

Community Outreach & Listening Activities 2019

WOMEN WHO USE SUBSTANCES

TRANS WOMEN OF COLOR

CISGENDER AFRICAN AMERICAN WOMEN

Thank you to Collaborating Partners

- Women who use Substances COLA
 - June 19, 2019
 - Shanti Project, Courtney DeGiobbi
 - Facilitated by Jen Cust and Melina Clark
- Trans Women of Color COLA
 - July 24, 2019
 - SF Community Health Center, Marsha Davidson
 - Facilitated by Jen Cust and Melina Clark
- Cisgender African American Women COLA
 - December 9, 2019
 - UCSF Women's Health Program, Parnassus, Michelle Spence
 - Facilitated by Liz Stumm and Melina Clark

COLA: Limitations

- Small sample size
 - Clients may not be representative of the demographics of this target population
 - Measure used to collect the data
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- This report does not claim to be statistically significant or represent all of the target communities' needs.

Overview

Mission Statement:

It is the responsibility of the COLA (Community Outreach and Listening Activities) Team to proactively gather and disseminate relevant information to and from people living with HIV and at highest risk for HIV.

- The Community Engagement Committee determines target populations for Community Outreach & Listening Activities (COLA) focus groups.
- Post merge the council has endeavored to expand COLAs to include Prevention concerns
- The purpose of COLAs are to:
 - Disseminate information about the HCPC and the HIV Consumer Advocacy Project
 - Conduct outreach to consumers of services as potential Council members
 - Provide small scale needs assessments that focus on the San Francisco EMA system of care, in particular:
 - To collect information regarding Service Prioritization from consumer of services.
 - To collect information regarding unmet needs and barriers to care
 - To solicit input and obtain feedback on the overall service needs of HIV+ individuals and communities

Background

Structural Inequities and Health Disparities

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Background: Structural Inequities in African American Communities

- African Americans have **lower life expectancy** than other racial groups.
- A recent study released by the Centers for Disease Control and Prevention confirmed that **maternal death rates among black women are 3.3 times higher** than for whites.
 - “Even when all other factors are equal -- economic status, educational background, and access to health care – maternal death rates for black women are still higher compared to white women. “
- **Black women have higher death rates for nearly all cancers** than white women and are twice as likely to experience infertility problems
- The **infant mortality rate is more than twice as high** for black children than for white children

Southern Poverty Law Center, 2019

Background: Transgender Women

- A 2019 systematic review and meta-analysis found that an estimated **14% of transgender women have HIV**. By race/ethnicity, an estimated **44% of black/African American transgender women, 26% of Hispanic/Latina transgender women**, and 7% of white transgender women have HIV.
 - (Jeffrey S. Becasen MPH, Christa L. Denard, Mary M. Mullins, Darrel H. Higa, and Theresa Ann Sipe, 2018)
- Studies have reported **high prevalence of depressive symptoms, discrimination, and financial hardship** in samples of transgender women
 - (Balsam, Molina, Beadnell, Simoni, & Walters, 2011; Barrientos, Silva, Catalan, Gomez, & Longueira, 2010; Clements-Nolle, Marx, Guzman, & Katz, 2001; Clements-Nolle, Marx, & Katz, 2006).
- Research has documented **high prevalence of employment discrimination**, which leads to economic marginalization and financial hardship among transgender women.
 - (Bradford et al., 2013; Conron, Gunner, Stowell, & Landers, 2012; Lombardi et al., 2002).

Background: People who use Substances

- The National Survey on Drug Use and Health estimates that 20.6 million people in the US, or **8% of adults**, have Substance Use Disorders (SUDs)
 - **25% of PLWHA** in the United States have SUDs that required treatment last year.
- Despite extensive dedicated resources and availability of antiretroviral therapy (ART) in the United States, People who use Substances continue to experience:
 - **delayed HIV diagnosis**
 - **reduced entry into and retention in HIV care**
 - **delayed initiation of ART**
 - **inferior HIV treatment outcomes.**
- Culturally condoned and provider-perpetuated **stigma against People who use Substances** may deter some individuals from disclosing their HIV status, accessing care, or initiating ART.

Meyer et al., 2013. "Optimizing Care for HIV-Infected People Who Use Drugs: Evidence-Based Approaches to Overcoming Healthcare Disparities."

Background: Cisgender Women

- Women, especially members of marginalized populations face unique challenges
 - “Gender inequality compounded by social factors such as discrimination and low socio-economic status... can result in limited access to information, education, health care and treatment.” (Durvasula, R. 2018)
- **Women historically left out of medical research and clinical trials**
 - The National Institutes of Health (NIH) rejected women centered grants in HIV and felt that it was unnecessary to understand co-factors of HIV in low income ethnic minority women — assuming that a risk was a risk (Corea,1992).
- Researchers viewed women as “confounding, expensive test subjects because of their fluctuating hormone levels” (Liu, Major, 2016)
- “Pregnant women, and women of ‘child-bearing potential’ excluded from enrollment in trials, especially in early stages of research.” (Liu, Major, 2016)

Women living with HIV in San Francisco

WOMEN WHO USE SUBSTANCES

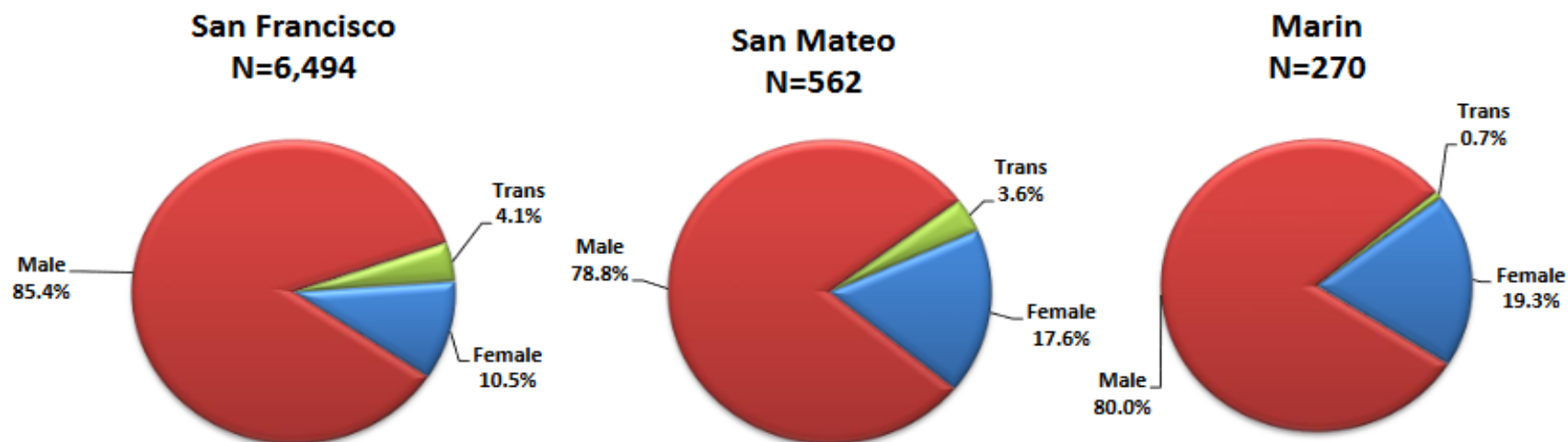
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Current Gender for EMA

Unknown 0.1% has been removed

Female	Male	Transgender
n=787	n=6,080	n=273
11%	84.6%	3.8%



Disparities and Health Inequities

2018 Epi Report

- New diagnoses increased among **people who inject drugs (PWID), African Americans (AA), Latinx persons**, homeless persons.
 - African American men and women had the highest HIV diagnosis rates by race, with rates per 100,000 population of 145 and 35, respectively, followed by Latinx men and women.
 - The number and proportion of diagnoses among PWID has continued to rise; there were 27 (14%) new diagnoses in 2018 compared to 21 (9%) in 2016.
- Compared to the overall proportion of **viral suppression among PLWH (74%), viral suppression was lower for women (66%), trans women (68%), African Americans (68%), PWID (65%), MSM-PWID (68%), TWSM-PWID (64%),** and was particularly low among homeless individuals (33%).
- **27% of trans women**, 23% of men and 15% of women had **no insurance** at time of diagnosis.
- Three-year survival following an AIDS diagnosis was **lowest among African Americans (82%)** compared to other races; **and PWID (79%)** compared to other transmission categories.

Trends in Rate of New Diagnoses among Women, by Race/Ethnicity

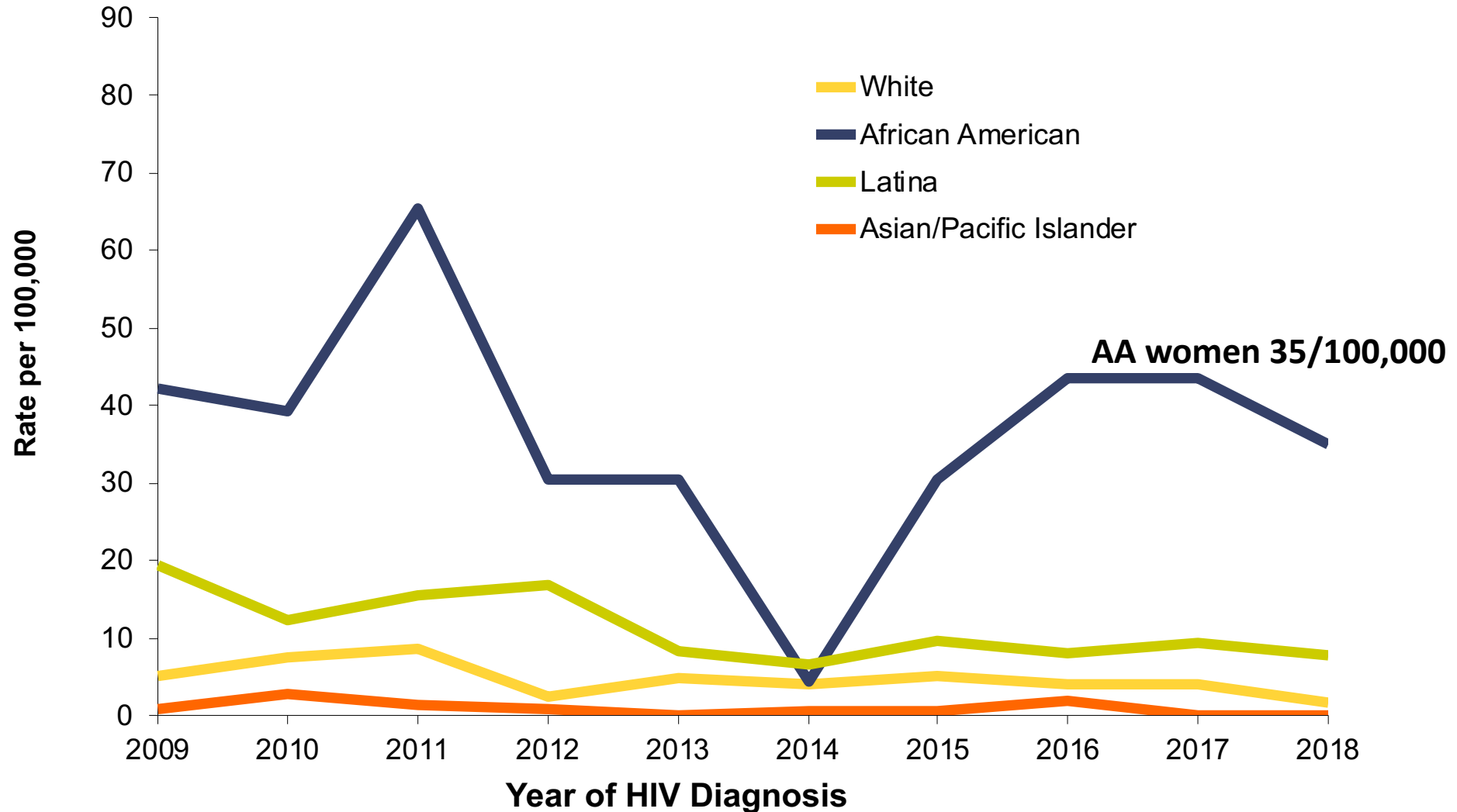
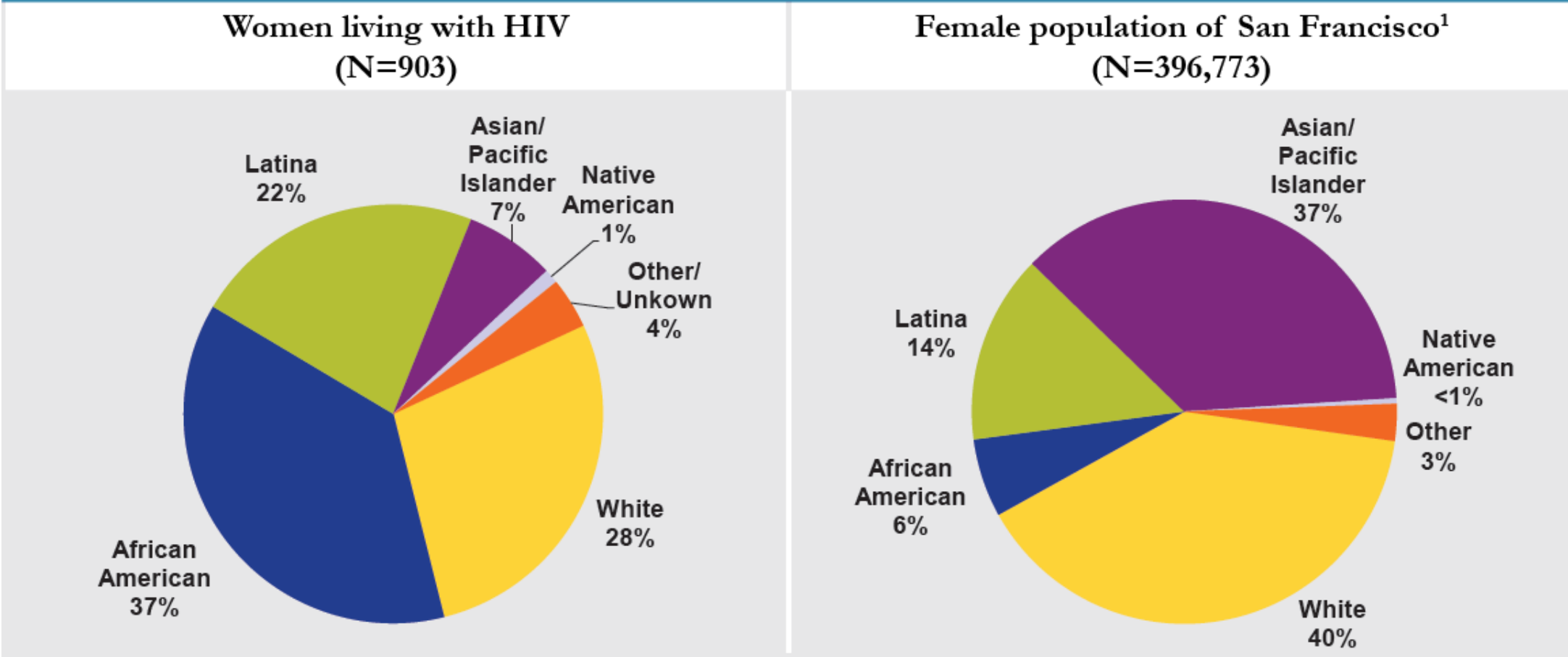


Figure 10.2 Women living with HIV diagnosed through December 2018 and female population by race/ethnicity, San Francisco



1 United States 2010 Census data.

Health Disparities among Trans Women

- As of December 31, 2018, **31% of the 396 trans women living with HIV in San Francisco were African Americans and 36% were Latinas.**
- 43% of trans women living with HIV were PWID.
- Similar to trans women newly diagnosed with HIV in 2009 to 2018, **trans women living with HIV were more likely to be non-white, PWID, and younger ages when compared to all persons living with HIV in San Francisco.**

Table 13.2 Characteristics of trans women living with HIV compared to all persons living with HIV, December 2018, San Francisco

		Trans Women PLWH ¹	All PLWH
		Number (%)	
Total		396	15,990
Race/Ethnicity	White	71 (18)	9,314 (58)
	African American	122 (31)	1,908 (12)
	Latina	141 (36)	3,184 (20)
	Asian/Pacific Islander	39 (10)	993 (6)
	Other/Unknown	23 (6)	591 (4)
People who Inject Drugs	Yes	172 (43)	3,243 (20)
	No	224 (57)	12,747 (80)
Age in Years (at end of 2018)	13 - 17	0 (0)	4 (<1)
	18 - 24	5 (1)	98 (1)
	25 - 29	14 (4)	346 (2)
	30 - 39	85 (21)	1,727 (11)
	40 - 49	120 (30)	3,124 (20)
	50+	172 (43)	10,691 (67)

¹ See Technical Notes “Gender Status.”

Health Disparities

Viral Suppression among PLWH

	Number of living cases ¹	% with >= 1 laboratory test in 2017 ²	% Virally suppressed (most recent viral load test in 2017 <200 copies/mL) ²
Total	12,778	81%	74%
Gender			
Men	11,688	81%	74%
Women	725	81%	66%
Trans Women	360	84%	68%
Race/Ethnicity			
White	7,095	81%	76%
African American	1,606	81%	68%
Latinx	2,742	78%	70%
Asian/Pacific Islander	815	81%	77%
Other/Unknown	520	84%	74%
Age in Years (as of 12/31/2017)			
13-24	83	87%	80%
25-29	382	80%	69%
30-39	1,715	77%	67%
40-49	2,804	77%	67%
50-59	4,542	81%	75%
60-69	2,548	86%	81%
70+	704	85%	83%
Transmission Category			
MSM	9,263	81%	76%
TWSM	207	88%	71%
PWID	745	82%	65%
MSM-PWID	1,719	81%	68%
TWSM-PWID	151	78%	64%
Heterosexual	470	81%	70%
Other/Unidentified	223	56%	51%
Housing Status, Most Recent			
Housed	12,447	81%	75%
Homeless	331	51%	33%
Country of Birth			
US	9,321	82%	75%
Non-US	2,201	73%	69%
Unknown	1,256	83%	76%

Overall PLWH viral suppression rate

Source: 2019 Epi Presentation to HCPC

2019 COLA Results

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Prioritization Comparison

Women who use Drugs	Trans Women of Color	Cisgender B/AA Women
Primary Care	Primary Care	Primary Care
Mental Health	Food	Case Management
Legal Service	Dental Care	Dental Care
Emergency/Transitional Housing	Case Management	Legal Service
Emergency Financial Assistance	Residential Programs	Transportation
Home Health Care	Substance Use Counseling	Food
Psychosocial Support	Mental Health	Emergency Financial Assistance
Food	Psychosocial Support	Emergency/Transitional Housing
Outreach	Legal Service	Outreach
Benefits Counseling	Hospice	Hospice
Hospice	Outreach	Benefits Counseling
Transportation	Emergency/Transitional Housing	Mental Health
Residential Programs	Money Management	Psychosocial Support
Substance Use Counseling	Emergency Financial Assistance	Residential Programs
Case Management	Home Health Care	Substance Use Counseling
Dental Care	Transportation	Money Management
Money Management	Benefits Counseling	Home Health Care

Women who use Substances COLA

- June 19, 2019
- Shanti
- Facilitated by Melina Clark and Jen Cust
- 4 participants

Women who use Substances

Location/Isolation

- Living in the Tenderloin is difficult. Drugs are easily accessible in SROs as well as right on the street.
- Former substance users remarked on losing community when they stopped using
- Others spoke to not feeling safe in their neighborhood or in their SRO.

“There are always drugs there.”

“I don’t have anyone I can talk to.”

“I need to make friends who don’t use.”

Women who use Substances

Mental health and substance use

- All attendees linked their current or former substance use to challenges with mental health.
- Some folks spoke to surviving abusive relationships.

“If my mental health isn’t balanced, I won’t take my meds, everything goes down the shit hole.”

“I’m grateful I’m still here, it’s so easy to OD.”

“I don’t trust people like I used to. I tend to isolate when I’m in pain.”

Trans Women of Color COLA

- July 24, 2019
- SF Community Health Center
- Facilitated by Melina Clark and Jen Cust
- 7 participants

Trans Women of Color

Political climate

- Folks feeling very afraid and unsafe in the current political climate. Some cited specifically fears regarding ICE and immigration raids.

“There’s people who don’t come out of their house because they’re scared.”

“The political climate affects the way trans and gay folks are treated in society. People of color too.”

Discrimination in medical and criminal justice systems

- Participants talked about feeling judged when they visit their doctor.
- Avoiding appointments because of how they expected to be treated.
- Discrimination and abuse at the hands of law enforcement, citing bad experiences with the police across the board.

“Important that I don’t feel judged, that the doctor is really listening to me.”

“The way we get treated is different.”

Trans Women of Color

Need for tailored services for trans folks

- Participants spoke to the difficulties of getting work as a trans person and needing a well-paying job in order to survive in San Francisco.
- Need for more employment and job training, as well as empathy and attention to the needs of the trans community.
- Folks discussed wanting to work somewhere where they feel comfortable.
- Attendees talked about feeling the most welcome at places where there are trans folks on staff.
- Folks also cited being able to access drop-in spaces specifically for trans folks as really important to their social and psychological health.

“They have to be more empathetic go what the trans community is asking.”

“Need to feel comfortable in workplace.”

“They make everyone feel welcome”

Cisgender African American Women COLA

- December 9, 2019
- UCSF Women's Health Program, Parnassus
- Facilitated by Melina Clark and Liz Stumm
- 4 participants

Cisgender African American Women

Sharing of resources

- Participants cited a lack of awareness of available services.
- Folks spoke to a feeling that this information is not shared with black women, while citing experiences of meeting white gay men who are very familiar with the system of care.
- The group also talked about the importance of case managers. Only through case managers were people able to get the information they needed.

“The case manager should help. I only found out about services through primary care.”

“A Caucasian man asked if I knew about these services... Why does he know and I don’t?”

“Information doesn’t get passed on. Is it racial, demographics?”

“Given demographics of city, we should be entitled to services.”

Cisgender African American Women

Psychosocial-- Support Groups, Community, Retreats

- Need more support groups for African Americans-- mixed groups with men and women.
- Retreats and social activities.
 - Socialize outside of hospital setting, offer groups outside of 9-5 business hours.
- Participants spoke to the rarity of seeing other black women in San Francisco.
- The women also spoke of changing communities in the city, gentrification.

“I was surprised there’s a focus group for African American women. I thought I was the only one.”

“We need to talk to each other.”

“If I knew about support groups, I wouldn’t have been as sick the first year”

“What gave me life, strength, hope, was going on a retreat.”

“Knowing other people who are positive helps.”

Cisgender African American Women

Caregiving/Familial responsibilities

- Some women described the added responsibilities of being mothers and grandmothers. In addition to taking care of their own physical and psychological health they were supporting children and grandchildren
 - Requires money, time, emotional labor
- Not being able to do things without accessible childcare
 - Further increases isolation.
- Fears about disclosing status to children

“It was nowhere how to tell your kids you have HIV.”

“I’m constantly on a budget.”

Commonalities

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Commonalities

Housing

- Folks spoke across the board about the importance of a stable housing situation in maintaining their health and well-being.
- Trapped in situations due to lack of affordable housing

“If you don’t have somewhere to call home, nothing can fall into place.”

“I need my own space. It’s hard on me mentally, physically.”

Case management/Care Navigation

- Participants spoke to the importance of their care navigators or case managers in their lives. They felt more respected and heard at appointments when accompanied by a case manager, as well as getting help with things that would’ve been difficult on their own.
- Some folks found out about services exclusively through case managers.

“It helps to have someone go with you.”

Commonalities

Female erasure

- Feeling that all the services are geared towards men, especially white gay men
- Lack of studies and research focused on women

“How are meds for men going to be the same for me?”

“Everything we have now is geared towards men.”

“They rarely have studies for women.”

Commonalities

Isolation/Psychosocial Support

- Need for more social activities, connecting with other people who are positive
- Not being able to work (physically unable or because of not qualifying for benefits) led to isolation
- Loss of community
- Stigma

“It’s hard for me to ask for help.”

“I don’t know how not to work.”

“Otherwise I’ll be in the house all day with nothing to do.”

“I don’t have anyone I can talk to.”

Commonalities

Resilience

“It’s only gonna make me stronger. I want to advocate for other people.”

“Having HIV is a small fraction of my life.”

“Seeing women who were truly living—inspiring.”

“I’m grateful I’m still here.”

“It helps to think about the needs of others.”

“We need more services teaching women about themselves.”

Conclusions

- Housing is ongoing challenge for clients we serve
- Case management/care navigation is crucial
- Women face unique challenges: Caregivers, survivors of domestic abuse, living in a system of care not designed for them
- Need for tailored services for both cis and trans women
 - Support groups for positive women, black women, trans women
 - Support groups for african americans of all genders
- Resources and information are not equitably shared
- Lack of community for women living with HIV in San Francisco

Thank you!