Radical Healthcare: Fighting Transphobia, Providing Trans-affirming HIV Care

TransAccess, SPNS Initiative
CONTEXT & HISTORY

Why we’re here and why we do this

HIV CRIMINALIZATION

is a threat to transgender health

58% transgender respondents feel it is reasonable to avoid getting tested

48% transgender respondents feel it is reasonable to avoid treatment

source: National HIV Criminalization Survey

SOFTWARE

Transgender Law Center

MURDERED IN SAN FRANCISCO

photo: facebook

Getting to Zero in San Francisco
Progress, Draft Plans & Community Feedback

Monday, December 1, 2014
6:30 – 8:00 PM
San Francisco Department of Public Health
25 Van Ness Ave & Market Street, 5th Floor

Get the latest data on San Francisco’s progress against HIV/AIDS, hear about a draft plan to fulfill the city’s Global Zero Commitment, and engage with the latest research into effective prevention and treatment strategies. This event will also feature an update on progress in San Francisco’s efforts to end the AIDS epidemic.
Scope of the problem: National

• TW most disproportionately affected by HIV in US and world\(^1\)
• TW highest rate of HIV infection\(^2\)
  – Cis-male (0.9%), cisfemale (0.3%), trans (2.6%)
  – African-american & trans (4.4%)
• TW significantly less likely on ART
• Lowest rate of engagement in care
• Lowest rate of retention in care

1. Herbst et al 2008
2. See RFP
Scope of problem: SF data

GENDER of HIV/AIDS LIVING CASES
(n=15,979)

- Male: 92%
- Female: 6%
- Transgender: 2%

HIV PREVALENCE AMONG GROUPS AT RISK for HIV in SF

- Transwomen (2013)
- MSM (2011)
- PWID (2011)

While the trans community is smaller than other groups, it is disproportionately affected by HIV.

* limitation: derived from the medical record; likely underestimate for transgender

Scope of the problem: Local

- In San Francisco, SFDPH data shows\(^1\)
  - Highest HIV prevalence of any at-risk population
  - Highest proportion AIDS cases,
  - Fastest rate of death from AIDS

- HIV prevalence increasing and disproportionately affects AA transwomen\(^2\)
  - 2013 study: AA nearly half of 341 HIV+ TW sampled

- Higher community VL amongst transwomen in SF\(^3\)

- ART coverage: transwomen (65%), vs. gen. (83-89\%)\(^4\)

1. SFDPH 2008
2. Rapues 2012, Rapues 2013
4. SFDPH 2011
Special Project of National Significance: **TransAccess**

- Public-private demonstration project funded by HRSA
- RFP announced 2011, in growing recognition that TWOC, as a group, are the most disproportionately impacted by HIV\(^1\)
- Evaluate models of care/approaches to care that enhance engagement and retention in care

1. Poteat, German, & Kerrigan, 2013
Public-private partnership

TOM WADDELL URBAN HEALTH CLINIC

**Strengths:**
- Medical expertise in HIV and TG care
- Leader in TG care
- Access to DPH resources

**Limitations:**
- Appt.-based system
- Drop-in access limited
- Frequency & length of provider visits may not adequately meet clients’ needs
- Space not TG specific
- No in-house CM or trans peers

ASIAN & PACIFIC ISLANDER WELLNESS CENTER

**Strengths:**
- CBO/ASO with well-established TG services & reputation
- Less institutional, more familial feel
- Strong HIV wrap-around services
- Roots in community
- POC-led organization

**Limitations:**
- Limited medical services on site (pre-2015)
- Less access to acute medical resources
TransAccess program model

TransAccess Program (M-F):

- drop-in access, trans-positive space*
- Peer navigator and case manager on demand*
- Support groups (ie seeking safety, wellness)
- Building community & chosen families
- Empowerment (digital stories, volunteering)
- LGBT movement (Pride, Trans march, testifying city hall)
- Seminars & workshops
- Housing assist
- Benefits counseling
- Substance use services
- Employment assist
- Volunteer

TransAccess Clinic (Thurs)
- Primary care (HIV & TG)
- Medical social work
- Psychiatry

San Francisco
Department of Public Health
TransAccess staffing

TransAccess Program (M-F):

Direct Service
• 2 Peer navigators (2.0)
• 1 case manager (1.0)

Administrative & Research
• 1 program director (0.5)
• 1 evaluator (0.5)

SFDPH staffing
• 1 MD (0.2 FTE in kind)
• 1-2 RN (0.2 FTE)
• 1 LCSW (0.2 FTE)
Snapshot:  Program outcomes to-date

- 75 clients enrolled
  - Full: 45 on-site primary care
  - Partial: 30 wrap-around services only

- High acuity, inner-city population
  - 22% of PC clients in top 1-5% medical utilizers in SFDPH

- Outcome: 61% viral load suppression (compared to 28% national average, on par SF average)

- Of active clients, 75% retained in care
Learning objectives & presentation outline

**WHY?**
- Why this SPNS initiative?
- Why this model?
- Why do TWOC have such poor HIV outcomes?

**WHAT?**
- What are the TransAccess program’s interventions?
- What are the program outcomes?
- What did we learn?

**HOW?**
- How did we achieve these results?
- How can others replicate our successes?
Learning objective #1:

*Audience members will be able to identify intersecting medical and psychosocial factors that frequently impede access to and retention in care among transgender women of color living with HIV*
Why do TWOC have such poor HIV outcomes?

Johanna’s story

What can you glean about barriers to HIV care from Johanna’s story?
Structural Disparities for TWOC Living with HIV

- 27% of transwomen were unstably housed
  - Living with friend/relatives
  - In substance use treatment
  - Jail/prison
  - Shelters
  - Street

- 2/3 or 66.8% lives at or below 100% of FPL

- 22.9% of MTF transgender clients lack insurance of any kind

source: ARIES (RYAN WHITE DATA) 2011
Lit. review: HIV Barriers for SF Transwomen

• Gender stigma/lack of gender affirmation
  ➢ Risks of ridicule/harassment en route to clinic, heightened risk of detection in daytime\(^1\)
  ➢ Gender affirmation: few sources of positive affirmation of one’s gender identity & expression

• Peer distrust
  ➢ Risk of being “outed” going to clinic serving HIV+\(^1\)

• Institutional distrust
  ➢ Perception of providers “not caring”\(^1\)
  ➢ “We don’t care how much you know, until we know how much you care.”\(^3\)

3. Olivia Lewis, trans peer navigator/advocate.
TransAccess Baseline data
structural factors as markers of acuity on entry

- 36.6% EXPERIENCING SEVERE MENTAL ILLNESS
- 70.7% SUBSTANCE USING
- 63.4% EXPERIENCING HOMELESSNESS
- 39.0% ENGAGED IN SEX WORK

- 22% of TransAccess primary care clients in top 1-5% of SFDPH medical utilizers in 2014-2015

1. SFDPH CCMS system

- 78% at least 1 structural factor

• 14.6% 1 STRUCTURAL FACTOR
• 19.5% 2 STRUCTURAL FACTORS
• 19.5% 3 STRUCTURAL FACTORS
• 24.4% 4 STRUCTURAL FACTORS
Barriers to engagement & retention in care

**Systemic**
- Transphobia
- Institutionalized racism
- HIV stigma
- Economic disparities
- Access to employment
- Social justice

**Structural**
- Trans-affirming clinics & providers
- Urgent life priorities
- Housing crisis
- Acuity >> Access
- Multidisciplinary needs

**Interpersonal**
- Coping and behaviors due to trauma exposure
- Trust & support
- Shared decision making
- Trauma-informed care
- Gender affirming care

**Trans-specific**
- Gender affirming therapy
- Trans-competency
- Trans visibility, peers & community engagement
- Margins ➔ center of larger LGBT movement
What are TransAccess’s program interventions? Outcomes? Lessons learned?

**Learning objective #2:**

Audience members will review and interpret preliminary mixed-method intervention outcomes, which illustrate the effectiveness of increasing the number, length, and quality of visits with clients.
81% of all clients linked to TRANS-ACCESS (N=75) are enrolled in the study component.

REASONS CLIENTS ARE NOT ENROLLED in MULTISITE EVALUATION:
- they were unable to consent
- they chose not to consent
- they were not enrolled within the allotted time

OTHER MEANS of SHARING:
- agency stories
  - podcast
  - digital stories
61% of all active clients are virally suppressed, compared to 28% of national population with viral suppression.

*source: SFDPH HIV/AIDS Epidemiology Annual Report 2014*
Figure 3.1 Continuum of HIV care among persons diagnosed with HIV infection, 2010-2013, San Francisco

1. Number of new diagnoses shown each year is based on the evidence of a confirmed HIV test and does not take into account patient self-report of HIV infection.
2. Defined as the latest viral load test during the specified period ≤ 200 copies/ml.
Intervention Exposure: # of visits by discipline

TransAccess starts

<table>
<thead>
<tr>
<th>Year</th>
<th>Medical</th>
<th>Case Mgmt</th>
<th>Peer Nav</th>
<th>Soc. work</th>
</tr>
</thead>
<tbody>
<tr>
<td>2012</td>
<td>4</td>
<td>N/A</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>2013</td>
<td>4</td>
<td>N/A</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>2014</td>
<td>11</td>
<td>19</td>
<td>30</td>
<td>0</td>
</tr>
<tr>
<td>2015</td>
<td>13</td>
<td>25</td>
<td>6</td>
<td>7</td>
</tr>
<tr>
<td>2016</td>
<td>14+</td>
<td>9</td>
<td>9</td>
<td>8</td>
</tr>
</tbody>
</table>
In 2015 & 2016, Trans-Access provided the following services to client JB:

- Sabina (Case Management): 34 visits
- Talia (Peer Navigation): 15 visits
- Ilona (Social Work): 15 visits

For every two visits with her case management team, she received a primary care visit.

<table>
<thead>
<tr>
<th>Total Count (N)</th>
<th>Average Length of Visit</th>
<th>Sum of Staff Time</th>
</tr>
</thead>
<tbody>
<tr>
<td>56</td>
<td>44 minutes</td>
<td>42 hours</td>
</tr>
</tbody>
</table>
Intervention Exposure Data:
Case Management, Peer Navigation, & Medical Social Work

Between the intervention’s 2nd and 3rd year, Trans-Access saw an increase in:
- # of individual and group encounters
- length of visit, due to high acuity of clients
- # of staff hours

<table>
<thead>
<tr>
<th>Year</th>
<th>Total Encounters</th>
<th>Sum of Staff Time</th>
<th>Average Length of Encounter</th>
</tr>
</thead>
<tbody>
<tr>
<td>2015</td>
<td>433</td>
<td>383 hours</td>
<td>53 minutes</td>
</tr>
<tr>
<td>2016 (Jan-July)</td>
<td>318</td>
<td>343 hours</td>
<td>64 minutes</td>
</tr>
</tbody>
</table>

Staff time spent with **high acuity & high needs clients**

*Note: Sum of staff time includes high acuity and high needs clients.*
Do we really need such an intensive intervention?

A CLOSER LOOK: TA client case study

- Acuity vs. access
- How gender identity issues affect HIV care and outcomes
- Where does medical care ends & psychosocial services begin?
Case Example (pre-TransAccess) -- Limitations of the status quo

44 yo African-American transwoman seen at SFDPH clinic. Engaged in care, but not on ART. Hx multiple missed appointments.

8/5/13: CD4 606, VL 67,786
- Unstably housed.
- Auditory hallucinations.
- Started ARVs 2wks ago. Adherence ?.
- Not on psych meds.
- F/u sporadic
- “Why don’t the hormones work for me like they do for the other girls?”

10/18/13
- Lost job. Hearing voices. Opens door. No one there
- Admits meth: “I dabble...when I do I hole up”.
- Unstable housing in SRO (mice, roaches)
- Not taking ARVs

missed appts
12/4/13: CD4 803, VL 5339
- PCP stopped HIV meds due to instability
- Resistance test ordered
- “I was doing a lot of lying to cover up who I am, what I do, and what I feel.”
1/23/14
- CM helped clt obtain supportive housing
- Prescribed new antipsychotic
- PCP restarted HIV meds
- Continue hormones, but “...when I go home, I have to dress as a boy”

4/3/14
- self referred SA program
- Attributes to ↑self-worth
- voices ↓ on psych meds.
- Back on ARVs
- Expresses desire for mammo
- PCP: Yes to GCS. Framed as pathway to readiness.

8/14/14: CD4 1193, VL <40 **
- Back on psych meds & ARVs
- CM: fewer crisis drop-ins

12/11/14
- Feels more joy
- “I feel I have more control over my life”
- New relationship

7/3/14
- Voices ↑
- “…they critique my femininity” *
- Self DC’ed ARVs. Off psych meds

9/18/14 ***
- Referred mammoplasty

19 CM
30 PN
10/29/15: CD4 1006, VL <40
- Testified at City Hall

6/9/15: CD4 842, VL <40
- Sober 9 months
- "I can walk past dealers without being triggered."
- "I've got my power back, and I will never give it away again."
- Starts volunteering

11/30/15
- Successful mammoplasty!

3/12/15
- 6 months sobriety
- "I can walk past dealers without being triggered."
- "I've got my power back, and I will never give it away again."
- Starts volunteering

We’ve arrived!!!
- VL <40
- Employed
- Empowered
- Surgery
2/4/16: CD4 898, VL 988
- Adherence hiccups. Relapsed.
- “I’m so used to being down here [gestures to floor], that I don’t know how to handle myself now that I’m up here.”
- Having trouble at work: multiple missed days

3/3/16
- Voices back
- Client agrees to medical leave & SA treatment

3/31/16 – 7/28/16
- In residential treatment program

7/21/16: CD4 1183, VL<40
- Left treatment program
- Staying on meds
- Wants to return to work in fall

Or have we?
What does stability mean?
Lessons learned

• Multiply-diagnosed, highly traumatized clients require medical and psychosocial care access that matches the acuity of their lives

• “Stability” is dynamic, not static

• Multidisciplinary approach is essential

• Co-locating HIV and TG primary care, with case management, peer navigation, and social work can help meet interlocking medical and psychosocial needs
How did TA achieve these outcomes? How can our successes be replicated?

Learning objective #3:

*Audience members will name and define programmatic elements that contribute to successful HIV care.*
Identifying key programmatic elements toward successful engagement and retention in care

KEY PROGRAM ELEMENTS
KEY program elements

- Trans-affirming environment
- Locate services in CBO recognized as a trans community safe space
KEY program elements

- Co-location of HIV and TG expertise
- Joint TG/HIV services on-site
KEY program elements

☑ Holistic, community-oriented, multi-disciplinary approach

➡ Supportive team (PN, CM, SW, community) available on-demand 5days/week
KEY program elements

- Access to care and level of care sufficient to meet medical/psychosocial acuity

- Staffing, panel size, drop-in (open-access) model
Administrator’s perspective

• Supervision challenges: The impact of emotional labor on peer navigators
• The cost benefit of cross training: A doctor’s time vs. time with support services
• *What brings clients in?:* The importance of word-of-mouth recruiting
• Off ramp from the streets: monumental task
Identifying critical approaches to care that facilitate successful engagement and retention in care for TWOC

KEY APPROACHES TO CARE
Trauma, coping, & behavioral health

• Trauma often leads to:
  - poor coping skills
  - Unhealthy coping mechanisms
  - difficulty forming/sustaining relationships
  - behavioral dysregulation
  - personality disorder
Trauma-informed Care

“Individual trauma results from an event, series of events or set of circumstances that is experienced by an individual as physically or emotionally harmful or life threatening and that has lasting adverse effects on the individual’s functioning and mental, physical, social, emotional, or spiritual well-being.”

1. Safety
2. Trustworthiness and Transparency
3. Peer support
4. Collaboration and mutuality
5. Empowerment, voice and choice
6. Cultural, Historical, and Gender Issues

Substance Abuse and Mental Health Services Administration
http://www.samhsa.gov/nctic/trauma-interventions
1. **SAFETY:**

   Example: How do you communicate a climate of *psychological* safety to a transgender client who is homeless, engaged in sex work, using meth, and recently stopped taking HIV meds?

**Practice suggestions**

- Radical acceptance
- Signal understanding that socio-political-economic context drives behavior
- Non-verbal cues
2. **TRUSTWORTHINESS & TRANSPARENCY:**

Awareness that many trans peoples have been lied to or been let down many times in their lives, including by healthcare providers

**Practice suggestions**

- Acceptance that one has to work harder at establishing trust with highly traumatized populations
- Transparency: do things in realtime (e.g. calling in Rx, calling CM, etc.)
- Follow through on promises; consistency
4. **Collaboration and Mutuality:**

*How do you create a climate of collaboration, and invite mutual input and decision-making with your client?*

**Practice suggestions**

- **ASK QUESTIONS:** What’s important to you? What are your 2-3 top priorities that you’d like me to help you with today?
- **PROVIDE INFO** that allows client to be able to make an informed decision. Then **EMPOWER** client to make their own decision based on their values:
Institutional Distrust

“…They just go through the format. I mean medication, blood draw, and uh, medication, blood draw, and check up. That’s about it, that’s all I can expect from them.”

“…You’re going to have to let them know that you are truly there to help them and not just to do a job, you know. ‘Cause some people are just doing their job, but some people put more of themself into it, and this woman put more of who she was for me, out of her heart. And um, I really miss her too, I miss her, I really miss her.”

Radical healthcare

Radical /ˈradək(ə)l/ adj.¹

• (esp. of change or action) relating to or affecting the fundamental nature of something; far-reaching or thorough
  — “a radical overhaul of the existing regulatory framework”

• (of surgery or medical treatment) thorough and intended to be completely curative
  — “radical mastectomy”

• Characterized by departure from tradition; innovative or progressive
  — “a radical approach to electoral reform”

Core Values

1. **Self-actualizing services:** we ground our provision of services in the rights, values, and preferences of the client

2. **Mindful medicine:** medical care and clinical interventions are grounded in a psycho-social and holistic understanding of the client

3. **Care coordination and continuity:** we coordinate any and all types of services and assistance to meet the client’s identified needs

4. **Trans-affirming care:** we hold trans-affirming care as equally necessary and as pertinent to the client’s care plan as more traditional standards of HIV care

5. **Harm reduction:** we use a non-judgmental and non-coercive approach to providing services, in order to assist clients in minimizing risk in their environment

6. **Community-centered:** create a familial environment between staff and clients; non-hierarchical team dynamic, in which all input is weighted equally

7. **Radical healthcare:** maintain a political commitment to ending transphobia in local and national healthcare; contribute to the growing body of trans-health research
“All of the services go hand in hand for me [...] when you can come to one spot, and get all of those programs taken care of, it’s a burden off your shoulder.”

“If it wasn’t for the drop-in model, I wouldn’t be here right now.”
Acknowledgements

Funded by Health Resources & Services Administration (HRSA)

Kate Franza
Janell Tryon
Sabina Simmons
Maureen Byrne
Angie Davidson
Janet Moomaw
Jasmine Powell
Max Ruben
Niko Kowell
Ilona Margiotta
Kandi Patterson
Amber Gray
Nikki Calma
Brett Augsjoost
Bobbie Jean Baker
Stephanie Gray
UCSF TETAC
Digital Storytelling Center
Stephanie Goss
Johanna Brown
Angel Blaylock
George Bracey
Talia Dela Cruz
Niko Kowell