Transgender Women’s Needs Assessment

Final Report to the HIV Health Services Planning Council

August 20, 2012

Jae Sevelius, PhD
JoAnne Keatley, MSW
Enzo Patouhas, MA
Angel Ventura

UCSF
University of California
San Francisco

center of excellence for TRANSGENDERhealth
Overview

- Specific aim of the needs assessment
- Intro to the Center of Excellence for Transgender Health at UCSF
- Background information
- Research methods
- Results
Specific Aim

- To complete a needs assessment of transgender women living with HIV in San Francisco, San Mateo, and Marin counties to guide the HIV Health Services Planning Council (HHSPC) in its decision-making process regarding Ryan White Part A service category prioritization and resource allocation.
Our mission is to increase access to comprehensive, effective, and affirming healthcare services for trans and gender-variant communities.
Background

Compared to other groups, transgender women:
- Have higher HIV prevalence rates, in the range of 38 – 64%
- Experience disproportionate mortality rates
- Are less likely to be on antiretroviral therapy than other groups
- Report lower rates of adherence
- Report less positive interactions with providers
- Face culturally unique challenges in accessing services
Community Involvement and Council Input

5 focus groups, held January – March 2012

4 in English (n=33), 1 in Spanish (n=5)

38 participants total

$30 incentive
Research methods

- Eligibility criteria:
  - assigned ‘male’ gender at birth and currently identify as ‘female’ or ‘transgender’
  - 18 years of age or older
  - currently living with HIV (by self-report)
  - residing, receiving, or eligible for Ryan White–funded services in SF, San Mateo, or Marin counties
  - able to speak English or Spanish
Research methods

- Recruitment:
  - Direct street outreach
  - Community-based service providers in SF, Marin, San Mateo
  - Working Group members
  - Snowball sampling
# Demographics

<table>
<thead>
<tr>
<th>Race/ethnicity</th>
<th>N (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>African American</td>
<td>27 (71)</td>
</tr>
<tr>
<td>Latina</td>
<td>7 (18)</td>
</tr>
<tr>
<td>Pacific Islander</td>
<td>3 (8)</td>
</tr>
<tr>
<td>Native American</td>
<td>4 (11)</td>
</tr>
<tr>
<td>White/Caucasian</td>
<td>3 (8)</td>
</tr>
<tr>
<td>Multiracial</td>
<td>3 (8)</td>
</tr>
</tbody>
</table>
## Demographics

<table>
<thead>
<tr>
<th>Age</th>
<th>N (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>20-29</td>
<td>1 (3)</td>
</tr>
<tr>
<td>30-39</td>
<td>7 (18)</td>
</tr>
<tr>
<td>40-49</td>
<td>10 (26)</td>
</tr>
<tr>
<td>50-59</td>
<td>18 (47)</td>
</tr>
<tr>
<td>60-69</td>
<td>1 (3)</td>
</tr>
</tbody>
</table>
## Demographics

<table>
<thead>
<tr>
<th>Financial situation</th>
<th>N (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>I have enough money to live comfortably.</td>
<td>9 (26)</td>
</tr>
<tr>
<td>I can barely get by on the money I have.</td>
<td>19 (54)</td>
</tr>
<tr>
<td>I cannot get by on the money I have.</td>
<td>7 (20)</td>
</tr>
<tr>
<td>Ever homeless</td>
<td>30 (81)</td>
</tr>
</tbody>
</table>
## Where receiving HIV services

<table>
<thead>
<tr>
<th>Location</th>
<th>Count (Percentage)</th>
</tr>
</thead>
<tbody>
<tr>
<td>San Francisco</td>
<td>35 (95)</td>
</tr>
<tr>
<td>San Mateo</td>
<td>1 (3)</td>
</tr>
<tr>
<td>Marin</td>
<td>1 (3)</td>
</tr>
<tr>
<td>Alameda</td>
<td>1 (3)</td>
</tr>
<tr>
<td>Other</td>
<td>2 (5)</td>
</tr>
</tbody>
</table>
Most frequently mentioned categories:

- Primary medical care
- Housing
- Mental health care
- Case management
Medical concerns

- Distrust of providers
- Certain medications are not covered
- Doctors not prescribing preferred meds
- Too many pills/hard to manage
- Fear of long term effects of meds
- Few holistic care options
Barriers to medical care

- Different providers for HIV & hormones
- CD4 count < 200 for ART
- Closing of service provider agencies
- Waitlists > 6 months
- Must travel to several pharmacies for meds
Concerns about medical providers

- Low transgender competence and sensitivity
- Low levels of knowledge related to hormone therapy, including possible interactions between hormones and HIV medications
Mental Health Care – Concerns

• Too often referred to psychiatrist (for meds) without options for counseling/psychotherapy
• No African American trans specific services
• Lack of wrap-around setting
• Waitlists > 6 months
• Transportation
“I don’t take medicine for my mental health but, I do like to talk to someone. The thing is that right now I don’t have that option. I have to write my name in a waiting list right now. I have to wait between one to two years before I get a therapist. And if I want a therapist right now, in some places I must see him only twice or three times a year... Normally you can see him three to four times a year. What happens if I need to talk more than four times a year? You know? That scares me.”
Oral Health Care – Barriers to access

• Too expensive, decreased funding
• Long wait lists
• Do not know where to access
• Provider insensitivity towards HIV status
• Unsatisfactory past experiences with dental work
Peer Support – Concerns

- No African American transgender specific groups
- Difficulty relating to others’ experiences in non–transgender specific groups
- Discrimination
- Few transgender support group leaders
Case management – Concerns

• Low cultural competence and transgender sensitivity
• Low levels of knowledge regarding available transgender–specific resources
• Often services are discontinued leaving patients without resource referral
• Access requires travel and travel costs
Substance abuse – Barriers to access

- Need for transgender-specific substance abuse treatment programs or components
- Existing programs do not address unique challenges and issues transgender women face
- Discrimination and stereotyping
- Substance abuse groups often disappear
“I personally feel that it’s hard to concentrate on my recovery when I have to protect myself from things that people are saying to me. If there was another substance abuse program that would only focus on trans people, it would be great.”
Food Concerns

- Food bank portions are decreasing
- Engage in food hoarding when possible
- Without food transgender women struggle to adhere to HIV medication regimen
- The expense of medications can override food and vice versa
- Transportation barriers
“[I am not currently using any of the services] because they cut back on a lot. So it was, like, well, you standing in line to get some services, you know, and it’s not even compared to what you can really make yourself on the street or wherever. You know, so it’s a waste of time.”
Housing – Concerns

• Waitlists, shelters often full
• Unsanitary conditions, insect infestation
• No pantry or kitchen
• Drug abuse in common areas
• Stigma and discrimination, lack of safety
Housing – Barriers to Access

- HIV housing is temporary
- Few low income housing options
- Few resources for finding and obtaining housing
- No transgender specific housing
- No transitional housing post-incarceration
- Employment disqualifies for assisted housing
Employment – Concerns

- Many transgender women desire employment and job skills training
- Face discrimination based on race, ethnicity, and gender identity
- Need for assistance with job search
- Inconsistent or lack of housing
- Transportation barriers
Transportation – Concerns

- Transportation is of utmost importance to appointment keeping, accessing services
- Transportation tokens have been replaced by Clipper cards that are too expensive for transgender women to purchase
- Transgender women reported that there is no paratransit without housing
- Wrap-around settings are strongly desired
Legal concerns

- Most often access legal services when:
  - changing identity documents
  - Facing criminal charges and/or incarceration
  - Need a legal resource for political asylum
  - Fear of being reported to immigration by health systems, providers
  - Discrimination from within legal system
<table>
<thead>
<tr>
<th>Ryan White Program Services</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Housing</td>
<td>36</td>
</tr>
<tr>
<td>Medical</td>
<td>24</td>
</tr>
<tr>
<td>Mental Health</td>
<td>21</td>
</tr>
<tr>
<td>Oral Health</td>
<td>18</td>
</tr>
<tr>
<td>Substance Abuse Treatment</td>
<td>17</td>
</tr>
<tr>
<td>Peer Support</td>
<td>17</td>
</tr>
<tr>
<td>Case Management</td>
<td>16</td>
</tr>
<tr>
<td>Food</td>
<td>15</td>
</tr>
<tr>
<td>Legal</td>
<td>14</td>
</tr>
<tr>
<td>Medication</td>
<td>13</td>
</tr>
<tr>
<td>Transportation</td>
<td>1</td>
</tr>
<tr>
<td>Vision Health</td>
<td>2</td>
</tr>
</tbody>
</table>
Low levels of knowledge and cultural competence regarding trans–specific issues and medical concerns

Transportation issues

Perception that fewer services are available specifically for African–American transwomen

Low level of awareness of payer source across services
Recommendations

- Offer provider training (i.e. National Transgender Health Summit, UCSF)
- Carve out trans-specific components of existing services (i.e. substance abuse treatment programs, housing)
- Increase visibility of transgender people in peer and professional support roles
- Ensure agencies that serve transgender women are fully informed of service options available to improve linkage to care
- Create a centralized, up-to-date, and comprehensive transgender resource guide
Contact information

JoAnne Keatley, MSW, CoE Director
Joanne.Keatley@ucsf.edu

Jae Sevelius, PhD, Assistant Professor
Jae.Sevelius@ucsf.edu

www.transhealth.ucsf.edu