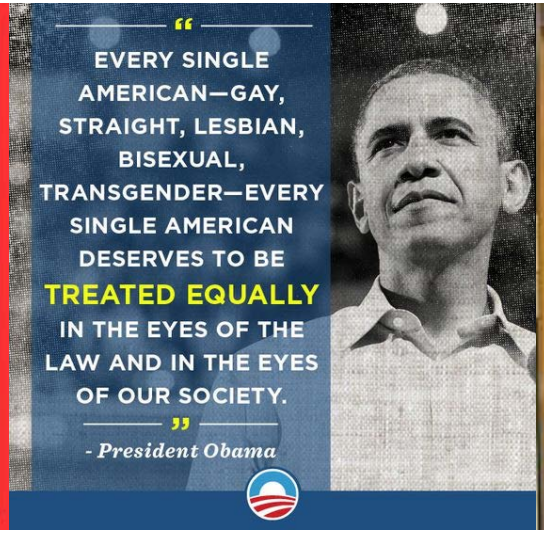
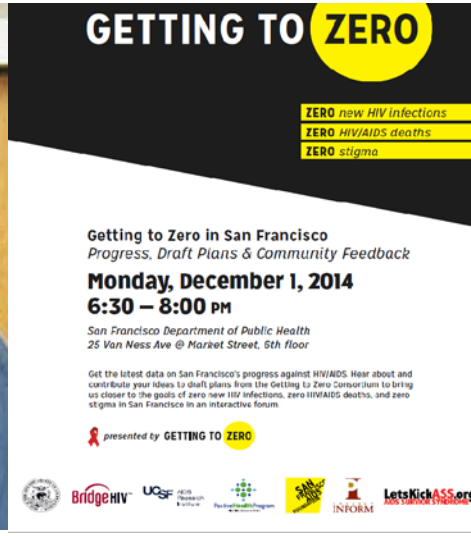
Radical Healthcare: Fighting Transphobia, Providing Trans-affirming HIV Care

TransAccess, SPNS Initiative

San Francisco
Department of Public Health

ASIAN & PACIFIC ISLANDER
WELLNESS CENTER





CONTEXT & HISTORY

Why we're here and why we do this

Scope of the problem: National

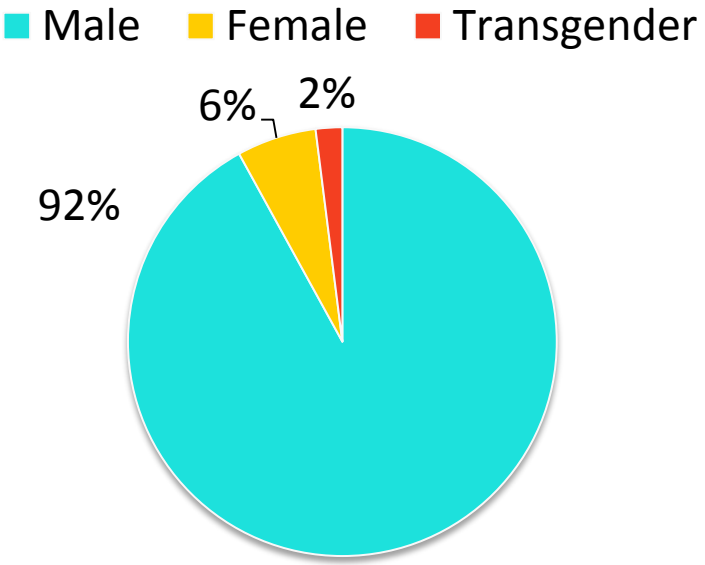
- TW most disproportionately affected by HIV in US and world[1]
- TW highest rate of HIV infection[2]
  - Cis-male (0.9%), cisfemale (0.3%), trans (2.6%)
  - African-american & trans (4.4%)
- TW significantly less likely on ART
- Lowest rate of engagement in care
- Lowest rate of retention in care

1. Herbst et al 2008
2. See RFP

Scope of problem: SF data[1]

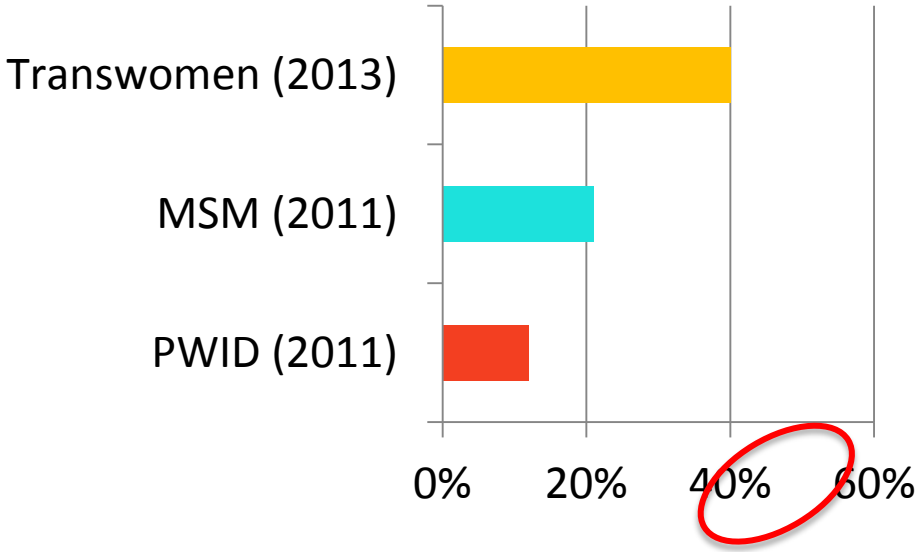
GENDER of HIV/AIDS LIVING CASES

(n=15,979)



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

HIV PREVALENCE AMONG GROUPS AT RISK for HIV in SF



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

1. *source: SFDPH HIV/AIDS Epidemiology Annual Report 2014*

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
3. Das, et al, 2010
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. Herbst et. Al, 2008
1. Poteat, German, &Kerrigan, 2013

Public-private partnership

TOM WADDELL URBAN HEALTH CLINIC

Tom Waddell Urban Health Clinic TRANSGENDER 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

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): ASIAN & PACIFIC ISLANDER WELLNESS CENTER

- **drop-in access, trans-positive space***
- **Peer navigator and case manager on demand***
- Support groups (ie seeking safey, 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):

ASIAN & PACIFIC ISLANDER WELLNESS CENTER

Direct Service

- 2 Peer navigoators (2.0)
- 1 case manager (1.0)

Administrative & Research

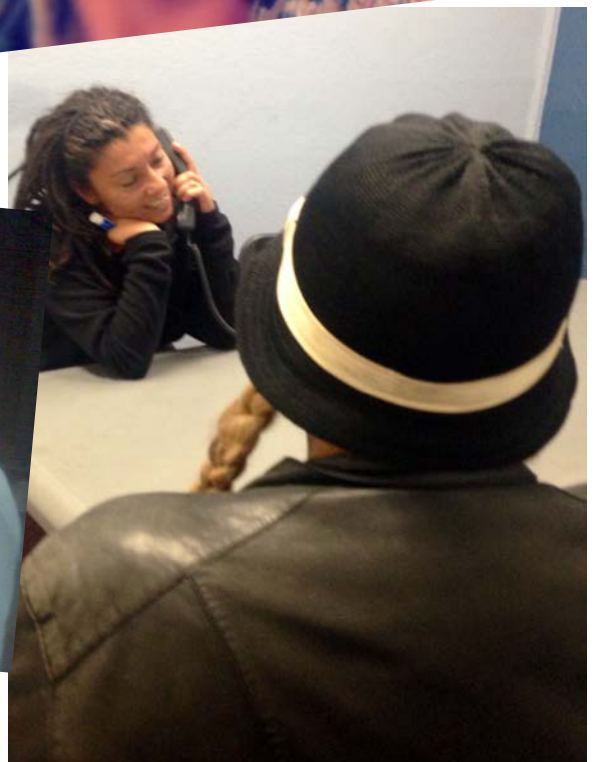
- 1 program director (0.5)
- 1 evaluator (0.5)

SFDPH staffing

- **1 MD** (0.2 FTE in kind)
- **1-2 RN** (0.2 FTE)
- **1 LCSW** (0.2 FTE)

San Francisco Department of Public Health

Photos of TransAccess



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?

Why do TWOC have such poor HIV outcomes?

Learning objective #1:

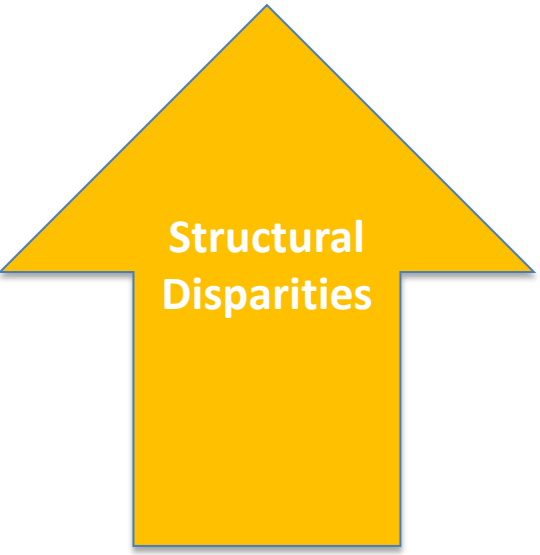
Audience members will be able to identify intersecting medical and psychosocial factors that frequently impede access to and retention in care among transgender women of color living with HIV

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

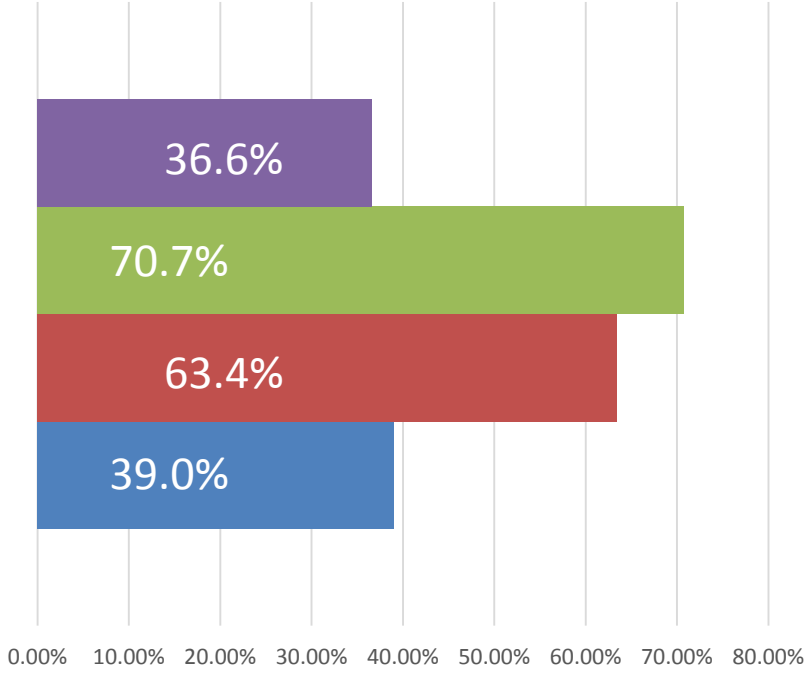
Lit. review: HIV Barriers for SF Transwomen

- 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]

1. Wilson E, Arayasiricul S, Johnson K. "Access to HIV care and support services for African American transwomen living with HIV". International journal of Transgenderism. 14:182-195, 2013
2. Sevelius, J. Gender Affirmation: A Framework for Conceptualizing Risk Behavior among Transgender Women of Color. Sex Roles. 2013 Jun 1; 68(11-12): 675–689, 2013.
3. Olivia Lewis, trans peer navigator/advocate.

TransAccess Baseline data

structural factors as markers of acuity on entry



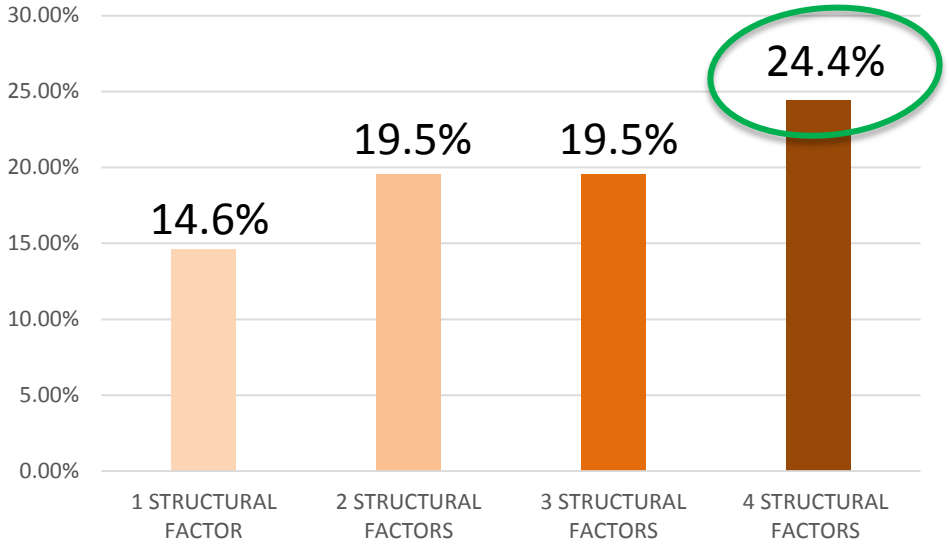
EXPERIENCING SEVERE MENTAL ILLNESS

SUBSTANCE USING

EXPERIENCING HOMELESSNESS

ENGAGED IN SEX WORK

- **78%** at least 1 structural factor



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

1. SFDPH CCMS system

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:

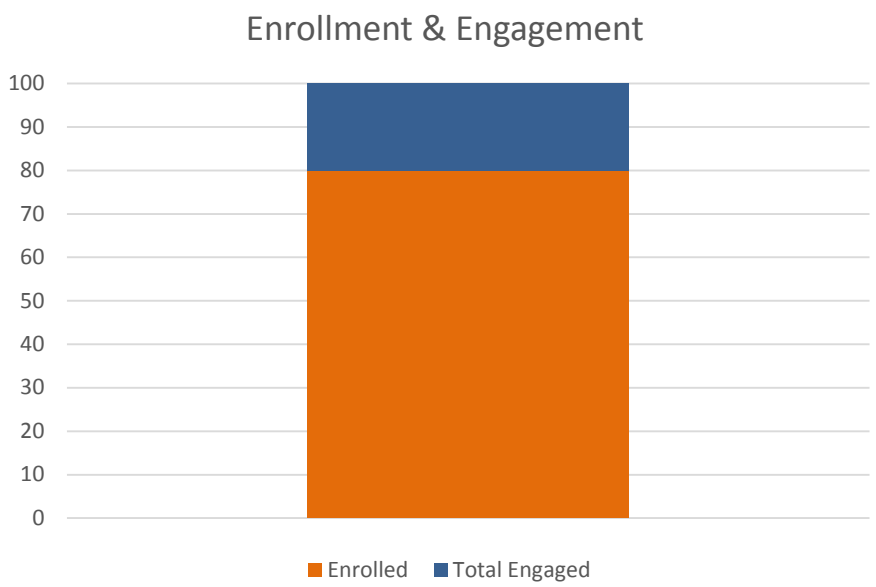
Audience members will review and interpret preliminary mixed-method intervention outcomes, which illustrate the effectiveness of increasing the number, length, and quality of visits with clients.

SHARING OUT

TRANS-ACCESS

ENROLLMENT in the MULTISITE & LOCAL EVALUATION

81% of all clients linked to TRANS-ACCESS (N=75) are enrolled in the study component



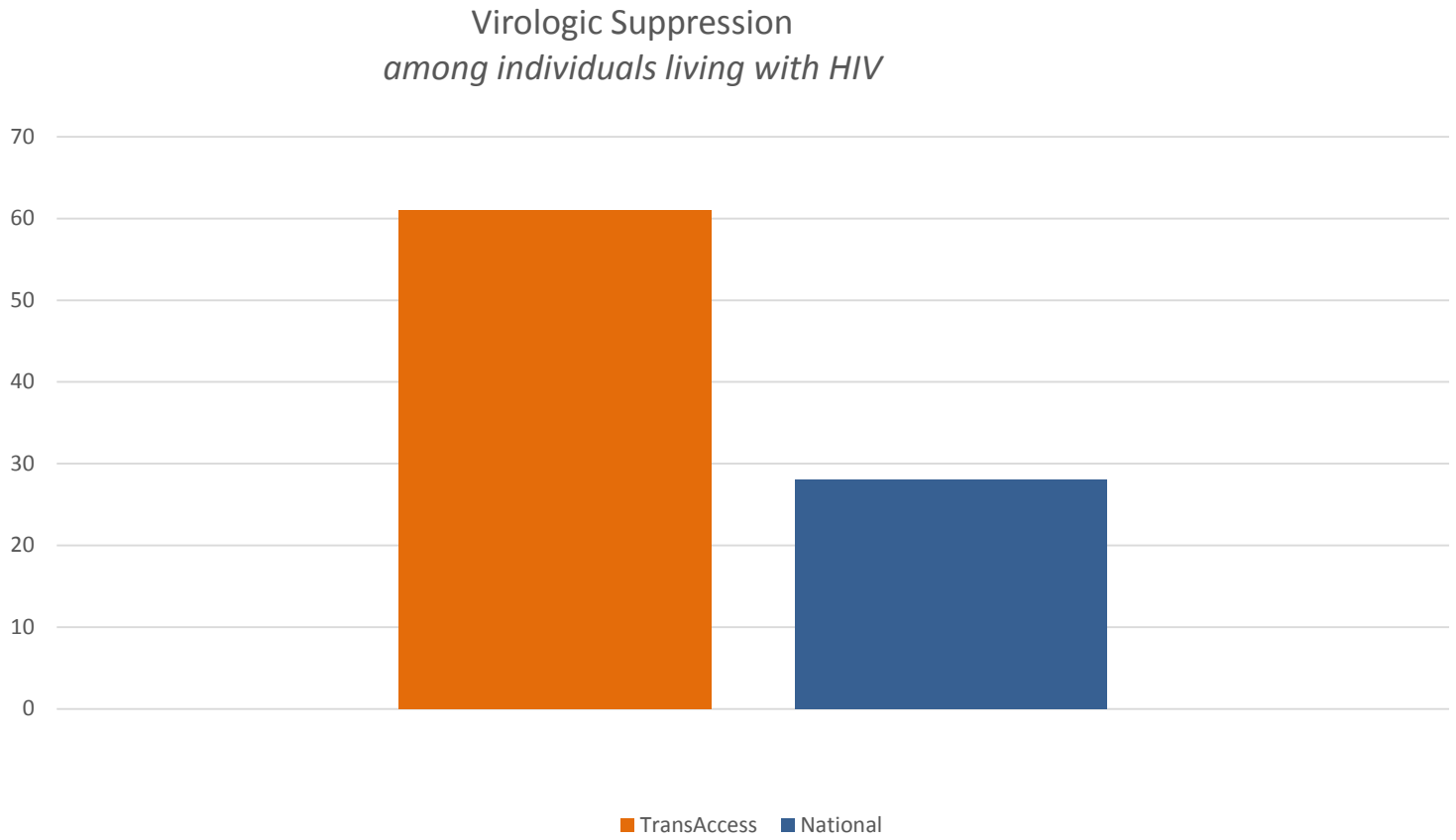
<u>REASONS CLIENTS ARE NOT ENROLLED in MULTISITE EVALUATION</u>

- they were unable to consent
- they chose not to consent
- they were not enrolled within the allotted time

<u>OTHER MEANS of SHARING:</u>

- agency stories
  - podcast
  - digital stories

CLINICAL OUTCOMES

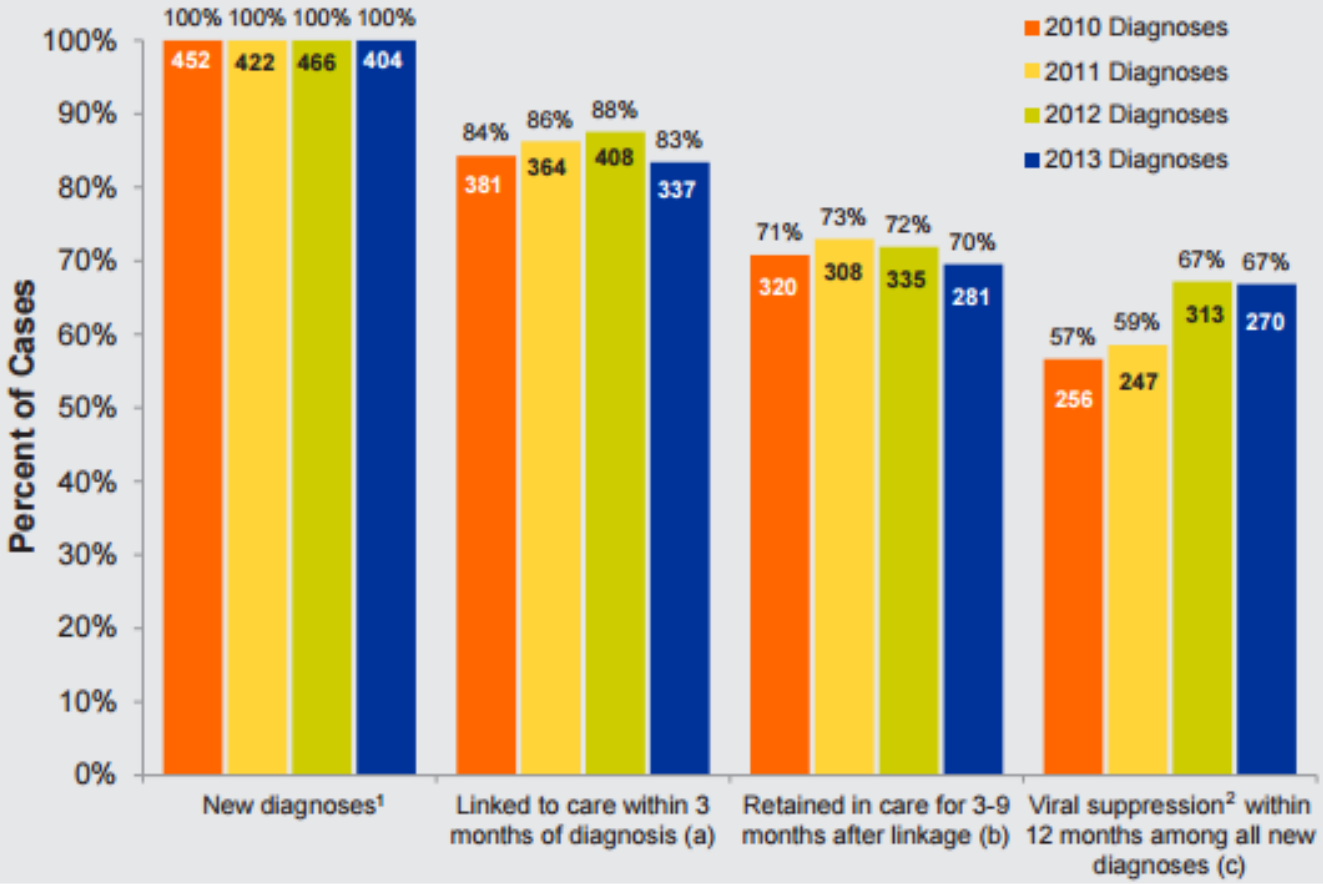


61% of all active clients are virally suppressed, compared to 28% of national population with viral suppression.

source: SFDPH HIV/AIDS Epidemiology Annual Report 2014

CLINICAL OUTCOMES

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.

source: SFDPH HIV/AIDS Epidemiology Annual Report 2014

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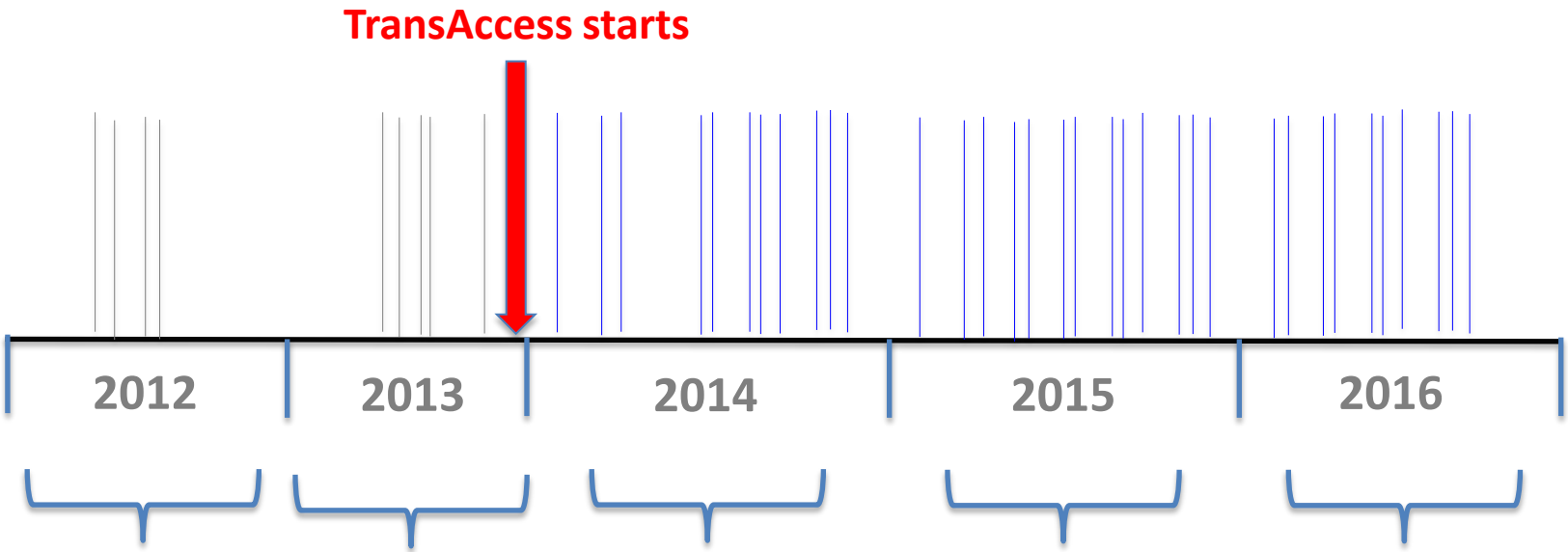
Intervention Exposure: # of visits by discipline

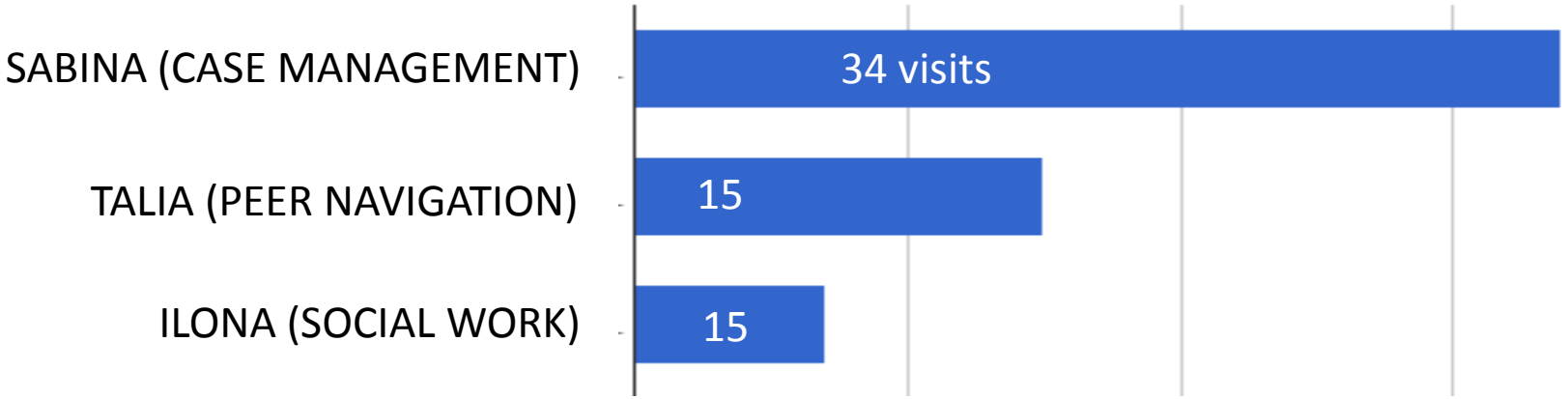


	2012	2013	2014	2015	2016
Medical	4	4	11	13	14+
Case Mgmt	0	0	19	25	9
Peer Nav	N/A	N/A	30	6	9
Soc. work	0	0	0	7	8

Intervention Exposure: PSYCHOSOCIAL

In 2015 & 2016, Trans-Access provided the following services to client JB

for every TWO visits with her case management team, she received a primary care visit

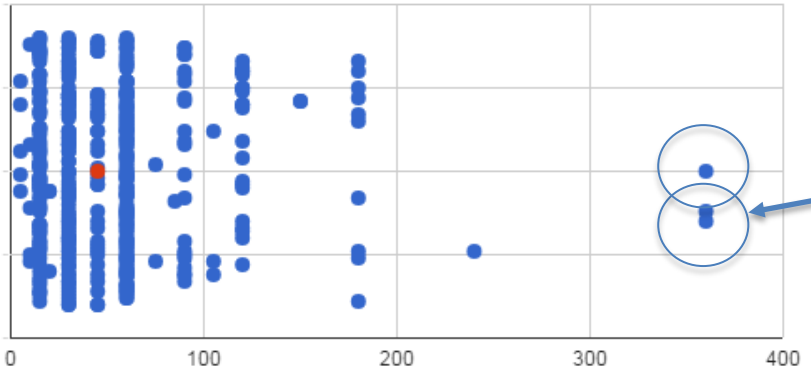


Total Count (N)	Average Length of Visit	Sum of Staff Time
56	44 minutes	42 hours

Intervention Exposure Data:

Case Management, Peer Navigation, & Medical Social Work

2015

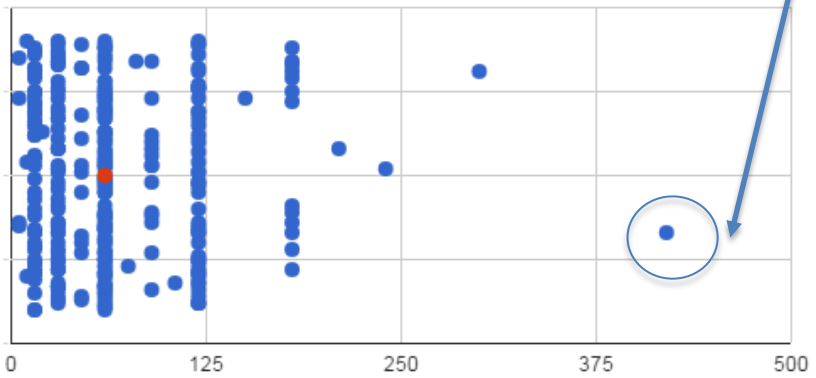


Staff time spent with **high acuity & high needs** clients*

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

Year	Total Encounters	Sum of Staff Time	Average Length of Encounter
2015	433	383 hours	53 minutes
2016 (Jan-July)	318	343 hours	64 minutes



2016

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.

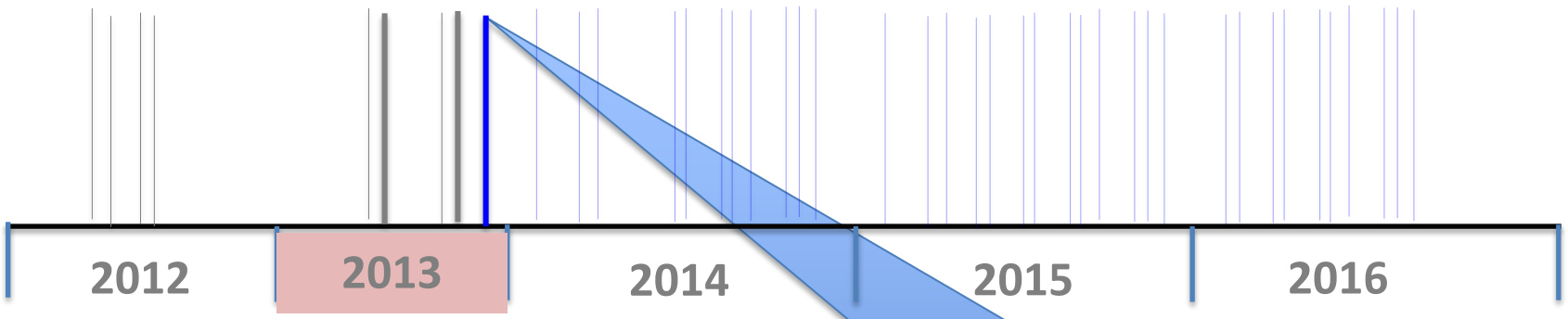
8/5/13: CD4 606, VL 67,786

- 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

Start TransAccess intervention: 2013



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

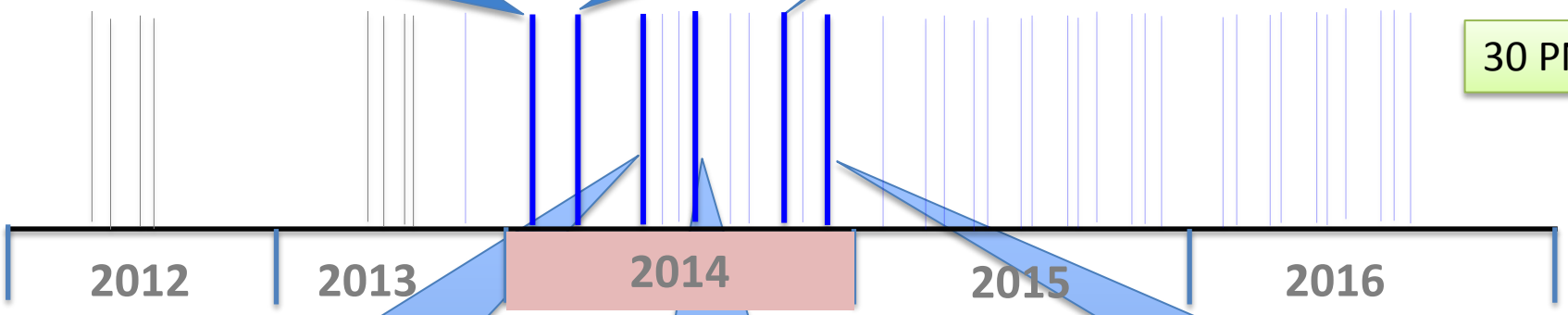
- self referred SA program
- Attributes to ↑self-worth
- voices ↓ on psych meds.
- Back on ARVs
- Expresses desire for mammo
- PCP: Yes to GCS. Framed as pathway to readiness.

9/18/14 ***

- Referred mammoplasty

19 CM

30 PN



7/3/14

- Voices ↑
- ***"…they critique my femininity"*** *
- Self DC'ed ARVs. Off psych meds

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

3/12/15

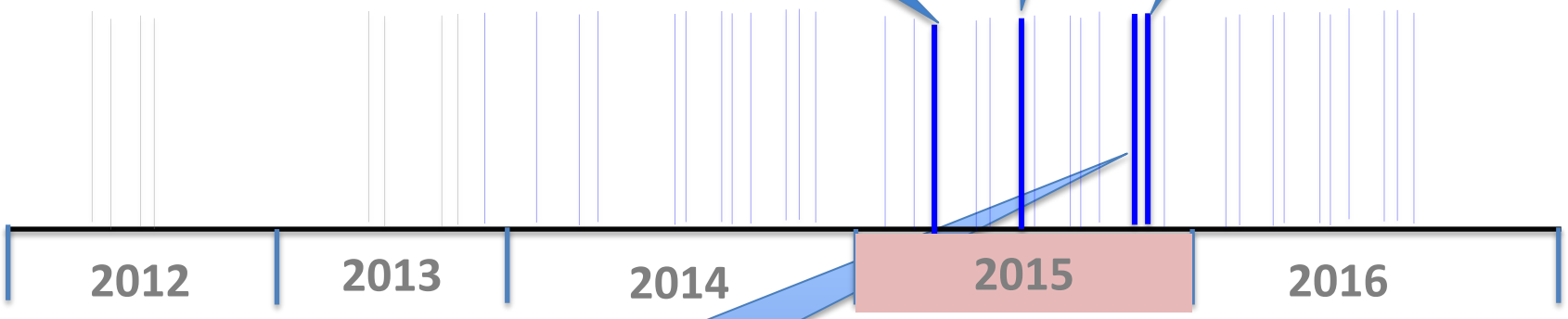
- 6 months sobriety
- ***"I can walk past dealers without being triggered."***
- ***"I've got my power back, and I will never give it away again."***
- Starts volunteering

6/9/15: CD4 842, VL<40

- Sober 9 months

11/30/15

- Successful mammoplasty!



10/29/15: CD4 1006, VL <40

- Testified at City Hall

We've arrived!!!

- VL<40
- Employed
- Empowered
- Surgery

2/4/16: CD4 898, VL 988

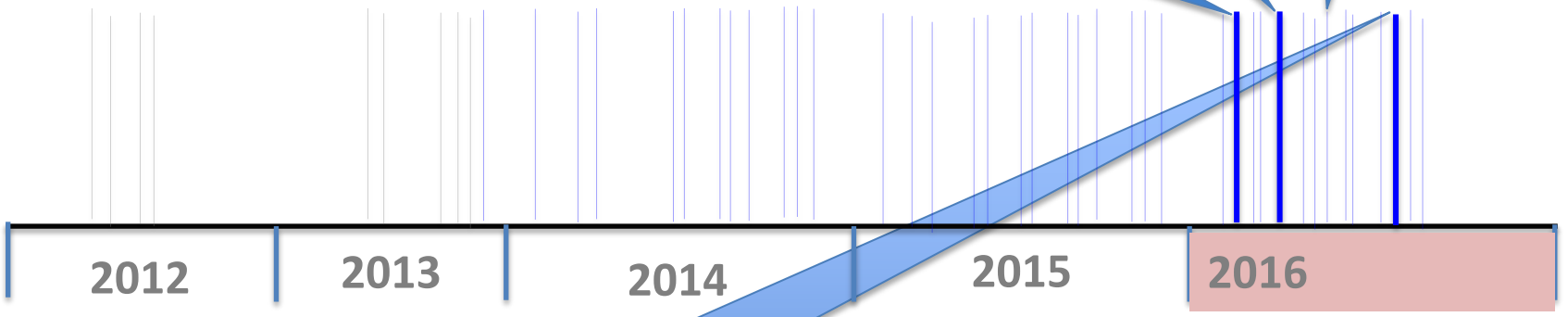
- Adherence hiccups. Relapsed.
- ***"I'm so used to being down here*** [gestures to floor]***, that I don't know how to handle myself now that I'm up here."***
- Having trouble at work: multiple missed days

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." SAMHSA

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

Tips and Food for thought

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

Tips and Food for thought

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

Tips and Food for thought

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."

Wilson E, Arayasiricul S, Johnson K. "Access to HIV care and support services for African American transwomen living with HIV". International journal of Transgenderism. 14:182-195, 2013

Institutional Facilitators of Trust

"…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."

Wilson E, Arayasiricul S, Johnson K. "Access to HIV care and support services for African American transwomen living with HIV". International journal of Transgenderism. 14:182-195, 2013

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"*

1. Oxford English Dictionary, online 2016

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

Success: AS OUR CLIENTS SEE IT

TRANS-ACCESS CLIENT FEEDBACK from our 2015 focus group:

"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."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&
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Acknowledgements

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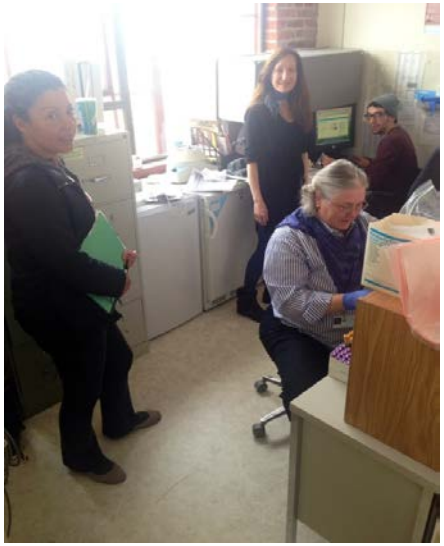

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