIV transmission will not occur. Adherence has been shown to be higher in those who are older and, among those with a self-perception of being high-risk. However, this does not hold for transgender women, who were found, overall, to be more non-adherent than MSM in the iPrEX study, regardless of demographic factors or social context.

Depression, other mental health co-morbidities, and substance use have been examined as mechanisms for non-adherence among transgender women and MSM. Substance use can be used as a coping mechanism for the social stress transgender women constantly experience<sup>2,5,7,11,12,15,19,21,24-50</sup>, but

investigations on additional specific risk factors for non-adherence among transgender women are lacking.

Compared to MSM, transgender women face exacerbated experiences of discrimination, social isolation, and stigma, which may manifest into acute negative mental health outcomes such as depression and anxiety. Results from the open label extension of the iPrEX study showed depressive symptoms were linked to non-adherence, but compared to MSM with mild to moderate depressive symptoms, transgender women with mild to moderate depressive symptoms had higher odds of non-adherence<sup>30</sup>, further highlighting the difference in risk factors for these two groups and the need for them to be investigated separately.

### Barriers to PrEP

There are social and structural barriers transgender women encounter that can reduce their likelihood of electing to use PrEP. These barriers, which limit access to primary care, PrEP or, other medical services, include transgender women's distrust of the medical community, perceived discrimination from the medical community, lack of financial resources, prioritization of hormone therapy, being un-insured, and lack of trans-competent providers.<sup>51-57</sup>

For a population already struggling to access basic medical services, PrEP may not be a priority. In the past seven years since the drugs for PrEP have been on the market, the cost has increased from \$700–\$800 to \$1300–\$1500 per month<sup>58,59</sup>. When deliberating whether to use PrEP within their limited financial resources, transgender women may consider seeking basic care or gender affirming services that can boost confidence and improve perceptions of self-efficacy to be more important<sup>54</sup>.

Integrated medical services may be one cost-effective option to alleviate the struggle of competing medical services for transgender women<sup>60,61</sup>. By providing integrated services whereby psychosocial, preventive care, and gender specific services are offered in one clinical setting, transgender women may be better equipped to receive all or more of the services they need to improve their personal agency, and reduce their risk. Additionally, initiating PrEP may be an opportunity to engage and retain transgender women in routine care<sup>62</sup>.

Medical providers should, at a minimum, ensure that transgender patients are cared for in a way that respects their gender identity and expression as well as addresses privacy and confidentiality concerns. For example, providers can make an effort to adhere to the convention of medical consultations being conducted in private spaces, allowing transgender women to speak freely about their sexual history without fear of confidentiality being compromised. This may encourage transgender women to seek care, an integral initial step in the PrEP continuum.

Marketing of PrEP across the U.S. has not been adequately transgender inclusive, and alternative bio-medical strategies



**A recent study demonstrated MSM and transgender women were willing to engage in PrEP therapy once they became aware of the drug as an option, suggesting that low PrEP uptake may be associated with low knowledge and self-efficacy.**

such as use of antiretrovirals for post-exposure prophylaxis (PEP) are more accepted<sup>63</sup>.

Transgender women may be aware of PrEP as an option for risk reduction, but they have not necessarily accepted the therapy as a viable option for them, nor are they receiving all of the information they need to help make that decision.

Concerns transgender women may have include possible or unknown long-term side effects of PrEP and negative interactions of PrEP with concurrent medications. Trans-specific side effects have not been determined, but to date, no negative interactions with hormone therapy has been observed, although the body of evidence on this subject is scant<sup>34</sup>.

If PrEP is to become more widely accepted and used, promotion of PrEP among transgender women must be based

on scientific evidence conducted in their population<sup>14</sup> and the information should be publicly accessible.

## Conclusion

Advances made with PrEP are encouraging, but at this juncture, rigorous research and action items are necessary to address current gaps in knowledge that may prevent transgender women from using the promising preventive therapy. Some recommendations to address these gaps are:

- More funding and research dedicated to the investigation of efficacy, effectiveness, and acceptability of PrEP among more representative samples of ethnic and racial minority transgender women;
- Validation of transgender specific evidence based interventions that can facilitate more wide-spread dissemination and implementation of PrEP;
- Further investigation on reasons for non-adherence, interactions with concurrent therapy, and side effects (short and long term);
- Education and public health programs to aid in reducing social stigma and discrimination within communities, and among medical providers;
- Collaboration with researchers, providers and community members to implement cost-effective but impactful transgender clinical and behavioral programs.

The concentrated HIV epidemic among transgender women may seem unrelated to the general population, but implications may be more far reaching than what is apparent. Data reflect an increase, over time, of individuals in the U.S. who identify as having some type of gender dysphoria<sup>6</sup>, and the overlapping social and sexual networks among cis-gender and transgender individuals<sup>64</sup> indicate a public health issue important for transgender women and their communities. **HIV**

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# TRANSGENDER Hormone Therapy

Practical  
guidelines for  
the HIV care  
provider

BY MEERA SHAH, MD, MS  
and ASA RADIX, MD, MPH

**A COMMON CLINICAL SCENARIO:** a 25 year-old HIV positive trans-female, virally suppressed on dolutegravir/abacavir/lamivudine, presents to establish care and desires hormone therapy. How would you approach this patient?

It has become increasingly more known that transgender people, particularly transgender women, are among the groups most affected by HIV and it is for this reason that HIV care providers should integrate transgender care into their scope of practice.

There are several reasons why trans-identifying patients are at higher risk for HIV and while this is a complicated issue that stems from discrimination and stigma, these reasons include:

- Exchanging sex for money, high-risk sex (condomless sex, anal sex)<sup>1</sup>
- Sharing needles to inject hormones and silicone<sup>2</sup>
- Gender-based violence<sup>3</sup>.

It is important for HIV care providers to understand these risk factors in order to improve screening for HIV and to prevent transmission of HIV.

Unfortunately, many HIV positive transgender women do not seek care out of fear

of being shamed for their gender identity or because of cost and therefore obtain hormones and procedures through oftentimes unsafe methods. It is important for clinicians to understand that HIV may not be the transgender patient's priority, so addressing their psychosocial and transgender-specific health needs can often times improve linkage and retention to care.<sup>4</sup>

Transgender hormone therapy is the process of administering masculinizing or feminizing hormones for individuals who

### **The first step in addressing this 25 year-old patient's needs is determining her past use of hormones and surgical history and what she is hoping for in her transition.**

desire a transition or change from their sex assigned at birth.

The first step in addressing this 25 year-old patient's needs is determining her past use of hormones and surgical history and what she is hoping for in her transition. While some individuals desire maximum feminization or masculinization from hormone therapy, others want to relieve or minimize some of their secondary characteristics in order to achieve a more androgynous presentation.

The next step would be to take a thorough medical and social history and physical exam. Certain medical conditions, such as breast cancer and active venous thromboembolism can be contraindications to hormone use or may require that the patient use a lower dose or alternate route of hormone. Hormone therapy can be administered safely in the setting of antiretroviral therapy for HIV positive trans-women with little concern for adverse outcomes due to drug-drug interactions.<sup>5</sup>

Smoking is common among the transgender population, with some data showing up to 30%, so evaluation for tobacco use as well as smoking cessation counseling should be incorporated into the patient's visits given the risks associated with hormone use.<sup>6</sup>

The initiation or maintenance of hormones should always include a risk/benefit discussion with the patient. Many protocols require a consent form to be reviewed and signed between the provider and patient.

While guidelines and protocols exist to help guide hormone management, a patient's specific preferences and goals must be taken into consideration. For example, our patient might desire the feminizing effects of estrogen, but want to maintain erectile function and therefore not want to take an androgen blocker. Also, if she has undergone orchiectomy, she will not need androgen blockade and may require lower doses of estrogen.

A discussion about fertility should be held early on with this patient. While sperm-banking is best to do prior to initiating hormones, many transgender women have had

successful sperm-banking and sperm-washing once hormones have been discontinued.<sup>7,8</sup> Expectations of changes to one's body should be addressed and managed early on and patients should be reassured that the transition process is slow—up to two years and sometimes longer. Some of these changes are not fully reversible, others are and it is difficult to predict the reversibility.

### **Initiating hormone therapy**

There are several organizations that have outlined recommendations for hormone therapy for transgender or gender non-confirming individuals. The Endocrine Society and The World Professional Association for Transgender Health have protocols for hormone management that are widely used,<sup>7,9</sup> however many individual organizations also have created their own protocols. Also, practices for hormone therapy vary from provider to provider and are tailored based on a patient's individual need.

### **Estrogen**

Estrogen can be given in several forms: estradiol tablets, patches or injections. Estradiol patches may be preferred in certain circumstances such as age over 45, history of venous thromboembolic disease or cardiovascular risk/disease based on evidence from postmenopausal non-transgender women.<sup>10,11</sup>

Estrogens are metabolized by cytochrome P450 enzymes in the liver<sup>12</sup> as are protease inhibitors and non-nucleotide reductase inhibitors. Ritonavir and cobicistat are used in combination with some antiretroviral agents as "boosters" to increase their efficacy. Both are potent inhibitors of cytochrome P450 enzymes and can have interactions with estrogen.

Boosted protease inhibitors tend to reduce estradiol levels and dose adjustments may need to be made when co-administered with estrogens. Non-nucleoside reverse transcriptase inhibitors may also affect estradiol levels. In both instances the medical provider should obtain estradiol levels to allow for appropriate titration of estrogen dose. Nucleoside reductase inhibitors do not affect cytochrome P450 enzymes, and are therefore unlikely to have a drug interaction with estrogen.<sup>13,14</sup> For this reason, pre-exposure prophylaxis, or emtricitabine-tenofovir disoproxil is safe to use with estrogen. Integrase inhibitors and entry inhibitors have no known significant drug-drug interactions with estrogen.

### **Anti-androgen**

Oral anti-androgens can come in the form of an androgen blocker (spironolactone) or dihydrotestosterone (finasteride) blockers. They are used in conjunction with estrogen as part of the feminizing regimen for transgender women. There are no significant interactions between spironolactone or finasteride and antiretroviral medications.

## Effects of feminizing hormones

Effect	Onset (months)
fewer erections, difficulty having and maintaining an erection	1-3
decreased ability to make sperm or ejaculatory fluid	Unknown
slower growth of facial hair	3-6
nipple and breast growth	3-6
softening of skin	3-6
decrease in muscle mass and increase in body fat	3-6
decreased testicular size	3-6

## Adverse effects/risks of feminizing hormones

increased risk of venous thromboembolism
increase risk of stroke
increase risk of heart disease
liver toxicity
increase risk of gallstones
increase blood pressure (can be offset by the addition of spironolactone, which is also an antihypertensive)
breast cancer is rare in transgender females, but patients should be evaluated for risk of estrogen-dependent cancers
elevated potassium if on spironolactone
increase in prolactin and/or prolactin-secreting tumor

## Monitoring and titrating hormone therapy

Our patient has no other medical or surgical history besides HIV and is virally suppressed on dolutegravir/abacavir/lamivudine. She was initiated on biweekly delestrogen injections and low dose spironolactone for androgen-blockade. Follow up visits include monitoring of liver and kidney function, prolactin levels, serum potassium, and blood pressure.

It is important to periodically monitor the patient for satisfaction with her transition and evaluate for adverse side effects. Mid-cycle estradiol levels can be checked if there is concern for toxicity or non-therapeutic dose. A testosterone level can be checked in order to titrate dosage of spironolactone (with close attention to blood pressure and potassium level) until testosterone is suppressed. If she desires orchiectomy or vaginoplasty, androgen-blockade should be discontinued and low-dose estrogen started after the surgery. **HIV**

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## Benefits of Ongoing Small Talks About Partner Services in HIV Care

**O**VER 30 YEARS INTO THE EPIDEMIC, HIV stigma remains very prevalent. Fearing stigma and discrimination, people living with HIV may be reluctant to notify their partners of their possible exposure to HIV or other sexually transmitted infections (STI).

As HIV care providers, we often see HIV-infected patients uncomfortable revealing their status despite understanding the importance. Whether immediately after diagnosis or years later, our assistance in helping patients to learn techniques to disclose their status is essential and should be tailored to meet the needs of each patient; some will choose to do this on their own, while others may use Partner Services.

Partner Services is a valuable resource through which health department staff can contact reported sexual or drug-injection partners of potential exposures in a confidential, anonymous manner; offer on-site testing and counseling; and provide linkage to care and treatment and other services at a location convenient to the potentially exposed person. Following are two instances in which I discussed Partner Services with some of my patients and how they benefitted my patients and their partners.

### Assisting a patient who develops an STI

Mario is a bisexual African-American man in his mid-20s who has been diagnosed with HIV infection for about five years. For the first two years after his diagnosis, Mario did not inform anyone of his HIV status and refused to share any names with the Disease Intervention Specialist from the state-run Partner Services when he was contacted for partner tracing. Mario is excellent about his adherence to his single-tablet antiretroviral therapy (ART) regimen and has had an undetectable viral load for at least three years. He has been in a relationship for about two years with another man who was HIV-negative and they are “mostly monogamous.”

One day I received a call from Mario that he had developed a few non-painful sores on his penis, and he was concerned. When he showed up, we began a discussion about his recent sexual activities. I routinely inquire with all patients about the number of sexual partners for “any activity beyond kissing” since their last visit. Previously Mario stated that he was only with this partner for male-to-male activity, but occasionally would have protected vaginal sex with a few female friends. At this visit, he stated that he had gone to a bar in New Orleans about two to three weeks prior and allowed a man to give

him oral sex in the bathroom. He denied any fever, dysuria, penile discharge, joint aches, or rashes that he had noticed.

Upon examination, I found Mario had multiple abnormalities: three annular lesions on his tongue mucosa, three painless ulcerations on his penile shaft about 1 cm across with raised borders, and two verrucous small masses in his perirectal region. He also had a few hyper-pigmented lesions on his palms, but no lesions on his soles. No discharge was elicited during examination of his penis.

I explained to Mario that it appeared that he likely had simultaneous primary and secondary syphilis. He had a negative rapid plasma regain (RPR) test about five months prior to this visit (with screening done annually). I explained that occasionally in HIV-infected patients, primary syphilis—as evidenced by the penile ulcerations—and secondary syphilis—as evidenced by the palmar and tongue lesions and the condyloma lata near his anus—can occur simultaneously.

I also informed him that primary syphilis can present with multiple chancres in HIV-infected patients. Mario said he only had protected vaginal sex with women outside his relationship and that his partner was always the insertive partner in anal sex, thus they don’t always use condoms. I explained to Mario that syphilis can also be transmitted via oral sex, either from his brief encounter with the man from the bar, any of his female partners, or possibly from his male partner, if any of them were infected.

We discussed the importance of partner notification when a suspected or confirmed STD is diagnosed. We talked about the very high incidence of gonorrhea, chlamydia, and syphilis in our state and the association of HIV transmission with the presence of another STI.

Since Mario was uneasy about telling his partner himself, we discussed two other options: (1) using Partner Services to anonymously inform his partner about a possible syphilis exposure and provider testing or (2) enlisting my assistance to help Mario inform his partner in a controlled environment, such as our medical clinic. Mario said he felt comfortable with us working together to inform his partner of his recent syphilis diagnosis and to allow his partner to then ask questions.

I gave Mario a single dose of Bicillin L-A for his syphilis, sent off an RPR. I also tested Mario for gonorrhea of the throat, urethra, and rectum. I told Mario that I would like to see him again in one week to assess response to therapy and invited him to bring his partner along to his appointment, offering to assist Mario with informing his partner of his syphilis diagnosis at that visit.

I urged Mario to use condoms for any sexual activity until we had a chance to inform his partner and treat his partner for syphilis exposure. I encouraged Mario to inform any of his casual sexual partners of his diagnosis if he had their contact information and reminded Mario about Partner Services, available through the state's health department, if he felt uncomfortable revealing the information himself to his casual partners. Mario said he would talk with Partner Services when they contacted him this time.

Mario and his partner returned one week later. All the skin and perianal lesions had resolved. I informed Mario with his partner present of the positive RPR titer of 1:256 and negative screening for gonorrhea and chlamydial infection. I offered to test the partner for syphilis and HIV at this visit and gave him a single dose of Bicillin L-A while awaiting his test results.

Mario's partner wanted to know where the infection came from, and we discussed the ways syphilis can be transmitted. This also opened up a discussion about the low, but present, risk of HIV transmission when having unprotected insertive anal sex with someone with a fully suppressed viral load. We also discussed the increased risk of HIV transmission when another STI is present.

Although a tense situation, this occurrence of an STI created a perfect opportunity to open a dialogue between the couple about boundaries and allowed me to have a more detailed discussion about safer sex with my patient and his partner. It also created a provider relationship with the partner and brought him into care. We discussed the possibility of PrEP, but Mario's partner wanted to consider this more before starting. Mario appeared to come away from the experience with a better understanding of what constitutes safer sex and the levels of risk of different behaviors.

### **Partner Services especially useful with new HIV diagnosis**

Jennifer is an 18 year-old Caucasian woman who presented to the clinic with complaints of a thick vaginal discharge. She reported that she was sexually active in a monogamous relationship with her boyfriend of the past two months and that they don't use condoms. She had been in five monogamous relationships sequentially over the preceding two years since she had become sexually active. Jennifer noted that she had been in good health except for a "flu" she had about four months previously.

On exam, Jennifer was noted to have a vaginal yeast infection. Since she was sexually active, Jennifer was offered both rapid HIV testing and syphilis testing. Her syphilis test was negative, but her rapid HIV test was positive. Another rapid HIV test, of a different brand than the first, was also positive, and the patient was informed of the results.

Jennifer began crying, stating repeatedly, "I can't have AIDS." I explained to Jennifer that the tests done so far only indicated that she was infected

## **Benefits of Using Partner Services for HIV Care Providers:**

- Helps relieve your workload by offering a free resource to help your patients notify their sex and drug-injection partners of their possible exposure to an infectious disease.
- Presents an opportunity for you to identify unsafe transmission behaviors and discuss how to reduce those behaviors with your patients
- Leverages your relationship with patients and maximizes that trust to help stop the spread of HIV and STIs.

## **Benefits of Using Partner Services for Your Patients and their Partners:**

- Informs your patient's sexual partner(s) of their exposure to HIV or STIs, while protecting confidentiality and removing the burden of disclosure from your patient.
- Ensures that adequate time is spent coaching your patient on how to inform his or her partners about their exposure, if the patient chooses to self-disclose.
- Helps partners get tested quickly and links exposed partners to care and treatment
- Provides a free resource for your patient and partners and access education and counseling about how to live successfully with HIV.

## Partner Services and other Resources:

- To locate a comprehensive risk counseling service program in your area, find your local health department at: <http://www.healthfinder.gov>Organizations>State Agencies>
- For CDC Partner Services Recommendations and Guidelines go to: <http://www.cdc.gov/hiv/prevention/programs/pwp/partnerservices.html>
- Order CDC's New CDC *Prevention IS Care* Resource Kit—This recently updated suite of materials was developed to assist providers with integrating prevention into care for their patients with HIV, including provider and patient brochures on Partner Services and a handy provider referral reference tool. To obtain free kits for your practice, go to: <http://www.cdc.gov/actagainstaids/campaigns/pic/materials/index.html>

with HIV and that, since she had only been sexually active for two years, it was very unlikely that she had progressed to having AIDS. We discussed that with the quality and simplicity of the current HIV therapies, Jennifer would likely be able to live a normal life span, but it was very important that she stay in care and take care of herself. Jennifer appeared to be feeling better about the diagnosis by the end of the visit.

Our Agency has funding for a Patient Navigator, who is able to meet with newly HIV-diagnosed patients and assist with their navigation of our health care system to improve their retention in care. Intake labs were obtained, and Jennifer was able to meet with our Patient Navigator.

When Jennifer returned one week later to review her lab results, she was more composed. She had met twice with the Patient Navigator to get some “HIV 101” teaching and seemed to accept her diagnosis. The Patient Navigator, during one visit, brought up the importance of notifying Jennifer’s previous sexual partners of their potential exposure to HIV and the need for the person who infected her to know of his status. Jennifer had not yet told anyone of her diagnosis, including her current boyfriend or any family members. I discussed with Jennifer the ways in which HIV is transmitted and the concern that the man who infected her may be unaware of his diagnosis and may be infecting other women in the community.

Jennifer was very leery about telling her sexual partners about her HIV diagnosis. We discussed the various options for disclosure for future partners and for previous contacts. Jennifer decided she wanted to inform her current boyfriend herself, but was very interested in the use of Partner Services to notify previous sexual partners. Her main concern was that disclosure of her own status would lead to the information getting out to her community.

I informed Jennifer that Partner Services requests contact information for previous and current sexual partners, but

never discloses the identity of the person who gave their name. I stressed to her that the Partner Services personnel contact the partners listed, inform them that they have been reported as having a possible HIV exposure at some time in their past, and offer on-the-spot rapid testing if the contact is interested. No details are ever given about the person who provides their name nor how they were exposed. Jennifer expressed concern that it may be obvious to some of her partners who reported their names, because they had only one or two other sexual partners of which she was aware.

Jennifer agreed to wait a half-hour to meet with Partner Services personnel, who came to our office to meet with her. During their visit, the Partner Services worker was very comforting and gentle with Jennifer, assuring her that all efforts would be made to not disclose her name or identity to any of the contacts she reported to them. She was tearful again during the session, but was willing to provide contact information for three men with whom she had been sexually involved in the past, but she chose to inform her current boyfriend herself, not giving his name or contact information to the Partner Services worker.

I did not learn the test results of Jennifer’s reported contacts, but I suspect the “flu-like” illness she had a few months ago may have been her initial infection. She had a high CD4 count and a reasonable viral load of < 50,000 copies/ml. Unfortunately, her boyfriend did not take the new diagnosis well and broke off contact with Jennifer.

We were able to get her scheduled with a behavioral health therapist, and Jennifer is now on anti-retrovirals, doing very well with no significant side effects. She reports that she has not heard any rumors about her status in her community and feels comfortable that the Partner Services worker was able to contact her previous partners for testing without revealing her identity.

The Partner Services personnel were very helpful in assisting this patient through a difficult time with her new diagnosis and were able to get the information they required in a sensitive, caring manner. We are currently working with Jennifer on skills to disclose her diagnosis to any family members she thinks should know as well as future sexual partners. **HIV**

\*Centers for Disease Control and Prevention. Recommendations for Partner Services Programs for HIV Infection, Syphilis, Gonorrhea, and Chlamydial Infection. MMWR (2008); 57(No.RR-9). Available at [www.cdc.gov/mmwr/preview/mmwrhtml/rr5709a1.htm](http://www.cdc.gov/mmwr/preview/mmwrhtml/rr5709a1.htm).



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**Dr. Ronald Wilcox** is the Chief Medical Officer for CrescentCare, a federally qualified health center that began as the NO/AIDS Task Force, an AIDS Service Organization, in the early 1980’s in New Orleans, LA, in response to the emerging epidemic. In 2014 and 2015 the Agency expanded services from serving strictly the HIV-affected community to a source of comprehensive primary care to at-risk populations including persons in the service industry and the large LGBTQ community of southeastern Louisiana.

BY JEFFREY T. KIRCHNER, DO, FAAFP, AAHIVS  
 and PHILIP J. BOLDUC, MD, AAHIVS

# Training Opportunities in HIV Medicine for Residents and Medical Students

**I**N THE LAST ISSUE OF *HIV Specialist*, a feature article by Bob Gatty, editor of the magazine, discussed the future of the HIV workforce in the United States, noting a growing concern regarding a future shortage of HIV-care providers.

As noted in the article, some training programs exist as focus areas within primary care residencies (Family Medicine and Internal Medicine) as well as post-graduate HIV Fellowships. Encouraging feedback and additional information was received by many academic programs throughout the country.

In addition, at the recent national meeting (May, 2016) of the Society of Teachers of Family Medicine, in Minneapolis, MN, a working group of Family Medicine Teachers/HIV Specialists shared data, information about their Residency programs and other aspects of their respective HIV curricula as they endeavor to train the next generation of HIV physicians. The list below includes current post-graduate training sites for HIV/AIDS medicine.

The Residency HIV “Clinical Tracks” or “Areas of Concentration” are most relevant to medical students seeking a Residency Program where they can get more HIV training than what is offered in a typical Residency Program and depending on the program may be prepared to care for HIV patients independently or in collaboration with an HIV Specialist. The post-graduate fellowships are one to two years in length and provide more intensive training in HIV/AIDS upon completion of a Residency in Primary Care, which could be Family Medicine, Internal Medicine, or Pediatrics.

## Residency Training Track or Area of Concentration (AOC)

1. Family Medicine Residency of Idaho, Boise, ID  
<http://www.fmridaho.org/residency/fellowship/hiv-primary-care>
2. Family Medicine Residency – Lancaster General Hospital, Lancaster, PA (AOC)  
<http://www.lancasterfamilymed.org/Home.aspx>
3. Family Medicine Residency – Lawrence, MA  
[http://lawrencefmr.org/site/?page\\_id=1393](http://lawrencefmr.org/site/?page_id=1393)
4. Family Medicine Residency – Montefiore Medical Center, Bronx NY  
<http://www.einstein.yu.edu/departments/family-social-medicine>
5. Family Medicine Residency – McKeesport - University of Pittsburgh, Pittsburgh, PA  
<http://mckeesport.familymedicine.pitt.edu/content.asp?id=2458>
6. Family Medicine Residency – Southern New Mexico, Las Cruces, NM  
[http://www.nmfamilymedicine.com/article/hiv\\_hepc\\_services](http://www.nmfamilymedicine.com/article/hiv_hepc_services)
7. The Northwestern McGaw Family Medicine Residency, Humboldt Park, Chicago IL  
<http://www.familymedicine.northwestern.edu/education/residency-programs/humboldt-park/index.html>

8. Family Medicine Residency Training Program at Family Health Centers of San Diego (FHCSO)  
<http://www.fhcsd.org/fmresidency/>
9. Family Medicine Residency – University of California, San Francisco. San Francisco, CA.  
<http://fcm.ucsf.edu/education/sfghfcm-residency-program>
10. Family Medicine Residency – University of Texas South Western, Austin TX  
<http://www.utsouthwestern.edu/education/medical-school/departments/family-community-medicine/faculty.html>

## HIV Fellowship Programs (1 to 2 years in length)

1. Family Medicine Residency at University of Idaho  
<http://www.fmridaho.org/residency/fellowship/hiv-primary-care/>
2. University of Massachusetts – Worcester, MA  
<http://www.umassmed.edu/fmch/fellowships/hiv/background/>
3. University of Southern California – Keck School of Medicine, Alhambra, CA  
<http://www.keck.usc.edu/family-medicine/training-education/HIV-fellowship/>
4. University of Texas - Houston (TX) Medical Center  
[http://www.hivma.org/HIVMA/Site\\_Map/Careers\\_\\_\\_Training/HIV\\_Training\\_Programs/Texas/University\\_of\\_Texas\\_Houston\\_Medical\\_Center\\_Fellowship\\_in\\_HIV\\_Medicine.aspx](http://www.hivma.org/HIVMA/Site_Map/Careers___Training/HIV_Training_Programs/Texas/University_of_Texas_Houston_Medical_Center_Fellowship_in_HIV_Medicine.aspx)
5. The ViiV Healthcare/LA DHS HIV Public Health Fellowship Program  
<https://dhs.lacounty.gov/wps/portal/dhs>
6. HIVMA Clinical Fellowships (Variable clinical locations)  
[http://www.hivma.org/HIVMA/Career\\_Training/Minority\\_Clinical\\_Fellowship\\_Apply\\_Online/](http://www.hivma.org/HIVMA/Career_Training/Minority_Clinical_Fellowship_Apply_Online/)

HIV



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# U.S. Study Looks at Long-Term Durability of Hepatitis C Cure, Risk of Relapse and Liver Cancer

**R**ESearchers in several countries—including France, New Zealand, the U.K. and the U.S.—reviewed the records of several thousand people who had been cured of HCV using direct-acting antivirals (DAAs) and found very high rates of cure that were sustained up to three years after cessation of therapy. That is, once cured, the vast majority of participants stayed cured. Rates of relapse, reinfection and liver cancer were very low after cure was achieved.

## Study Details

Participants in Gilead Sciences' sponsored studies were encouraged to enroll in an observational study that monitored them for up to three years after cure was achieved. As part of this observational study, participants regularly visited study clinics where their blood was drawn for analysis.

There were 5,433 participants enrolled and their average profile upon entering the study was as follows:

- age—54 years
- 63% men, 37% women
- 20% had severe liver injury (cirrhosis)
- most (99%) had been infected with genotypes 1, 2, 3 or 4

## Results—Keeping Track of HCV

Researchers found the following:

- 99.7% of participants maintained their cure status.
- 0.1% of participants had evidence of late relapse.
- Participants who relapsed tended to have HCV genotype 1a or 3. Historically these genotypes have tended to respond poorly to treatment.
- 0.2% of participants had evidence of HCV re-infection.
- Reinfections began to occur as early as eight months after cure was achieved.

## Results—Monitoring Liver Cancer

Cases of liver cancer were detected after treatment cessation but were low. This is likely due to the smaller proportion of people with cirrhosis in this study compared to the previously reported French study (where more than 60% of participants had cirrhosis).

Most cases of liver cancer were distributed among people with pre-existing cirrhosis and occurred within the first year after treatment cessation.

Liver cancer diagnosed upon study entry

- among people with cirrhosis—5 cases
- among people without cirrhosis—3 cases

Liver cancer diagnosed 24 weeks after study entry

- among people with cirrhosis—5 cases
- among people without cirrhosis—1 case

Liver cancer diagnosed 48 weeks after study entry

- among people with cirrhosis—6 cases
- among people without cirrhosis—0 cases

Liver cancer diagnosed 72 weeks after study entry

- among people with cirrhosis—3 cases
- among people without cirrhosis—0 cases

After week 72, there were no further cases of liver cancer.

## Other Liver-Related Issues

A similar trend (a decrease over time) was seen with the relatively small proportion of cases of liver-related complications that were detected after treatment cessation. Complications included the following:

- build-up of fluid in the abdomen (ascites)
- internal bleeding
- brain-related issues
- yellowing of the skin and whites of the eyes (jaundice)

Over time there were fewer cases of these and by the third year of the study, there were no reports of these complications.

There was also a similar trend with analyses of blood tests with a trend to normalization over time.

Overall, the findings from this review are reassuring and show that the vast majority of people who are cured with DAAs remain cured. Rates of complications, including liver cancer, were lower than those found in another study from France (reported in this issue of *TreatmentUpdate*).

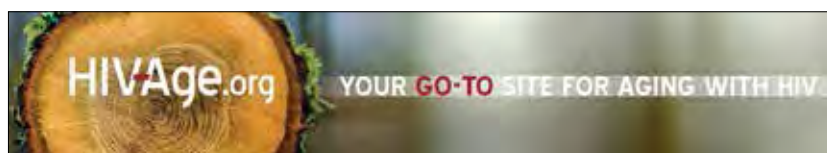
The lower rate of liver cancer seen in the present study likely arose because most participants were treated relatively early in the course of liver disease, before the onset of cirrhosis. **HIV**

## Reference

Lawitz E, Ruane P, Stedman C, et al. Long-term follow-up of patients with chronic HCV infection following treatment with direct-acting antiviral regimens: maintenance of SVR, persistence of resistance mutations and clinical outcomes. *The International Liver Congress*, 13–17 April 2016, Barcelona. Abstract 166.

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# High Prevalence of Geriatric Conditions Among HIV+ People Over Age 50 in San Francisco

**OLDER HIV-POSITIVE PEOPLE** have a high prevalence of multiple age-related problems, investigators reported in the March 29 online edition of the *Journal of Acquired Immune Deficiency Syndromes*. The research involved people aged 50 years and older receiving outpatient care in San Francisco. Overall, 40% reported difficulties with daily activities, most reported loneliness, many had mild cognitive impairment, and 30% had only poor to fair quality of life.

“This is one of the first studies to have evaluated a wide range of geriatric assessments among HIV-infected individuals in an outpatient clinical setting and provides a comprehensive overview of the health needs faced by the aging HIV-positive population,” wrote the authors. “We observed a high burden of clinically-concerning deficits in older HIV-infected adults across multiple domains, including functional impairment, falls, depression, and social isolation.”

The investigators believe their findings have implications for patient care, commenting, “our results highlight the importance of systematically providing functional, social, and mental health support for the aging HIV-infected population.”

Improvements in treatment and care mean that many people with HIV are now living well into old age. Over half of HIV-positive adults in the U.S. are now age 50 years and over. Previous research has shown that these individuals frequently have multiple health problems and develop conditions associated with old age earlier than the traditional cut-off for old age—65 years.

The Veterans Aging Cohort Study (VACS) Index, a prognostic tool based on markers associated with HIV and other health conditions, can be used to identify older HIV-positive people with a high risk of illness and death. The VACS Index score has also been associated with risk of fragility fractures, cognitive impairment, and reduced exercise capacity. However, less is known about its association with geriatric conditions, such as functional status.

Investigators therefore designed a cross-sectional observational study assessing the physical, cognitive, social, and behavioral health of a large sample of older HIV-positive adults receiving outpatient care at 2 clinics in San Francisco. A combination of geriatric and other assessments were used to assess psychosocial issues observed in older patients with HIV. The investigators

hypothesized that both age and VACS Index score would be associated with the geriatric conditions identified in the assessments.

Recruitment occurred between December 2012 and December 2014 and English-speaking patients aged 50 years and older were eligible to participate.

Assessments included questions on physical, social, mental, and cognitive health. The investigators used a combination of assessments that addressed traditional geriatric conditions and also specific issues faced by older HIV-positive people.

The researchers assessed 4 broad areas of health:

- Physical health and functioning, falls, and walking speed (Activities of Daily Living and Instrumental Activities of Daily Living);
- Social support, including physical and perceived support and loneliness;
- Mental health, including depression, anxiety, and post-traumatic stress disorder (PTSD);
- Behavioral and general health, including adherence to HIV therapy and overall quality of life.

A total of 359 patients were assessed. Most (85%) identified as men, two-thirds were in the men who have sex with men (MSM) risk category, and approximately 60% were white. Approximately three-quarters had attended college. Half were receiving disability benefits and the majority had an annual income below \$20,000. Most (85%) had been living with diagnosed HIV infection for 10 years or more. As regards HIV-related markers, 82% had an undetectable viral load and over half had a CD4 cell count above 500 cells/mm<sup>3</sup>.

The median age was 56 years and two-thirds of patients were in their fifties. Patients aged 60 years and older were more likely to be white, college educated, and to have a higher annual income when compared to younger participants.

The patients had a high burden of conditions associated with older age, with 41% reporting a

fall in the previous year, almost 60% reporting loneliness, half reporting low levels of social support, and over a third met the criteria for mild cognitive impairment.

Patients aged 60 and older were more likely to report problems with balance than patients in their fifties (47% vs 33%). Prevalence of problems with physical health and functioning was similar in the 2 age groups (12%), but people in their sixties had slower walking speed.

However, the older patients reported less anxiety and had higher levels of adherence to their HIV treatment. Although older patients were more likely to rate their health-related quality of life as “good,” fewer reported that it was “very good” or “excellent” compared to people in their fifties.

A higher VACS Index score—indicative of higher mortality risk—was associated with greater levels of dependence and Instrumental Activities of Daily Living scores, i.e., falls and slower gait speed.

“Our data add to the growing body of evidence that older HIV-infected adults are facing increasing medical, psychiatric, and social complexity and help to provide insight into how this complexity varies in different age groups in older adults,” concluded the authors. “Our findings highlight the importance of taking a comprehensive approach to identify health issues facing older HIV-positive patients and the critical need to develop interventions to improve the quality of life and address the multifaceted needs of older HIV-infected patients.” **HIV**

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\*\*Please note that this article is a reprint originally appearing on [HIVandHepatitis.com](http://HIVandHepatitis.com), written by Michael Carter published on May 8, 2016.





# Transgender Issues in

# HIV

Providers need accurate, current information to provide optimal care

**BY JAE SEVELIUS, PH.D.**

**A**S AWARENESS ABOUT THE EXISTENCE OF TRANSGENDER PEOPLE GROWS in mainstream consciousness, so does our knowledge about their unique strengths, needs, and vulnerabilities. Providers of HIV care need accurate and current information about transgender people living with HIV, including potential barriers and facilitators to engagement and retention, as well as strategies for optimizing HIV care and treatment for transgender patients. ▶

THINKSTOCK

## Terminology

‘Transgender’ is an umbrella term for individuals whose gender identity differs from the sex they were assigned at birth.

‘Transgender women’, sometimes referred to as ‘male-to-female’ (or ‘MTF’) are individuals who were assigned male sex at birth, but who identify as women or as transgender women.

Similarly, ‘transgender men’ (‘female-to-male’ or ‘FTM’) were assigned female sex at birth, but identify as men or as transgender men. Some transgender people do not identify within the male/female binary at all.

Furthermore, current literature is moving away from the MTF and FTM terminology for a variety of reasons; a summary of selected common terms is provided in Table 1. Terminology used to describe transgender identities varies widely by geographic region, age, ethnicity, and other factors. When serving transgender patients, providers can build trust by asking for and using the terminology preferred by each patient and by ensuring that the patient’s preferred name and pronoun is recorded in his/her medical record and used by every staff person who interacts with the patient.

## Stigma and Discrimination

Transgender people often experience stigma and discrimination, resulting in social marginalization and negative health outcomes. Because their gender identity and/or presentation differs from the sex they were assigned at birth, transgender people challenge society’s most basic assumptions about the binary nature of sex and gender and the stability of identity.

The discrimination, rejection, and violence experienced by transgender people are often referred to as ‘transphobia’. Just as homophobia negatively affects lesbians and gay men, transphobia affects transgender people in a multitude of deleterious ways. Experiences of discrimination and victimization negatively impact mental health by increasing anxiety, depression, and suicidality.<sup>1-3</sup>

Transphobic discrimination, victimization, and lack of social support consistently are associated with attempted suicide, substance use, dropping out of school, and unprotected sex among transgender youth<sup>4</sup>. Transgender people have shockingly high rates of suicidal ideation and suicide attempts compared to the general population (31 percent vs. 2 percent),<sup>1</sup> and often report using substances to cope with the intense stressors associated with the stigma of being transgender.<sup>5</sup>

## HIV in Transgender Populations

Transgender women are one of the most highly impacted groups in the HIV epidemic to date, yet they are disproportionately under-researched and underserved by current treatment efforts. Transgender women have 49 times higher odds of HIV infection compared to other groups, a disparity that exists across race, culture, and socioeconomic boundaries.<sup>6</sup> Disparate prevalence rates of HIV are particularly pronounced for African American transgender women when compared with transgender women of other races and ethnicities.<sup>7</sup> Furthermore, HIV+ transgender women have an almost

three-fold higher community viral load than non-transgender HIV+ adults in San Francisco (64,160 vs. 22,376),<sup>8</sup> and likely elsewhere. HIV-related mortality and morbidity rates have also been found to be higher among transgender women.<sup>9</sup>

In addition, there is evidence that current efforts to provide effective treatment to transgender women living with HIV are not as successful as with other populations. In the only study of its kind to date, transgender women living with HIV were less likely to be receiving antiretroviral therapy than a control group of non-transgender men and women.<sup>10</sup> Furthermore, transgender women living with HIV who were on antiretroviral therapy demonstrated worse adherence than non-transgender people, reported less confidence in their abilities to integrate treatment regimens into their daily lives, and experienced fewer positive interactions with their healthcare providers.<sup>11</sup>

To date, there are few studies of HIV incidence among transgender men in the literature. Transgender men at risk for HIV are those that report sex with non-transgender men (trans MSM), a subgroup that has only recently begun to receive attention in public health research. The few research studies focused on trans MSM to date have found relatively high levels of reported risk behavior, but lower levels of HIV prevalence (0-3 percent).<sup>12</sup> Some trans men who are on cross sex hormone therapy (i.e. testosterone, or ‘T’) self-report a link between testosterone use, increased sex drive, increased interest in engaging in sexual activity, and exploration of sexual behaviors that may include sex with non-trans men. For trans men on testosterone, the masculinization of the body may lead to increased access to non-trans MSM partners, and a willingness to take sexual risks that could potentially place trans MSM at risk for STI and HIV infection.

## Engagement and Retention in HIV Care

Because transgender women are extremely disproportionately affected by HIV, and because the vast majority of HIV-related research has focused on transgender women, this discussion will focus on what we know about transgender women’s experiences with seeking HIV care. Much of this information may be applicable to transgender men as well, but transgender men are likely to face qualitatively different issues as well.

Transgender women living with HIV face culturally unique and substantial challenges to adhering to HIV care and treatment regimens, such as limited access to and avoidance of healthcare due to stigma and past negative experiences, prioritization of gender-related healthcare, and concerns about adverse interactions between antiretroviral therapy and hormone therapy. Issues that affect other marginalized populations, such as mental health issues, substance use, and poverty, are barriers to care among transgender women as well, but additional transgender-specific barriers exist as a result of transphobia, as well as needs for gender affirmation and transition-related healthcare.

## Importance of Gender Affirming Health Care

“Gender affirmation” is the process by which individuals feel socially validated in their gender identity through interpersonal

**Table 1. Selected common terms used to describe transgender identities**

Term	Definition
<b>Transgender</b>	An umbrella term used to describe individuals whose gender identity differs from the sex they were assigned at birth
<b>Trans</b>	Shorthand term for 'transgender'
<b>Transgender woman/Trans woman</b>	Transgender person assigned male at birth, identifies as female
<b>Transgender man/Trans man</b>	Transgender person assigned female at birth, identifies as male
<b>Transvestite/Cross-Dresser</b>	A person who dresses in gendered clothing that differs from their own identity for entertainment or sexual purposes but does not necessarily identify as transgender
<b>Genderqueer</b>	Gender nonconforming person, a term increasingly used by youth
<b>Transsexual</b>	A term that is sometimes used to refer to transgender individuals who have undergone medical procedures to affirm their gender; currently a less favored term in trans-related literature

interactions, such as interactions with a healthcare provider. The Model of Gender Affirmation is a transgender-specific model developed to examine the role of gender affirmation in risk-taking, self-care, and healthcare-seeking behavior.<sup>13</sup> It posits that when a transgender woman places a high level of importance on gender affirmation, she will seek out opportunities to receive this affirmation and avoid experiences in which she is not affirmed in her gender.

A gender affirming healthcare experience would include, for example, a transgender patient being called by the correct name and pronoun by all staff throughout the healthcare encounter without unnecessary attention being drawn to her transition status. Gender affirmation also includes having access to and support for transition-related health care, such as hormones and surgeries, as desired by the patient. Evidence of the associations between access to gender affirmation and improved quality of life, mental health, and self-care behaviors among transgender people is growing rapidly.<sup>14,15</sup>

Gender affirmation is of paramount importance to many transgender women at every stage of the HIV care continuum. Transgender sensitivity and knowledge on the part of providers and clinics can be a crucial barrier when absent, and a powerful facilitator when present. Studies have reported that when transgender women do seek healthcare, patients' trust in their provider is compromised when they encounter insensitivity and low levels of knowledge. Diminished trust subsequently impairs patient-provider communication and can affect participants' decisions to initiate and/or adhere to antiretroviral therapy.

Multiple negative experiences can ultimately result in avoidance of healthcare settings altogether. Gender affirming

healthcare, however, can support engagement and retention in HIV care among transgender women by increasing patient-provider trust, fostering positive interactions, and supporting a collaborative relationship.

Intake forms should permit transgender patients to identify themselves and their records should correctly identify their preferred name and pronoun to all providers and staff that interact with them. This documentation should be handled as sensitive and confidential health information. This increases trust in the provider and clinic by ensuring that patients are not called by the wrong name and/or pronoun, an experience commonly reported by transgender people as highly detrimental to their health care experience.

Efforts are currently underway to allow for the identification of transgender patients using electronic medical records.<sup>16</sup> In the meantime, clinics should revise local systems to be inclusive and respectful of transgender patients. The UCSF Center of Excellence for Transgender Health's Recommendations for Inclusive Data Collection of Trans People in HIV Prevention, Care, and Services offer guidelines for clinics and have been implemented by agencies across the US.<sup>17</sup>

Currently, few formal medical education programs include transgender-specific medical care in their training of providers. Providers who serve transgender patients should be comfortable with transgender people at all stages of transition. Training providers to conduct thorough yet respectful health assessments, including mental health and sexual health, will help build trust and rapport with transgender patients. In addition, creating a safe clinic space, including respectful front line staff, sends the message that transgender patients are welcome and is more likely to yield positive health care experiences.

### **Integration of Hormone and Antiretroviral Therapy**

Transgender women living with HIV often juggle a variety of demands on their time and energy due to trauma, addiction, and the deleterious effects of transphobia in their day-to-day lives. Once they initiate antiretroviral therapy, transgender women often experience barriers to integrating the regimens into their daily lives.

One method for starting to address this barrier is the integration of hormone therapy and antiretroviral therapy in HIV primary care settings, a strategy that has been employed successfully and recommended by primary care clinics that serve transgender patients.<sup>18</sup>

Seeing the same provider (or at the very least, being seen at the same clinic) for both hormones and antiretroviral therapy may facilitate patient management of their appointments and medications, increase the likelihood that they keep their appointments (augmented by a high level of motivation to adhere to their hormone regimen), and increase trust in their provider.

Several resources are available to guide the provision of hormones for providers who are new to treating transgender patients. The UCSF Center of Excellence for Transgender Health has an online Primary Care Protocol for Transgender Patient Care that provides peer-reviewed guidelines and

additional resources for review.<sup>19</sup> In addition, the World Professional Association for Transgender Health recently revised its Standards of Care document that has long served as a resource for those wishing to increase their expertise and receive guidance in the provision of health care to transgender patients.<sup>20</sup>

### Additional Recommendations

- **Increase visibility of transgender people in peer and professional support roles.** Transgender patients often feel most comfortable with outreach and program staff who are also transgender. 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 and can serve as an invaluable resource in peer navigation programs.
- **Attend to transgender-specific needs.** Interventions specific to transgender patients are ideal. Programs such as a transgender-specific portal to a larger health clinic, use of peer health navigators, and transgender-specific clinic hours are exemplar models that have been successful. In areas where it is not possible to create transgender-specific services, explore aspects of existing programs that can be tailored to the transgender community, such as adding a transgender-specific support group to substance abuse treatment programs or housing programs.
- **Maintain current referral resources.** While some areas may not have many transgender-specific referral resources, identifying services that are informed and sensitive can help patients avoid negative experiences in the community. This may also increase the likelihood that they will access support services that may help them stay engaged in their treatment, such as complementary and alternative therapies that help alleviate side effects of HIV medications and spiritual and/or meditation groups that help promote healthy coping strategies. When possible, create a centralized, up-to-date, and comprehensive transgender resource guide that can be given to patients.

### Conclusion

Engagement and retention of transgender patients in HIV care and treatment will be optimized by services that are gender affirming and integrate transition-related healthcare needs. Such interventions must fully attend to the social, economic, and psychological context of transgender patients' lives and address the multiple barriers to healthcare engagement, treatment adherence, and empowerment that serve to create, maintain, and deepen HIV-related health disparities, particularly among transgender women living with HIV. **HIV**



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# THE LINK

*News About HIV Prevention, Care,  
and Treatment for Key Populations*

JULY 2015 | Issue 3

## TRANS-forming: DATA FOR DECISION MAKING

Throughout this edition of The LINK, our guest authors are brimming with optimism about the world's increased attention to the human rights and health needs of transgender people—thanks to decades of advocacy by the trans community. Internationally, the transgender movement has been particularly strong in Asia and Latin America, where trans men and women are celebrating their identity and fighting for social change. In Bangladesh, hijras, who identify as neither male nor female, led Dhaka's first pride parade in 2014. More than 1,000 Bangladeshi hijras marched to mark a year since their official recognition as a third gender. In 2012, Argentina's government passed transgender rights regulations that are considered to be some of the world's most progressive, and in 2013, Chile began to cover sex reassignment surgery under the government plan.

Certainly, we should celebrate these and other hard-won reforms. But the trans community and its allies also remember that trans men and women continue to face stigma, discrimination, violence, and, particularly for trans women, a disproportionate rate of HIV infection. Most of what we do know about trans women and HIV comes from studies in the United States and other western countries, though that has begun to change. (See Tonia Poteat's article on page 4 for more information about trans women in the HIV cascade.) Even less is known about trans men, though according to a Lancet analysis,<sup>1</sup> those who have sex with men are likely to experience a "heightened vulnerability" to HIV.

This dearth of information is not surprising. Few countries issue identification documents in which a person's self-identified gender differs from his or her assigned sex. Also, the way data are collected contributes to trans people's relative invisibility. When trans women are diagnosed with HIV, they are often coded as "male," which makes it difficult to gather reliable data on HIV in these communities. LINKAGES advisory board member JoAnne Keatley, in her article on page 3, provides a more in-depth look at the need to count trans people in public health measurements.

Beyond failure to officially recognize trans people, many countries criminalize "impersonations of the opposite sex," effectively forcing the transgender community underground. And in 2014, only 39 percent of countries reported that their national AIDS strategies specifically addressed transgender people.

Though their need for health services is great, their experiences in the health system are not. In a 2010 survey of 7,000 transgender people in the United States, 19% reported being refused care because of their transgender or gender

**ARTICLE CONTINUED ON PAGE 2**

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nonconforming status and 28% said they were subjected to harassment in medical settings.<sup>2</sup> Even trans-friendly health care providers often are not “trans-competent”; that is they lack training to address trans-specific medical issues. In this study, 50% of those surveyed reported having to teach their medical providers about transgender care.

Despite these often formidable obstacles, the trans community has shown resilience and strong leadership. Trans-led grassroots organizations are challenging the barriers that transgender people face, advocating for their rights, fighting stigma and discrimination, and demanding improved health care. For example, LINKAGES partner Sisters is a Thai organization run by and for trans women. Sisters employs community-based peer educators to help trans women navigate HIV treatment, care, and services. (Read more about Sisters on page 5.) Transgender constituency groups have been partners in the development of the *Transgender Implementation Tool* and the *Asia Pacific Trans Health Blueprint* which, as Darrin Adams discusses in his article on page 6, will be foundational guides

to improving health services for transgender people.

Until recently, the world’s response to HIV has largely overlooked trans people. But due to the hard work of the trans community and their partners, the tide has begun to turn. We must all continue to support these efforts, for trans people need and deserve to be counted. Health care providers must become trans-friendly *and* trans-competent. Researchers must study the needs of trans men and trans women specifically and collect data in a way that correctly captures gender identity. Governments and policymakers must codify the rights of trans people into law and then see that laws are enforced. For through combined efforts made at many levels, health care and social justice can really be transformative.

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## PROMISING STRATEGIES FOR STIGMA REDUCTION

The *Transgender Implementation Tool (TRANSIT)* operationalizes the trans-specific recommendations in the WHO’s *Consolidated Guidelines on HIV Prevention, Diagnosis, Treatment and Care for Key Populations*. (For more information about the *TRANSIT*, see page 6). Among other topics, the tool discusses promising strategies for building empowerment in the trans community and preventing and responding to stigma, discrimination, and violence. Following is a sample of the recommendations.

- Foster and support programs and advocacy led by the trans community. Areas that have a history of trans people organizing to advocate for their own rights tend also to have the highest standards of care and the most community-based organizations meeting transgender people’s needs.
- Reform laws so that trans people are allowed a legal identity, and all associated identity documents, based on the gender of their choosing.
- Increase the use of information and communication technologies, especially in languages other than English, to reach global trans audiences.
- Develop and improve strategies for measuring, documenting, and monitoring stigmatizing and discriminating events and experiences.
- Implement trans-specific trainings of health care workers on a systematic basis, with buy-in and participation by the ministries of health and in-country educational systems.



Photo Credit: © Ian Taylor

Ms. Popy is a hijra community leader in Bangladesh.



## COUNT ME IN!

It is an amazing time in transgender (trans) health. Never before has there been this level of interest and attention being paid to my community. Steadily there is progress being made toward health policy and human rights inclusion. Yet, for all the progress we've made, there remains a challenge in adequately addressing our health and wellness needs. Trans people cannot be fully accounted for in health policy if we are not counted in surveillance and public health measurements. Data used by governments and global health organizations to describe epidemics and allocate funds to steer public health responses do not consistently include measures that capture gender identity. As a result, trans people continue to be included in data describing gay men and other men who have sex with men. This practice leads to erroneous equating of gender identity with sexual orientation and a serious undermining of trans peoples' ability to take leadership of our own public health approaches. In spite of the lack of standardized measures capturing gender identity, studies that have intentionally sampled

trans women have consistently shown them to have among the highest HIV prevalence rates of any population. In some instances, public health data reflect that in addition to high HIV rates, trans women have to deal with a lack of trained, culturally aware providers. As a result trans women who are disproportionately affected by HIV also reflect lower percentages of being linked to and retained in ARV therapy.

Even when public health officials have good intentions and make attempts at inclusion, they often get it wrong. The use of inappropriate measures forces trans people to choose among male, female, and transgender options as if trans people do not have male and female identities. In the best case scenario, this practice captures the existence of a trans identity but does not distinguish between trans male and female identities. In fact many of the issues we deal with have to do with societal views of gender. For example, trans women face problems common to non-trans women, such as gender-based violence, lower pay for equal

work, and more. In order to adequately describe the public health status of all trans people one must distinguish between trans men, trans women, and people who are non-binary. Public health approaches cannot simply be reduced to a "one size fits all" model. We must tailor our efforts to account for the specificities within our community in order to be able to make an impact that is sustainable and that respects our bodies, minds, and identities.

At the Center of Excellence for Transgender Health ([www.transhealth.ucsf.edu](http://www.transhealth.ucsf.edu)) we advocate the use of a two-step model to capture both gender identity and sex assigned at birth. We believe that this approach is the most efficient way to delineate differences in identity and anatomy, both crucial for making health care decisions. The model can be used in surveillance as well and will more accurately describe not only issues affecting trans people but also distinguish them from non-trans people such as MSM. If this model is used consistently, we believe it will lead to greater clarity and understanding of the issues we have in common and the differences that make us distinct. At the end of the day, when you are not counted, you don't count.

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Photo Credit: © Cameron Wolf

[allianceaids.org](http://allianceaids.org)

*Members of Swing Thailand pose outside the transgender networking zone at the International AIDS conference, wearing costumes they made of condoms.*

# HIV CARE AND TRANSGENDER WOMEN: WHERE DO WE LOSE THEM ALONG THE CONTINUUM?

With the goal of ending the AIDS pandemic by 2030, UNAIDS has set ambitious intermediate targets: by 2020, 90% of people living with HIV will know their status, 90% of people diagnosed with HIV will be on treatment, and 90% of people on treatment will have a suppressed viral load. Ultimately, the ability to end AIDS depends on reaching key populations—the people who bear a disproportionate burden of HIV.

Transgender women are a highly vulnerable group among key populations; they have a global HIV prevalence of 19% and 49 times the odds of HIV infection compared to the general population.<sup>1</sup> Since these data suggest that about one in five transgender women worldwide may be living with HIV, it's critical to understand what the HIV care continuum looks like for them. The data to answer this question are limited, but what we do know tells us we have much work to do.<sup>2</sup>

One study among a probability-based sample of transgender women in San Francisco found that while 95% were previously aware of their HIV status and 87% had accessed care in the prior

6 months, only 65% of those living with HIV were on antiretroviral therapy (ART) and only 44% had suppressed viral loads.<sup>3</sup>

However, a nationally representative sample of people in HIV care in the United States suggests that the news may not be all bad. In this study of more than 36,000 people in HIV care, 80% of the 285 transgender participants were retained in care, 76% received ART, and 68% achieved viral suppression, and their outcomes were not significantly different from nontransgender men and women.

Another population-based study from the Medical Monitoring Project in the United States and Puerto Rico compared transgender women in HIV care to nontransgender people in care. The authors found no difference in the proportion receiving a prescription for ART; however, transgender women were less likely to report 100% adherence and less likely to have durable viral suppression than nontransgender men.<sup>4</sup> These differences took place in the context of significant structural disparities. The same study found that

transgender women had a greater need for supportive services ranging from mental health and domestic violence services to meals, transportation, and housing.<sup>4</sup> The need for meals and housing services were significantly less likely to be met for transgender women compared to nontransgender men.

All of these studies took place in the United States, a high-income country with some of the best health care resources in the world. While we don't yet have data about the HIV care continuum for transgender women from other countries, it is likely that transgender women living in countries with greater resource constraints will have more difficulty accessing HIV testing, care, and treatment services. When developing programs to better engage transgender women along the HIV care continuum, it will be important to keep in mind lessons learned from data. We know that it is possible to engage transgender women in HIV testing and care. However, once they are in care, we must address housing instability, food insecurity, and other structural barriers to ART adherence and viral suppression.

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Photo Credit: © Ian Taylor

# THE WHAT, WHERE, AND HOW: MAPPING THE HIV AND COMPREHENSIVE HEALTH IMPLEMENTATION STRATEGY FOR TRANS PEOPLE GLOBALLY

"This is the year for trans," said a donor representative at the kick-off consultation for the *Asia and the Pacific Trans Health Blueprint* (or *AP Blueprint*) in October 2014. In many respects, this was a reading of the tea leaves about what would indeed transpire in the months following—what many trans advocates and their allies have been working toward for years. As trans people have generally become more visible and some have achieved mainstream fame (read: Lavern Cox and Caitlyn Jenner), trans people have become a part of the public discourse.

Now, a collection of global and regional documents (see text box) is emerging that, together, will shift discourse into action to improve the health and human rights of trans people and their communities. Two of these documents are the *AP Blueprint* and the *Trans Implementation Tool (TRANSIT)*.

The *AP Blueprint* is being developed through a collaboration of the Asia Pacific Transgender Network, United Nations Development Programme, and the United States Agency for International Development (USAID)-

funded Health Policy Project. The purpose of the document is to provide a contextual map about where the gaps and points of intervention lie for the realization of comprehensive trans health. The document is grounded in the World Health Organization (WHO) *Consolidated Guidelines for Key Populations* and developed with regional input from trans people, trans health medical providers, WHO, and other stakeholders.

The *TRANSIT* is one of a series of global implementation tools for key populations—sex workers, men who have sex with men, transgender people, and people who use drugs. The *TRANSIT* is a programming guidance document that demonstrates *how* to implement the trans-related recommendations from the WHO *Consolidated Guidelines*. With chapters written by trans people who are members of regional and country-level initiatives, the *TRANSIT* compiles promising practices and evidence-based approaches in five key areas: community empowerment; stigma, discrimination, violence, and human rights; services; service delivery approaches; and program management.

On its own, the *AP Blueprint* could serve as an advocacy tool to demonstrate what is needed for comprehensive health services for trans people and their communities. This demonstration could be further highlighted in technical briefs that feature chapters or sections of interest in a particular region or country. Furthermore, the blueprint could be adapted to

## A FAMILY OF DOCUMENTS FOR TRANS HEALTH

A core set of documents has emerged to advocate for the implementation of HIV-specific and comprehensive trans health. They include, but are not limited to:

- The PAHO 2011 Latin America and 2014 English-speaking Caribbean Trans Health Blueprints
- WHO's 2014 HIV Consolidated Guidelines for Key Populations and a policy brief on trans people and HIV
- The forthcoming Trans Implementation Tool and the Asia and the Pacific Trans Health Blueprint

develop modular health provider trainings that might be instituted as part of a national curriculum and other pre-service training points of entry. Used together, the *TRANSIT* and the *AP Blueprint* could make an even larger impact in the region. The *Blueprint* could complement the *TRANSIT* by showing *where* to implement the *how*. Additionally, the *TRANSIT* is a global document that has been synthesized from regional approaches. The *AP Blueprint* could provide the cultural context needed to begin localizing the *TRANSIT* into implementation and adoption at the national and sub-national levels in the Asia-Pacific region.

The *AP Blueprint* and the *TRANSIT*—developed through the hard work of so many people passionate about these issues—will pave the way for trans health and human rights in the Asia-Pacific region and around the world.

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Photo Credit: © Rose Wilcher, FHI 360

**Beyonce Karungi, founder and executive director of Transgender Equality Uganda, participated in a TRANSIT consultation in Bangkok earlier this month.**



# BLOG.AIDS.GOV - Changing to HIV.gov in Spring 2017

## New Federal Actions to Address HIV in the Transgender Community

April 13, 2016 • By [Richard Wolitski, Ph.D., Acting Director, Office of HIV/AIDS and Infectious Disease Policy, U.S. Department of Health and Human Services](#) and [Laura Cheever, MD, ScM, Associate Administrator, HIV/AIDS Bureau, Health Resources and Services Administration, U.S. Department of Health and Human Services](#) and [Amy Lansky, PhD, MPH, Acting Director, Office of National AIDS Policy, The White House](#) and [Eugene McCray, M.D., Director, Division of HIV/AIDS Prevention, National Center for HIV/AIDS, Viral Hepatitis, STD, and TB Prevention, CDC](#)



Transgender communities in the United States are among the groups at highest risk for HIV infection. The National HIV/AIDS Strategy (NHAS) observes that, historically, our efforts focused on this population have been limited, but that the federal government has made strides in improving our response since 2010.

Urging that we remain vigilant in

increasing knowledge and appropriate support and interventions for this population, the Strategy rightly includes transgender women, especially Black transgender women, among the populations disproportionately affected by HIV for and with whom we must prioritize interventions.

Transgender leaders and their allies have been working to raise awareness about the unmet HIV prevention and care needs in the transgender community and to improve programs, policies, and data supported by the federal government. They have pressed the federal government, and the HIV community more broadly, to be more thoughtful and thorough in our follow through on the parts of the Strategy that are most important for improving the health of transgender persons living with HIV and preventing new HIV infections in this population.

Over the past several months, we and colleagues from CDC, HRSA, and the

White House Office of National AIDS Policy have had the opportunity to engage in a number of conversations – including a [White House meeting on HIV in the transgender community](#) – during which we heard from transgender women and men about their experiences and recommendations for improving the response to HIV in the transgender community. The data and lived experiences they brought to these meetings were compelling.

The White House meeting and subsequent discussions have identified a variety of on-going efforts to reduce HIV risk and improve health among transgender persons from across several HHS agencies. These discussions also resulted in specific new steps that could be taken in the near-term and down the road to continue and expand efforts to improve our nation’s HIV prevention and care efforts for transgender people. We are pleased to share an update on several of these new activities that are underway or about to begin:

- With resources from the Secretary’s Minority AIDS Initiative Fund, HRSA’s HIV/AIDS Bureau (HAB) will fund a new training program in FY16 to support leadership development and build capacity among people living with HIV from disproportionately affected groups of people of color, including transgender women. The HHS Office of HIV/AIDS and Infectious Disease Policy (OHAIDP) will provide additional resources to support expansion of the program to specifically increase the participation of transgender women of color as part of this three-year effort.
- An ad hoc subgroup of the NHAS Federal Interagency Workgroup is developing an indicator for HIV in transgender populations. The indicator is expected to be finalized this calendar year and data included in the 2016 NHAS Progress Report.
- OHAIDP will conduct a review of HHS-supported HIV activities for transgender persons to document both programs and research that are currently funded and identify potential gaps. The review will be completed by the end of this calendar year and released online.
- CDC has taken important steps to improve how HIV-funding to serve transgender communities is awarded. New funding opportunity announcements seeking specifically to improve HIV outcomes among transgender persons will no longer be combined with those serving men who

have sex with men (MSM), whenever feasible. If it is not feasible to have separate funding announcements, scoring criteria will include elements that clearly address applicants' ability to reach transgender persons and provide high quality, culturally appropriate services. Such criteria might include experience of the program manager and staff in providing services to transgender populations and/or a plan to ensure competent staff.

- CDC will expand the [National HIV Behavioral Surveillance](#), which conducts behavioral surveillance among persons at high risk for HIV infection, to include the transgender population. Specifically, CDC proposes to fund up to 10 sites, depending on the availability of funds, for a project period from January 1, 2017 to October 31, 2018.
- CDC will expand the scope of its HIV Prevention [Capacity Building Assistance](#) (CBA) Program to provide technical assistance to health departments and community-based organizations (CBOs) serving transgender populations, especially CBOs serving transgender women of color.
- A CDC/DHAP work group is exploring the possibility of developing activities to support capacity building/development of transgender organizations, with a particular focus on organizations serving transgender persons of color and transgender persons in the South.
- OHAIDP will confer with transgender HIV advocates and representatives of HHS agencies to discuss priorities for a potential FY17 demonstration project supported by the SMAIF that would seek to improve HIV prevention and care for transgender women of color.

We expect that these efforts will expand and enhance the HIV prevention and care services available to transgender people across the nation. We are hopeful that they will motivate partners – including health departments, health systems, clinicians, CBOs, faith communities, employers and others – to consider what steps they might take to augment and further strengthen their own efforts so that together we better serve this population that has suffered too many injustices for too long.





## TRANSGENDER HIV / AIDS HEALTH SERVICES

**Best Practices Guidelines**  
**[ BEST PRACTICES GUIDELINES ]**

The 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.

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# 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, two-and-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 transgender-specific 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.

**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.**

## 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.

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

[ 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 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 2** Client awareness of specific transgender 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 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 8 Building and engaging in a trusting 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 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.





## 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.

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.

## 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 gay, and three identified as other. The remaining three 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.

Other services participants reported utilizing were housing, money management, peer advocacy, primary health care, home health care, and case management.

## Service Utilization

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 ]

**a** Summary of Standards and Practices

**b** Literature Review of Best Practices for Transgender Care

**c** Bibliography

# 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 candidates. 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.

# appendix b

## [ LITERATURE REVIEW OF BEST PRACTICES FOR TRANSGENDER CARE ]

ARTICLE	SOURCE/YEAR	DESCRIPTION	MAIN POINTS AND STATISTICS
<p><i>Community Standards of Practice of Quality Health Care Services for Gay, Lesbian, Bisexual and Transgendered Clients</i></p>	<p>GLBT Health Access Project, Boston, MA  www.glbthealth.org</p>	<p>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.</p>	<p>The standards are summarized below:</p> <ul style="list-style-type: none"> <li>• <b>Standard 1:</b> Establish written non-discrimination policies</li> <li>• <b>Standard 2:</b> Support and encourage visibility of GLBT employees.</li> <li>• <b>Standard 3:</b> Equal employment opportunities for GLBT of all ages.</li> <li>• <b>Standard 4:</b> Comprehensive policies are implemented to prohibit discrimination in the delivery of services to GLBT clients and their families.</li> <li>• <b>Standard 5:</b> Ensure a comprehensive and easily accessible procedures for clients to file and resolve complaints alleging violations of policies.</li> <li>• <b>Standard 6:</b> Intake and assessment procedures meet the needs of GLBT of all ages and their families.</li> <li>• <b>Standard 7:</b> All agency staff have a basic familiarity with GLBT issues as they pertain to services provided by the agency.</li> <li>• <b>Standard 8:</b> All direct care staff are competent in identifying and addressing specific health problems and treatment issues for GLBT.</li> <li>• <b>Standard 9:</b> All case management and treatment plans include and address sexual orientation and gender identity where it is a necessary and appropriate issue in client care.</li> <li>• <b>Standard 10:</b> Client data including information about sexual orientation and gender identity issues are kept confidential.</li> <li>• <b>Standard 11:</b> 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 style="list-style-type: none"> <li>• <b>Standard 12:</b> The agency shall include GLBT and their families in outreach and health promotion efforts.</li> <li>• <b>Standard 13:</b> The composition of the agency Board of Directors and other institutional bodies shall encourage representation from GLBT communities.</li> <li>• <b>Standard 14:</b> Agency community benefits programs shall include GLBT people in the communities the agency serves.</li> </ul> <p>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.</p>
<p><b><i>Recommendations for Health Service Organizations to Improve Their Services for Trans Clients</i></b></p>	<p>Sausa, Lydia, PhD. <i>Human and Sexuality Educator, Trainer, &amp; Consultant</i>. Jan. 2006</p> <p>www.lydiasausa.com</p>	<p>Focuses on structural and organizational changes that can be made in order to provide culturally competent services for transgender clients.</p>	<ul style="list-style-type: none"> <li>• Provides specific recommendations for health service organizations in various areas of organization and suggests training needs in areas including: <ul style="list-style-type: none"> <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 gender-neutral 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> </li> </ul>
<p><b><i>Transgender Health</i></b></p>	<p>Feldman, Jamie, MD and Bockting, Walter, PhD. <i>Minnesota Medical Association</i>. July 2003, Vol. 86.</p>	<p>Presents a literature-based review of the health needs of the transgender patient.</p>	<p>Focuses recommendations/suggestions for medical providers in the following TG-specific health issues:</p> <ul style="list-style-type: none"> <li>• <b>Presentation</b> <ul style="list-style-type: none"> <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 style="list-style-type: none"> <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>• <b>Health History</b> <ul style="list-style-type: none"> <li>• Because TG persons may utilize hormonal or surgical interventions, a thorough 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>• <b>General Health Maintenance</b> <ul style="list-style-type: none"> <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>• <b>Mental Health</b> <ul style="list-style-type: none"> <li>• MH maintenance is important and should include depression screening and helping patient connect with TG support services.</li> </ul> </li> <li>• <b>Sexual Health</b> <ul style="list-style-type: none"> <li>• Providers should play a role in assessing their patients 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> </ul> <p>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 (<a href="http://www.hbgda.org/soc.html">www.hbgda.org/soc.html</a>); working closely (hormone</p>

ARTICLE	SOURCE/YEAR	DESCRIPTION	MAIN POINTS AND STATISTICS
			<p>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.</p> <p>The article also discusses medical conditions associated with TG hormone therapy including Type 2 diabetes mellitus, cardiovascular disease, venous thromboembolic disease, liver abnormalities, hyperprolactinemia, osteoporosis, and cancer.</p>
<p><b><i>Recommended Standards of Practice for the Provision of Quality Health Care and Social Services for Gay, Lesbian, Bisexual, and Transgender Clients</i></b></p>	<p>City of Tucson Commission on Gay, Lesbian, Bisexual, and Transgender Issues. Revised January 2005.</p> <p>www.pimamedical society.org/gender.php</p>	<ul style="list-style-type: none"> <li>• Purpose of document is to provide a set of recommended guidelines for service providers to help them better 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 style="list-style-type: none"> <li>• Presents four goals for organizations to strive for with help of the recommendations: elimination of bias and discrimination 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 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. <ul style="list-style-type: none"> <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> </ul> </li> <li>• The following recommended standard (brief summary) of practice and client rights are presented: <ul style="list-style-type: none"> <li>• <b>Standard 1:</b> Comprehensive policies are implemented to prohibit discrimination in the delivery of services on the basis of sexual orientation and gender identity.</li> <li>• <b>Standard 2:</b> Agency has written policy against discrimination in the delivery of services based on sexual orientation or gender identity.</li> <li>• <b>Standard 3:</b> Intake and assessment forms provide for self-identification in categories of gender identity, sexual orientation, marital, partnership and family status.</li> <li>• <b>Standard 4:</b> Procedures are in place for filing and resolving complaints alleging discrimination based on sexual orientation or gender identity.</li> </ul> </li> </ul>

ARTICLE	SOURCE/YEAR	DESCRIPTION	MAIN POINTS AND STATISTICS
			<ul style="list-style-type: none"> <li>• <b>Standard 5:</b> 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>• <b>Standard 6:</b> 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>• <b>Standard 7:</b> Clients are ensured the confidentiality of their records including information about sexual orientation and gender identity.</li> <li>• <b>Standard 8:</b> GLBT youth clients are provided with appropriate, safe, and confidential treatment to the appropriate legal limits as defined by state statutes.</li> </ul>
<p><b><i>Crossing to Safety: Transgender Health &amp; Homelessness</i></b></p>	<p>Healing Hands (a publication of the HCH Clinicians' Network). Vol. 6, No. 4. June 2002.</p>	<ul style="list-style-type: none"> <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 style="list-style-type: none"> <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 HBIQDA: "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: <ul style="list-style-type: none"> <li>• Educate medical providers and staff about gender variance (e.g, provide regular in-service training on TG issues)</li> </ul> </li> </ul>



ARTICLE	SOURCE/YEAR	DESCRIPTION	MAIN POINTS AND STATISTICS
			<ul style="list-style-type: none"> <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>
<p><b><i>The Transgender Community Health Project</i></b></p>	<p>San Francisco Department of Public Health, February 18, 1999.</p>	<p>A quantitative study designed to assess HIV risk among MTF and FTM transgendered persons in San Francisco.</p>	<ul style="list-style-type: none"> <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>
<p><b><i>Not ‘just’ a friend— Best practice guidance on health care for lesbian, gay, and bisexual service users and their families</i></b></p>	<p>Royal College of Nursing and UNISON, UK (no date of publication)</p>	<p>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.</p>	<ul style="list-style-type: none"> <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
<p><b><i>HIV Prevention and Health Service Needs of the Transgender Community in San Francisco</i></b></p>	<p>Clements et al. <i>International Journal of Transgenderism</i>, 1999.</p>	<p>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.</p>	<ul style="list-style-type: none"> <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 self-esteem, 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 identities); HIV prevention support groups (e.g., peer based support groups); and culturally appropriate prevention materials.</li> <li>• Participants also 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>
<p><b><i>Primary HIV Care for Transgender People</i></b></p>	<p>Kohler, Lori, MD. <i>Department of Family and Community Medicine, UCSF</i>. (no date)</p>	<p>A comprehensive Powerpoint presentation training for medical providers.</p>	<ul style="list-style-type: none"> <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 style="list-style-type: none"> <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: <ul style="list-style-type: none"> <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> </li> </ul>
<b><i>Transgender Health Care (various)</i></b>	<p>Transgender Health Program, Vancouver BC.</p> <p><a href="http://www.vch.ca/transhealth/">www.vch.ca/transhealth/</a></p>	<p>Various articles and information about clinical care for transgender</p>	<ul style="list-style-type: none"> <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

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