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. [1] 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.[1] One study of transgender people living with HIV/AIDS showed a statistically lower rate of HIV treatment when compared to nontransgender people.[2] 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.[3]

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,[4] and only 22 transgender-identified individuals participated in the EMA's most recent community-wide needs assessment of people living with HIV/AIDS.[5] 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: [6]

> **"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
	Feminine male
Transgendering	Masculine female
Transsexual	Third gender
Cross dresser	Two spirit
Androgynous	

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, [1] 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.[7] 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.[8]

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.

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) [a]
18-24	9%	3%
25-44	47%	44%
45+	44%	54%
Race/Ethnicity		[b]
White, non-Hispanic	17%	25%
African American	77%	50%
Hispanic	8%	23%
Other	4%	2%
Education		[a]
Less than high school	31%	19%
High school diploma/GED	58%	38%
Technical degree or above	11%	42%
Employment Status		[a]
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		[a]
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%[a]
Years of HIV Diagnosis (sd)	12.2 (8.2)	11.2 (7.3)[a]

[a]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
[b]Texas eHARS (as of 12/31/2011). Jurisdiction is Houston EMA

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.

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.[3,9] 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[9]) 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.[10]

(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%), [11] though lower than both local and national goals.[3,9] 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[a]	Goal[b]
Linked to HIV Care within 3 Months of Diagnosis	75.9%	77.4%	85.0%

[a]Texas Department of State Health Services, 8/20/12
[b]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%).[12] 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.[13]

(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[a]
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)	--

[a]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.[14] 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.

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[a]
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 *always* use condoms	60%	50%
Diagnosed with STD, last 6 mo.	13%	--
Mental Health Concern, last 30 days	70%	63%
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%	--

[a]2011 Houston Area HIV/AIDS Needs Assessment, April 2011 (n=924)

Risk Activities, Co-Morbidities, and Discrimination History

Multiple national studies of transgender people and two studies conducted in the Houston community[15, 16] 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, [13] with one exception. In our sample, a slightly lower percentage of respondents reported no condom during their last

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 [13] 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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Advisory Committee

Liah Brown, Health Educator, Legacy Community Health Services

Elia Chino, Executive Director, Fundación Latino Americana Contra el SIDA (FLAS), Inc.

Joseph Fuentes, Jr., Executive Director, Houston Area Community Services (HACS)

Jeffrey J. Guidry, PhD, Associate Professor, Texas A&M University, Department of Health and Kinesiology

Anna Henry, Planner, Houston Regional HIV/AIDS Resource Group, Inc.; and Member, Houston Area HIV Prevention Community Planning Group

Judy Hung, MPH, Data Analyst, Harris County Public Health Services, Ryan White Grant Administration

Rev. Kristen Klein-Cechettini, Resurrection Metropolitan Community Church of Houston

Gus Krucke, MD, Director, Transgender Clinic, Harris Health System, Thomas Street Health Center

Darcy Padgett, Executive Director, Bee Busy, Inc.; and Member, Houston Area HIV Prevention Community Planning Group

Michael Ross, MA, MS, PhD, Professor of Public Health, University of Texas, School of Public Health

Steven Vargas, Case Manager, Association for the Advancement of Mexican-Americans; and Member, Houston Area HIV Services Ryan White Planning Council

Cristan Williams, Director, Transgender Center; Executive Director, Transgender Foundation of America; and Member, Houston Area HIV Prevention Community Planning Group

Paige Padgett Wermuth, PhD, University of Texas, School of Public Health

L. Bunny Woods, Counseling, Testing, and Referral Coordinator, St. Hope Foundation; and Member, Houston Area HIV Services Ryan White Planning Council

Staff

Ryan White Planning Council
Office of Support
Tori Williams
Jennifer Hadayia
Diane Beck
Georgette L. Monaghan

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Community Recruitment Partners

Baylor College of Medicine, AIDS Vaccine Study
Rebecca Keo
Maggie White
Bee Busy, Inc.
Ty Vance
Bering Omega Community Services
Coalition for the Homeless of Houston/Harris County
Scot More
Harris County Jail
Bobby Davis
Joaquin Garza
Harris Health System, Thomas St. Health Center
Jeff Benavides
Michael Paul Doerflein
Diana Parkinson-Windross
House of Blaque
Herman L. Finley III
Houston Area Community Services
Giovanna Castro
Ernesto Macias
Fred Reninger
Legacy Community Health Services
Christopher Garrett
Montrose Center
Ann J. Robison
Keville Ware
Resurrection Metropolitan Community Church of Houston
Ryan White Grant Administration
Carin Martin
Part A Case Management Supervisors
St. Hope Foundation
Rodney Goodie
Tara Bates
Transgender Center
Lou Weaver
Cristan Williams
University of Texas, School of Public Health
Paige Padgett Wermuth

Members of:

Houston Area HIV Services Ryan White Planning Council
Houston Area HIV Prevention Community Planning Group
Serving the Incarcerated and Recently Released (SIRR) Partnership of Greater Houston
Project LEAP

Other Contributors

C. Dawn Meade, MSPH, Project Coordinator – CPCDMS, Harris County Public Health Services, Ryan White Grant Administration

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3. Houston Area Ryan White Planning Council and Houston HIV Planning Group. Houston Area Comprehensive HIV Prevention and Care Services Plan (2012 – 2014). May 21, 2012.
4. Harris County Public Health Services, Ryan White Grant Administration. Total number of net unduplicated clients served in calendar year 2011 by the Ryan White HIV/AIDS Program Part A, B, State Services and Minority AIDS Initiative (MAI). Run 4/12/12. Source: Centralized Patient Care Data Management System
5. Houston Area Ryan White Planning Council, 2011 Houston Area HIV/AIDS Needs Assessment, April 2011.
6. This text was modeled on terminology used in the National Transgender Discrimination Study (See Grant, JM et al., *Injustice at Every Turn: A Report of the National Transgender Discrimination Survey*. Washington: National Center for Transgender Equality and National Gay and Lesbian Task Force, 2011).
7. Unique identifying information was not collected on survey respondents, and surveys could be completed without in-person contact with an interviewer as well as through self-administration. This created the potential for duplicate respondents and for survey completion by individuals who did not meet screening criteria. Various de-duplication and authentification methods were applied throughout the study, and only results from the subsequent data set are presented here. A total of 142 surveys were completed; and 135 were determined to be non-duplicates meeting the screening criteria.
8. Living HIV/AIDS cases in the Houston EMA as of December 31, 2011. Source: Texas eHARS.
9. National HIV/AIDS Strategy for the United States (July 2010).
10. Health Resources and Services Administration (HRSA), HIV/AIDS Bureau (HAB)
11. Texas Department of State Health Services. New Dx Cases with Met Need But No Linkage to Care Dates, 2011.
12. Texas Department of State Health Services. Number & Proportion of PLWHA with Unmet Need for Medical Care by EMA/TGA, 2011
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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