



Getting to Zero:

The impact of women's lived experience of incarceration on HIV care & prevention

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Pronouns: she/her/hers
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Agenda

- Positionality
- Racial Disparity in HIV
- Prison as Structural Determinant of Health
- Research @ Lived Experience of Incarceration in the US
- Discussion

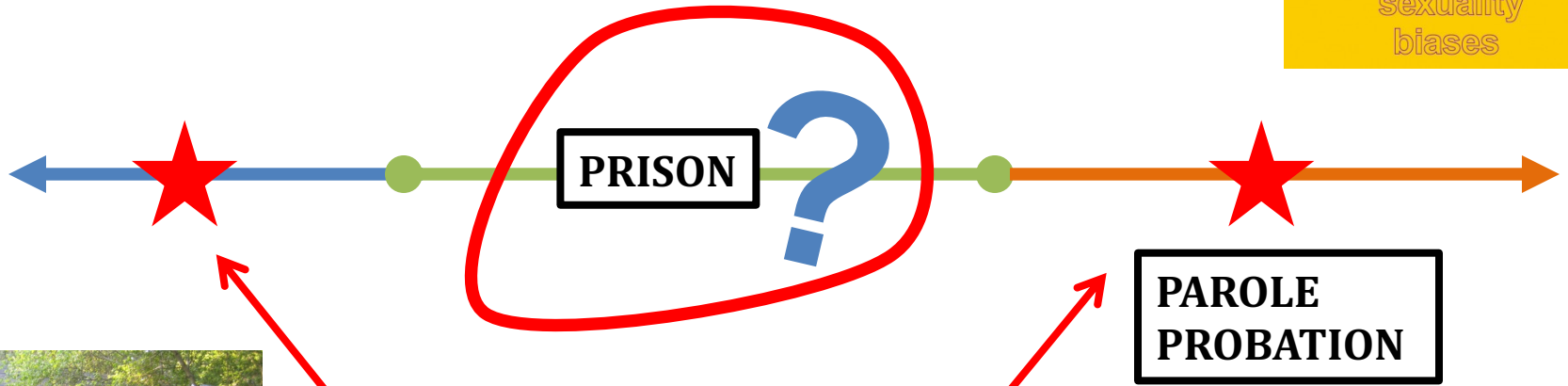


Gulsun Karamustafa (1946 -)
Turkish artist and former political prisoner (1971)
"I painted them in order to remember..."

Positionality

What are the stories we tell ourselves and other about who we are?

influences
wealth
gender
race
positionality
class
sexuality
biases



Southern CT State University

- Regional Public, State-Funded University
 - Tuition = \$12,000/year + Housing (70% commuters)
- 7,000 students, primarily undergraduates (6K) + graduate + doctorate
- Social Justice Institution - aspirational
- University of Access: 41% Pell Eligible
- Historically White Institution, today 46% White; 24% Latinx; 18% Black, 4% Asian



Department of Social Work

WHERE DO SOCIAL WORKERS WORK?

Social workers provide a majority of America's mental health services.

60% of mental health professionals are clinically trained social workers.

Child Protection Agencies
Schools
Family Service Agencies
Correctional Institutions
Government Agencies
Health & Community Centers
Hospitals & Mental Health Facilities
Private Practices

Source: <https://www.socialworkers.org/pressroom/features/issue/mental.asp>

GoodTherapy.org

Micro Level

- Clinical Social Worker
- Psychiatric Social Worker
- Child/Family Social Worker
- Medical Social Worker
- Substance Abuse Social Worker

Mezzo Level

- School Social Worker
- Community Social Worker
- Health Educators
- Social Service Manager

Macro Level

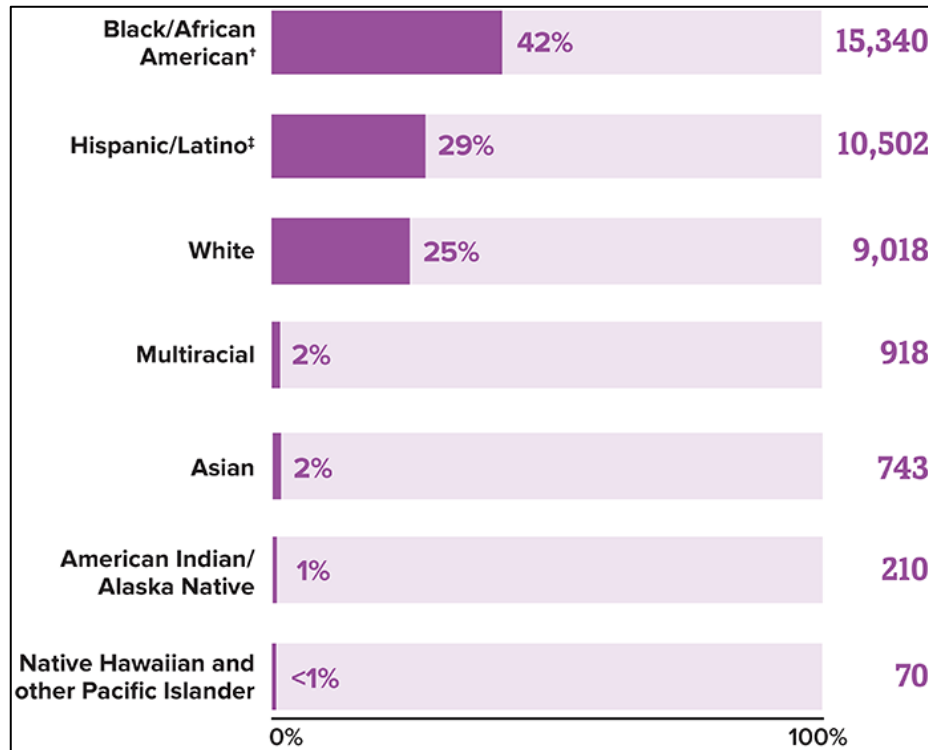
- Administrative
- Public Policy
- Research
- Community Planning/Organizing



CHRIS VOLPE PHOTO @NEWHAVEN365

Race Disparity in New HIV Infections

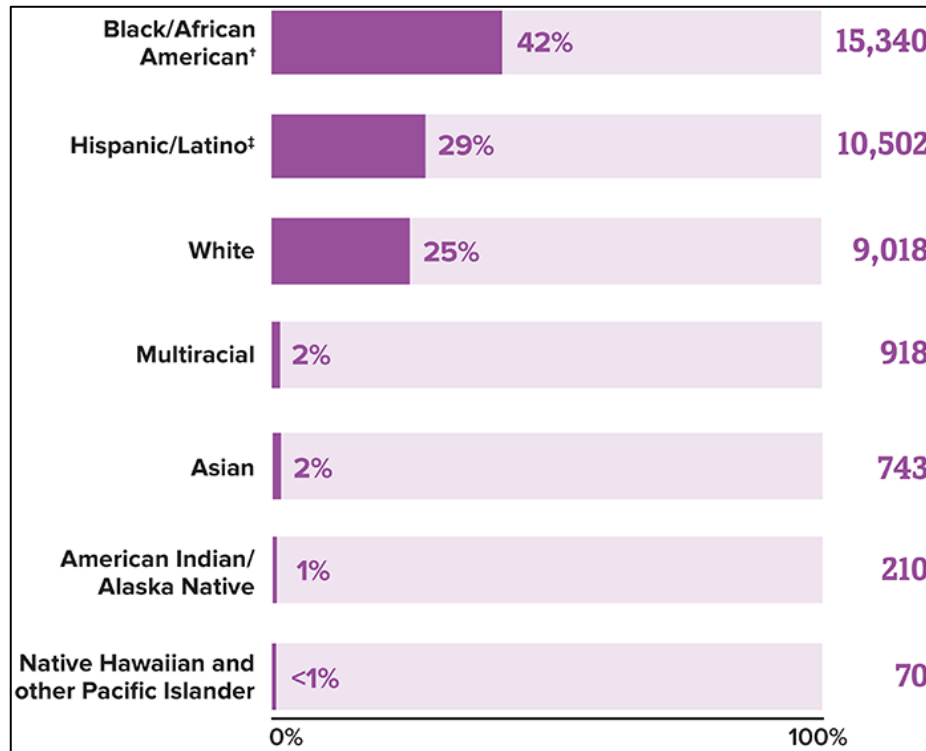
US Pop	
B/AA	12%
H/L	18%
W	60%
MR	3%
A	6%
AI/AN	3%
NHPI	<1%



Source: CDC. [Diagnoses of HIV infection in the United States and dependent areas, 2019](#). *HIV Surveillance Report* 2021;32.

Race Disparity in New HIV Infections

US Pop	
B/AA	12%
H/L	18%
W	60%
MR	3%
A	6%
AI/AN	3%
NHPI	<1%



Women† (N=6,999)		
B/AA	54%	3,812
H/L	19%	1,326
W	22%	1,508
MR	3%	202
A	1%	97
AI/AN	1%	44
NHPI	<1%	10

Source: CDC. [Diagnoses of HIV infection in the United States and dependent areas, 2019](#). *HIV Surveillance Report* 2021;32.

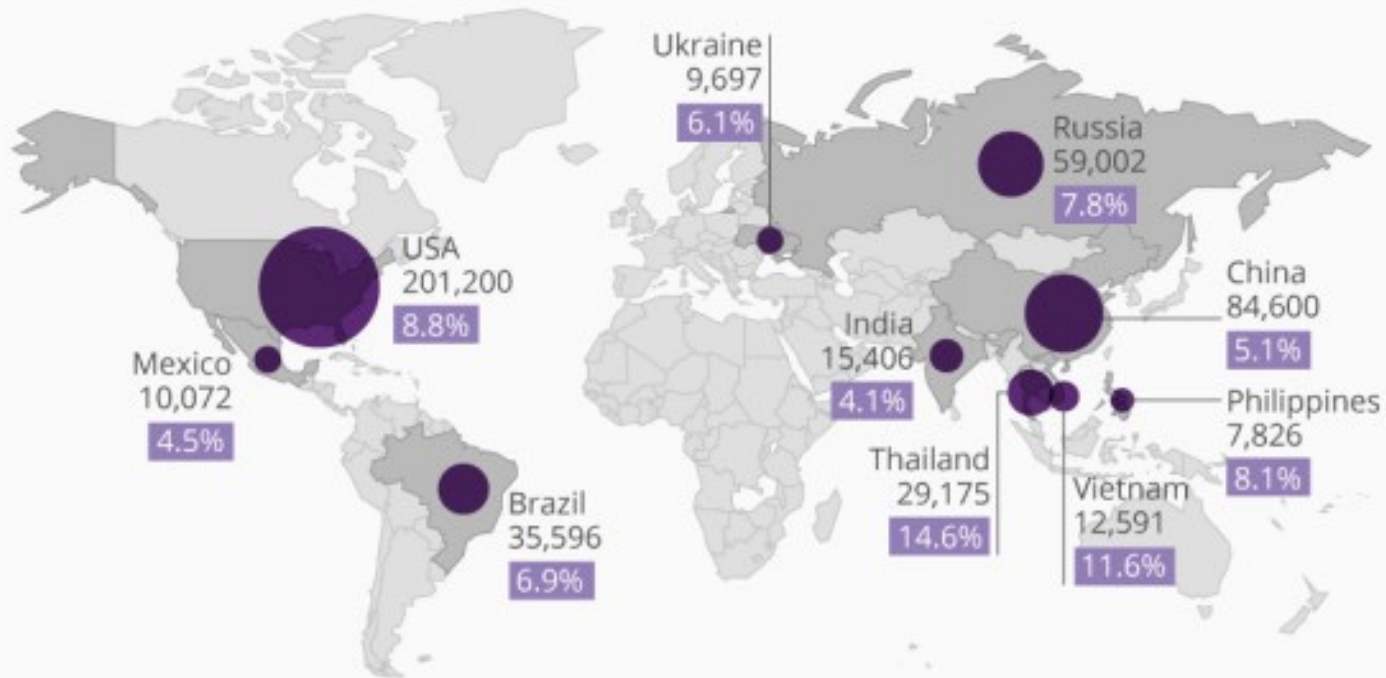
† Based on sex assigned at birth and includes transgender people.

Women & Incarceration in the US

No Country Incarcerates More Women Than The U.S.

Top 10 countries with the largest number of female prisoners in 2013

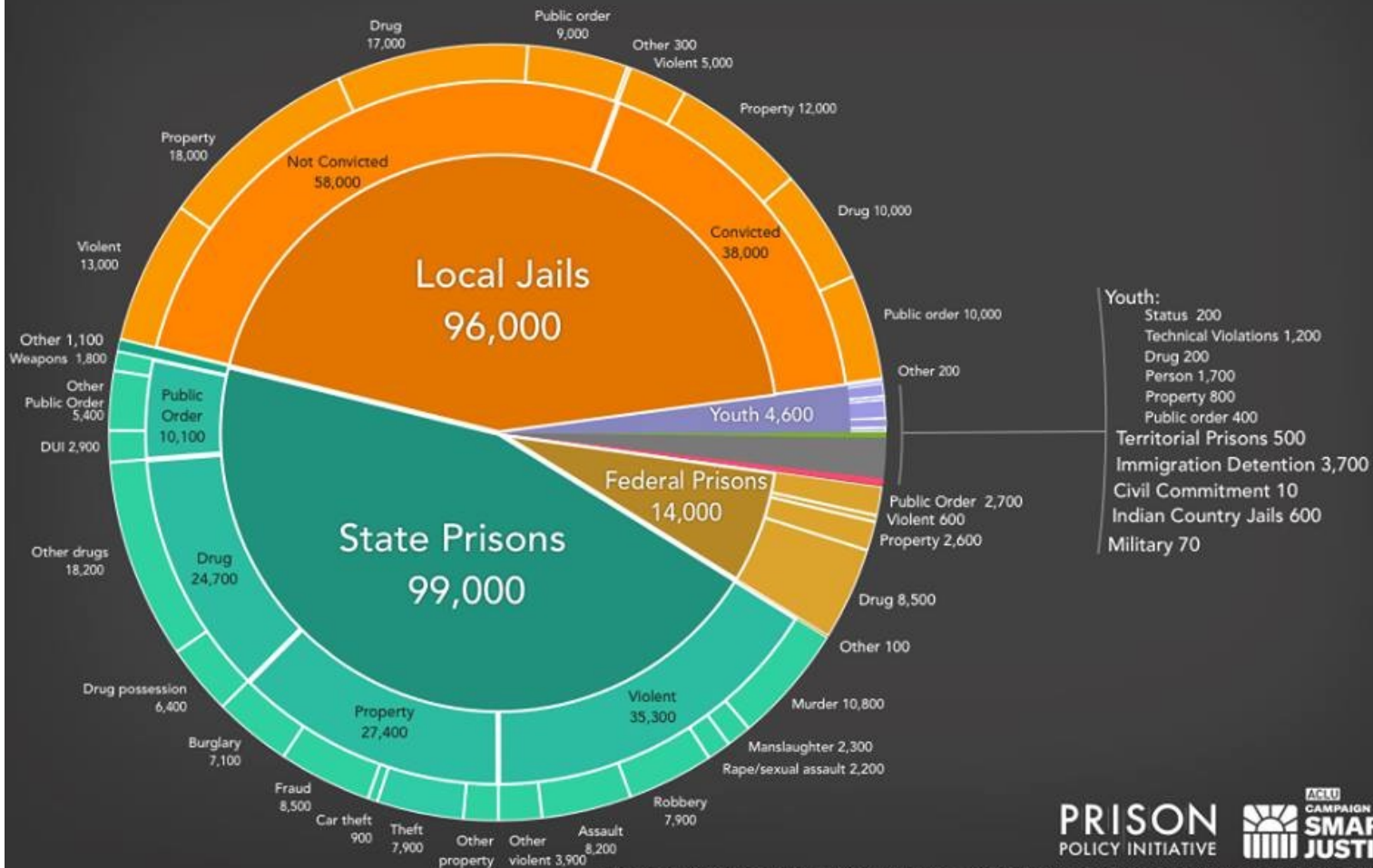
● Female Prison Population ■ % of Total Prison Population



Source: International Centre for Prison Studies

How many women are locked up in the United States?

The United States is one of the top incarcerators of women in the world. Changing that will require knowing where 219,000 incarcerated women fall within our decentralized and overlapping systems of mass incarceration.

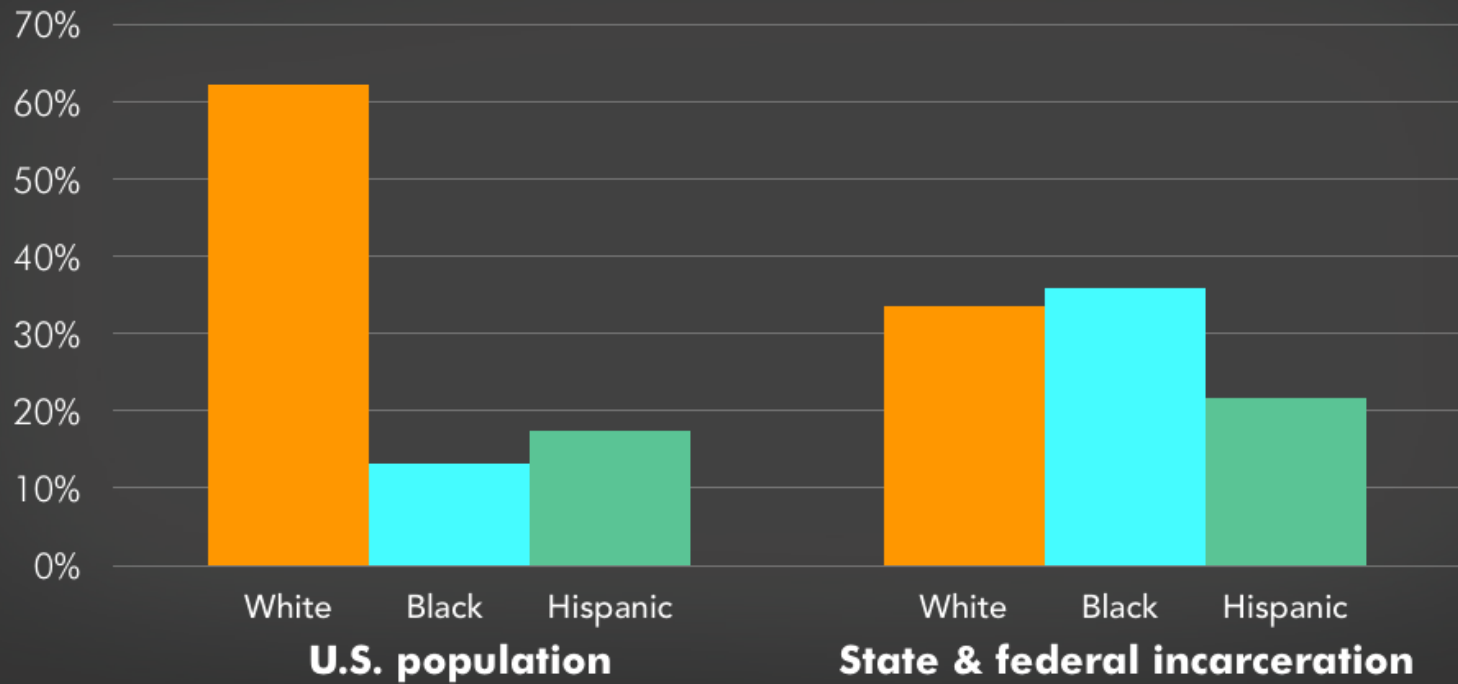


Sources & data notes: <https://www.prisonpolicy.org/reports/pie2017women.html>

PRISON
POLICY INITIATIVE

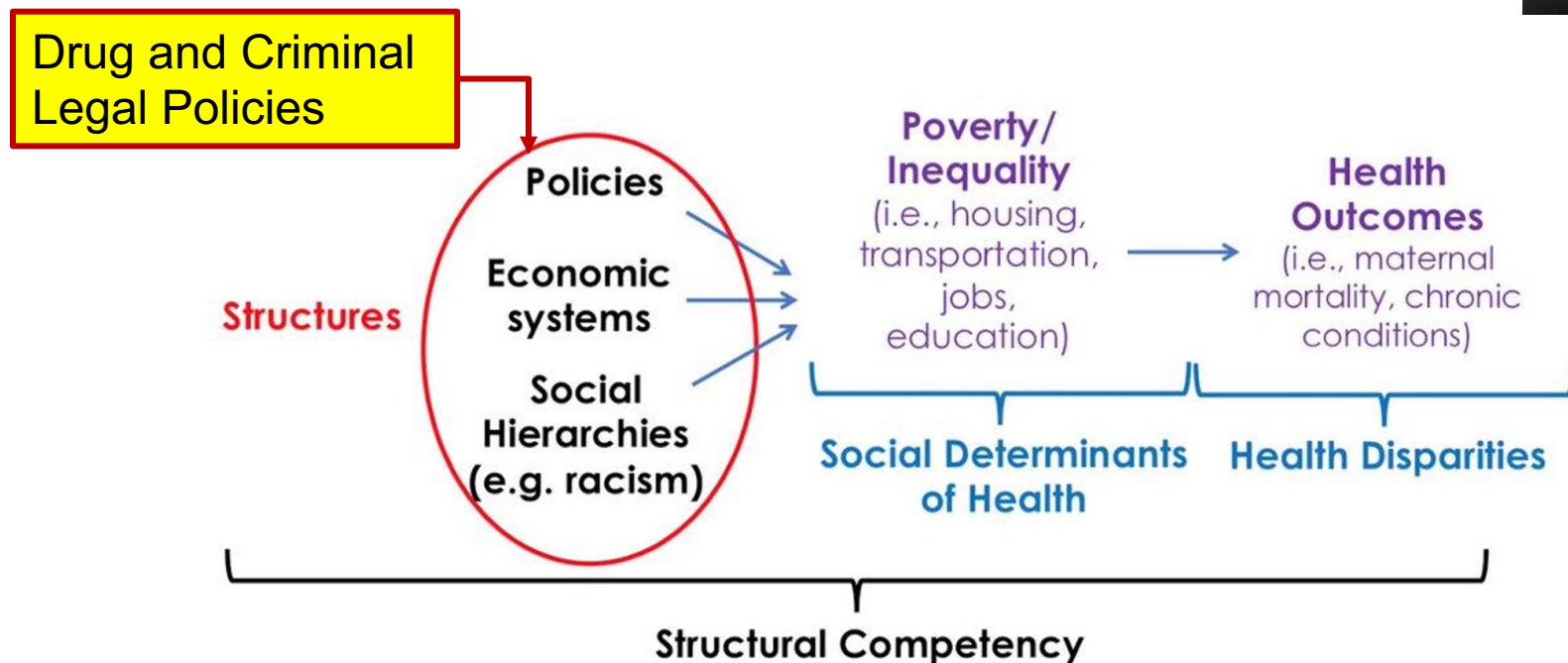
ACLU
CAMPAIGN FOR
SMART
JUSTICE

Incarcerated in state & federal prison



Prison Policy, 2016: <https://www.prisonpolicy.org/blog/2016/08/15/cjrace/>

Structural Determinants of Health



“Structural determinants of the social determinants of health”



HIV & Corrections: <https://www.hiv.uw.edu/go/key-populations/hiv-corrections/core-concept/all>

Figure 11 Estimated Number and Percentage of Persons with HIV in State and Federal Prisons, by Sex, United States, 2010 through 2015

Source: Maruschak LM, Bronson J. HIV in Prisons, 2015—Statistical Tables. Bureau of Justice Statistics: Office of Justice Programs, U.S. Department of Justice. August 24, 2017.

Year End	Male		Female	
	Number	Percent*	Number	Percent*
2010	18,510	1.4	1,780	1.8
2011	18,190	1.4	1,550	1.6
2012	17,680	1.4	1,490	1.6
2013	17,590	1.4	1,410	1.5
2014	16,410	1.3	1,330	1.4
2015	15,920	1.3	1,320	1.3

*Represents the percentage of all inmates of that sex diagnosed with HIV, including inmates in the custody of state and federal prison authorities with a confirmed diagnosis of HIV or AIDS.

There are 1.2 million people living with HIV in US.

HIV in community settings in the US = about 0.4%

HIV among incarcerated people in US = 1.3%

Figure 9 Persons in Prison with HIV in State Versus Federal Prisons, 1991-2015

The numbers for each year represent a sample taken at one point in time and represent persons with diagnosed HIV.

Source: Maruschak LM, Bronson J. HIV in Prisons, 2015—Statistical Tables. Bureau of Justice Statistics: Office of Justice Programs, U.S. Department of Justice. August 24, 2017.

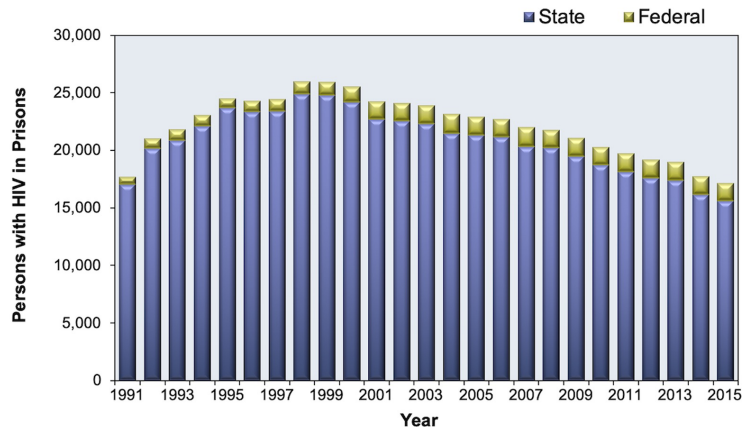
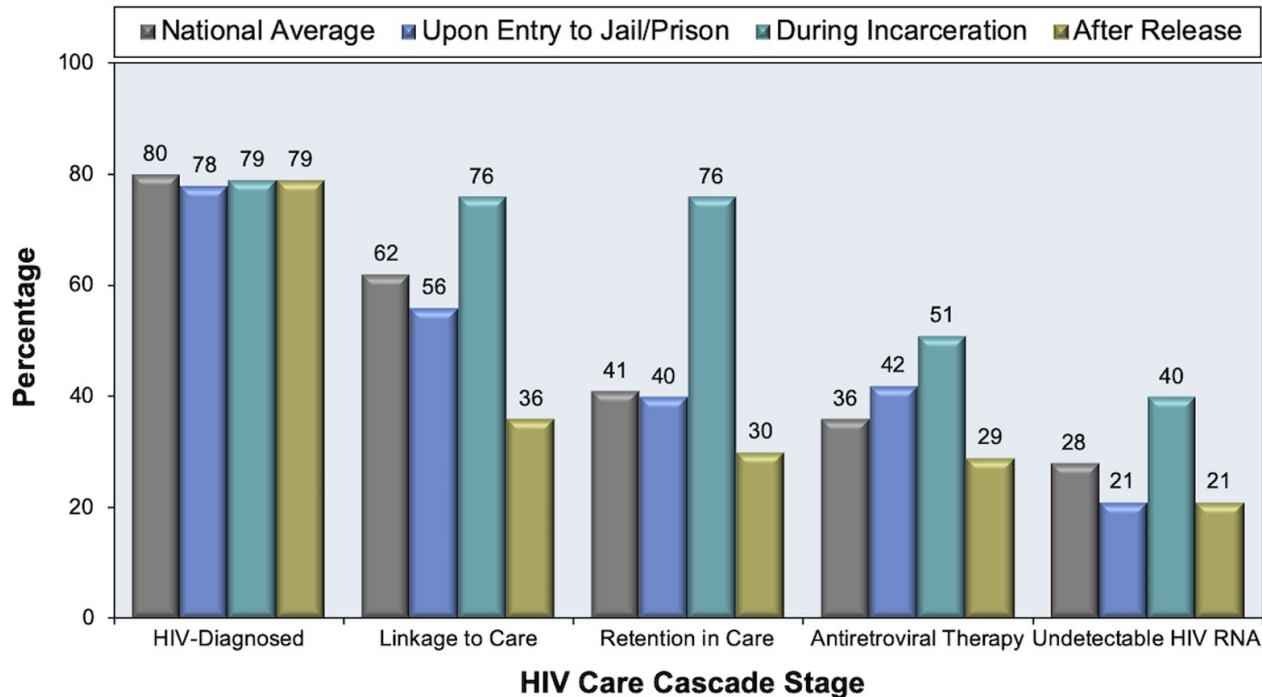


Figure 15 The HIV Care Cascade Before, During, and After Incarceration

This graphic represents systematic review and data synthesis compiled up to January 13, 2015. For this analysis, undetectable HIV RNA was defined as HIV RNA level of less than 500 copies/mL.

Source: Iroh PA, Mayo H, Nijhawan AE. The HIV Care Cascade Before, During, and After Incarceration: A Systematic Review and Data Synthesis. *Am J Public Health.* 2015;105:e5-16.

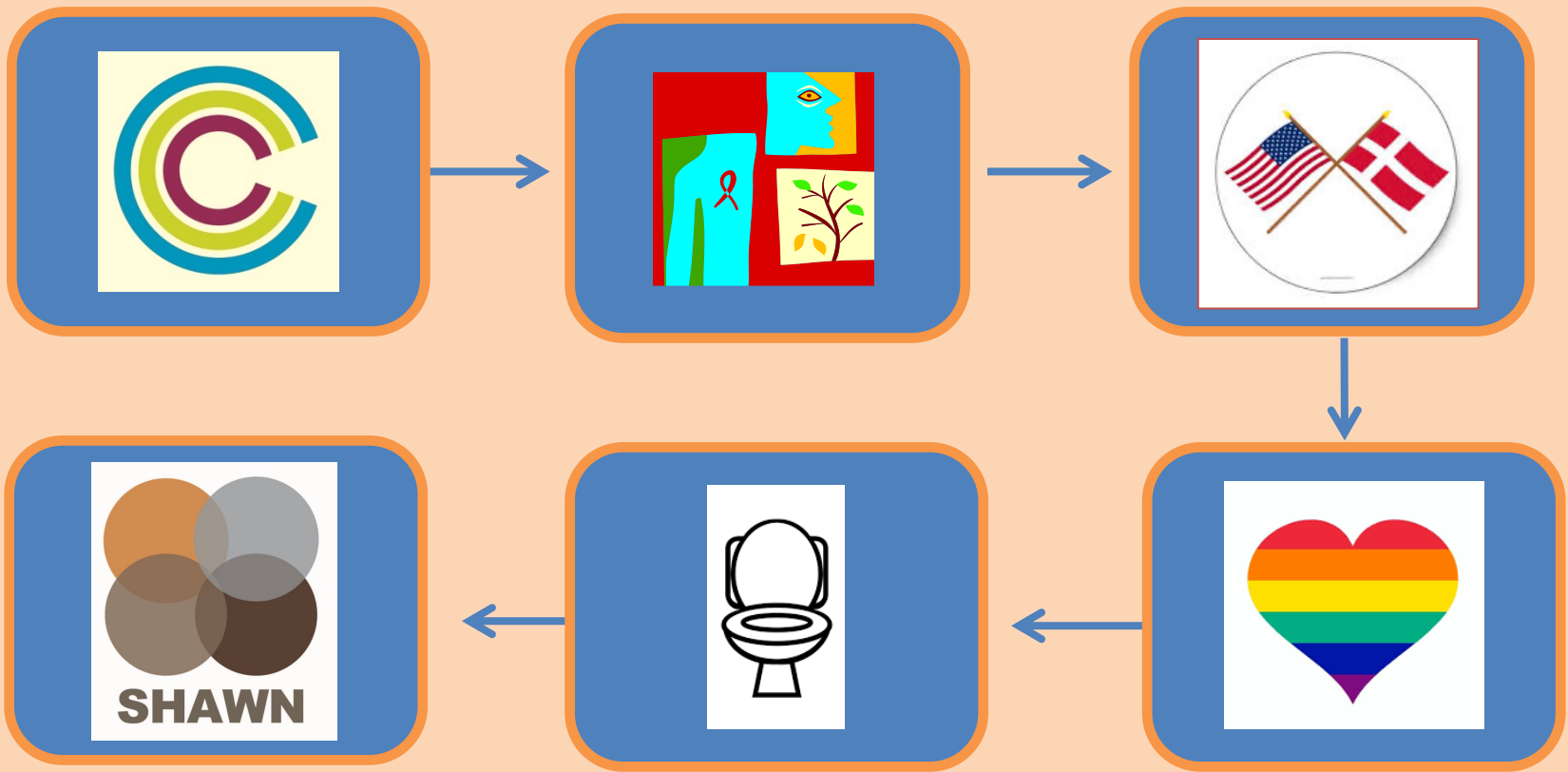


To build knowledge about women's experience of incarceration and the impact of these experiences on health and psychosocial outcomes.



- Inform our clinical practice by expanding understanding of clients' lived experiences.
- Encourage clients to engage in building narratives of strength and self-care.
- Consider how to harness the power of quotidian tasks to improve health and psychosocial outcomes.

Amy's Prison Research Projects

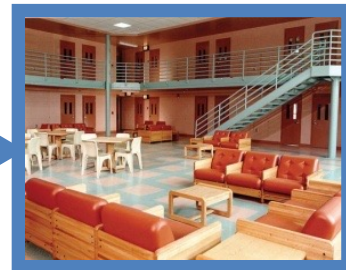
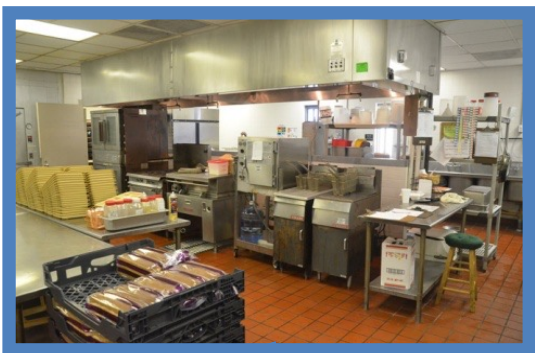


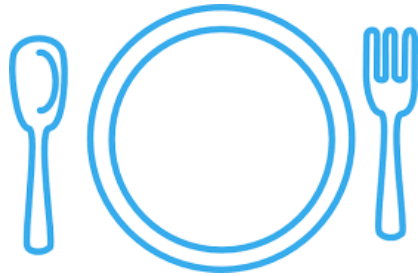


Cafeteria, Commissary & Cooking



www.amysmoyer.com





Place

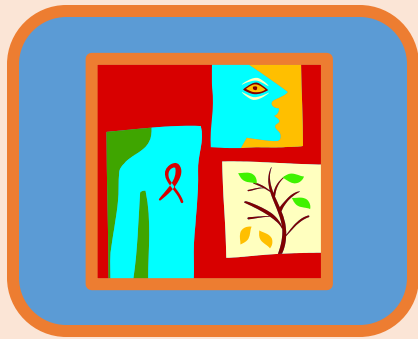


Identity



Relationships



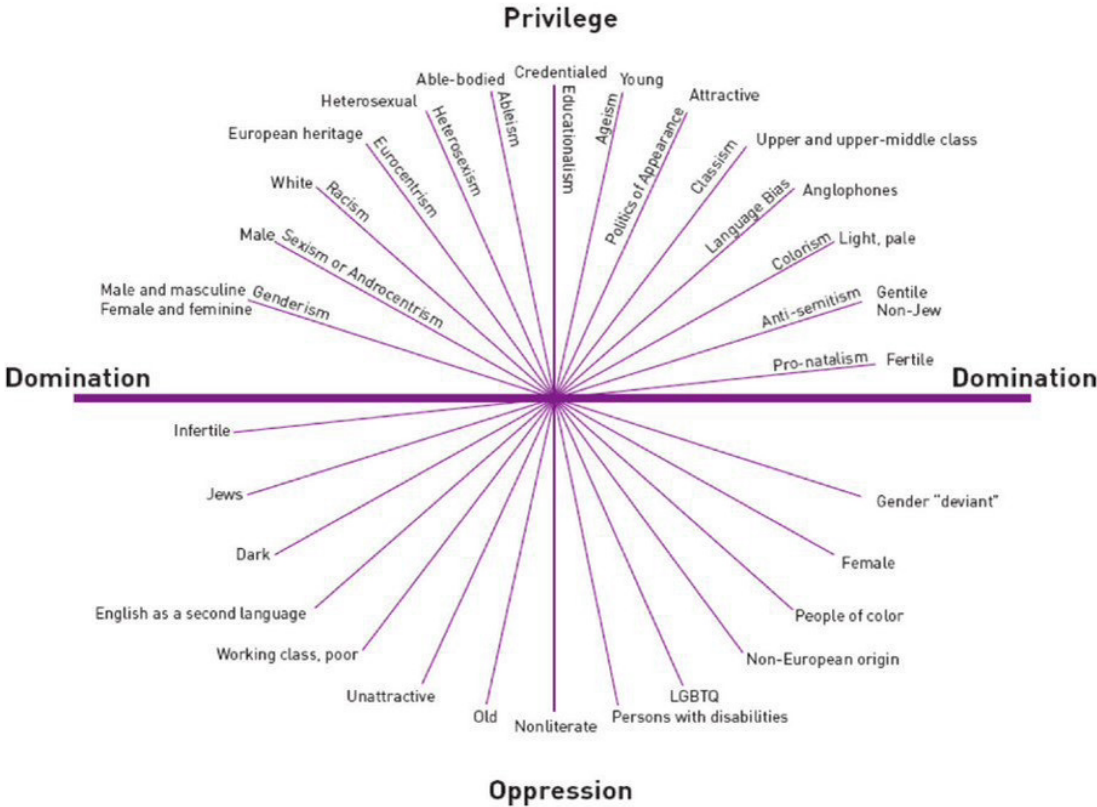


The Prison Nourish Project



Smoyer, A. B., *Ferris, S., & Earnshaw, V. (2022). Incarcerated people living with HIV: A qualitative exploration of stigma. *Health & Social Work, 47(4), 274-283.*

Intersectionality



Source: Morgan, K.P. Describing the emperor's new clothes: Three myths of educational (in)equity. In *The Gender Question in Education: Theory, Pedagogy, & Politics*. Westview Press, Boulder, CO, 1996, 105–122. Used in AWIS' intersectionality fact sheet at <https://www.awis.org/intersectionality/>

AWIS

Crenshaw, K. (1990). Mapping the margins: Intersectionality, identity politics, and violence against women of color. *Stanford Law Review*, 43, 1241.



Sexual Minority Women in Prison



AJPH TRANSGENDER HEALTH

Incarceration Rates and Traits of Sexual Minorities in the United States: National Inmate Survey, 2011–2012

Ilan H. Meyer, PhD, Andrew R. Flores, PhD, Lara Stemple, JD, Adam P. Romero, JD, Bianca D. M. Wilson, PhD, and Jody L. Herman, PhD



Data collected in 2011 from 55 formerly incarcerated women in New Haven as part of SHARRPP, a NIH/NIDA funded study (5R01DA025621-06). For more info: info@sharrpp.com

WOMEN @ RE-ENTRY NEW HAVEN

70% Have ever been homeless.

23% Were ever held in juvenile detention.

71% Have a child under age of 18.

60% Use city bus as primary form of transportation.

59% Report having been diagnosed with mental illness.

37% Have ever been married.

30% Identify as lesbian or bisexual.

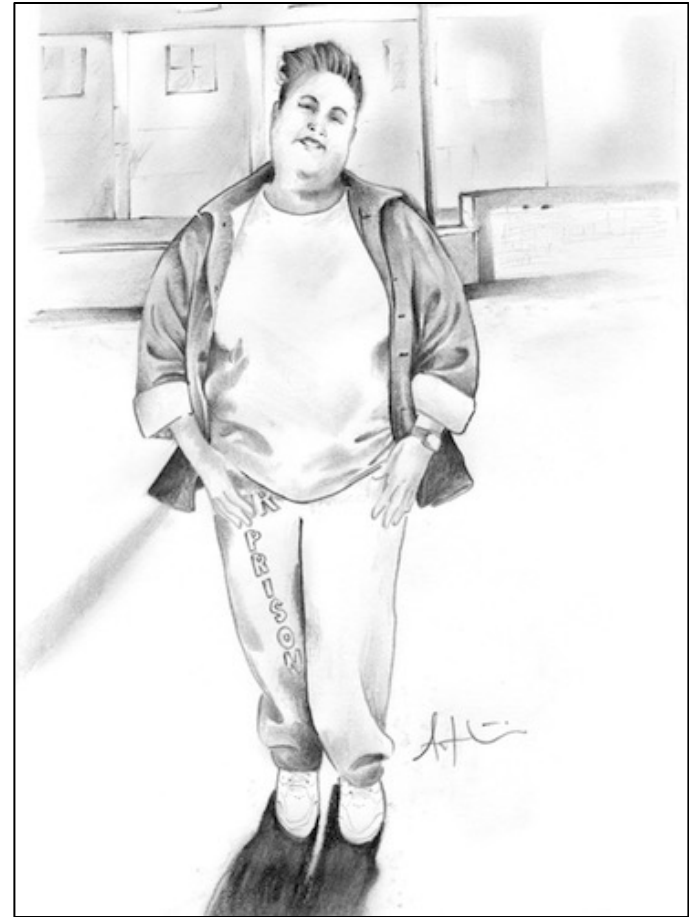
26% Have ever overdosed.

The New Haven Women's Resettlement Working Group is a group of formerly incarcerated people, community activists, academics, and service providers working together to support women during and after incarceration.

Join Us.
www.nhwrwg.blogspot.com

Smoyer, A. B., Divita, D., & *Perrault, A. (2021). Masculine embodiment among sexual minorities in a women's prison. *Australian Social Work* 74(2), 172-185.
<https://doi.org/10.1080/0312407X.2020.1850818>

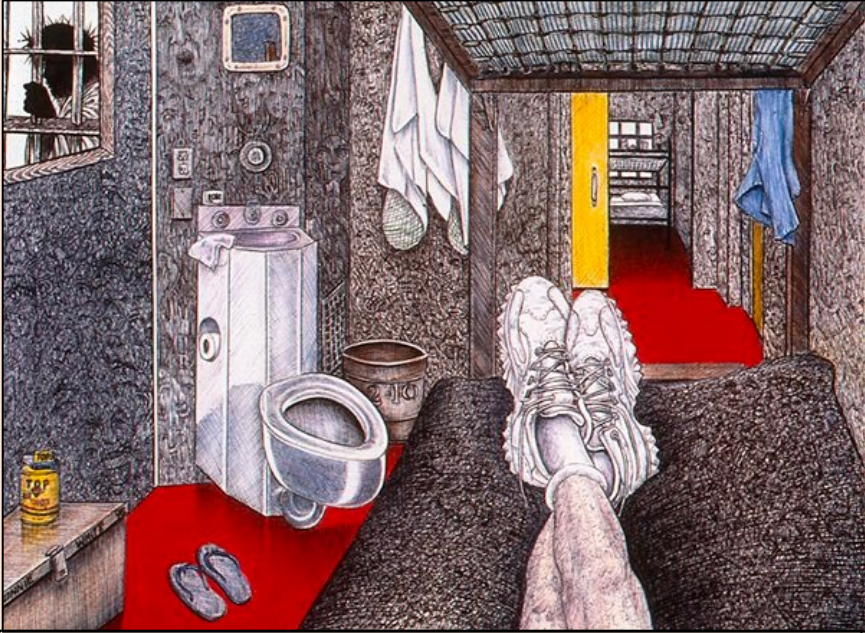
Smoyer, A. B. & Harvey, R. (*in press*). Desire on the inside: Incarcerated bisexual women, identity, and human connection. In R. Ryan-Flood & A. Tooth-Murphy (Eds.), *Queering desire: Lesbians, gender and subjectivity*. Routledge.



"Lady Jae" by Antwan Williams. Ear Hustle:
<https://www.earhustlesq.com/episodes/2018/6/6/do-wn-low>




Prison PLUS



Phyllis Kornfeld: <https://www.cellblockvisions.com/>



plus  **Prevention of Lower Urinary Tract Symptoms**
A Research Consortium of the National Institutes of Health

NIDDK Pilot grant under Award Number U01DK106786.

Privacy

Here you basically live in a toilet, let's keep it real. You live in a by cell with another person, your counter is there, your sink is there, your toilet is there, so you're living in a bathroom... You have no choice but to use the bathroom in front of someone else and psychologically, it affects you physically cause, until you kind of try to get used to it. As much as it's crazy to say that you have to get used to it, **sometimes it kind of hinders you from using the bathroom how you normally would.**
(Carol)

It's just my luck when I'm over there and I be trying to use the bathroom, I hear the door shut and I hear the keys. And the chair is like this close to me so I can grab the chair... And then they'll look in....Like you're trying to get a look or something? Like that's how I be feeling. **So I be having problems using the bathroom and stuff like that.**
(Denise)

Understanding Women's Lived Experience of Incarceration: Humiliation and Fear



From the *Coutumes de Toulouse* manuscript (1295-97). Courtesy of the [Bibliothèque Nationale](#), Paris/AKG

Humiliation: Food



- Eating from trash bags.
 - *You can throw a lot of soups in the [trash] bag. And you take hot water from the hot water pot, tie it in a knot. And let it sit 'til it swells up and you eat it. Sounds gross, I know, but that's just how they cook in bags in jail.*
 - *We would eat out of a garbage bag.*
- Keeping food cold in toilet.
 - *Get cold water and put it in the toilet and keep it cold like that. It's an experience you never want to have to go through.*
- Eating without utensils.

Humiliation: Toilet



- **Having to always ask:** Negotiating access to toilet.
 - Beginning in school, women reported being told when and where to pee, being forced to pee publicly, and being denied access to toilets.
 - Not believed when they said they had to urinate.
- **Limited access to toilet paper across settings:** prison, jail, halfway house, sober house, when homeless.
 - Intake, rec time, work, cafeteria
 - Women reported holding pee until need was urgent in order to conserve toilet paper.

Humiliation: Clothes and Gender

Toni: 26 yo, Black/African American, she/hers, gay, cisgender female

“I can’t wear my belt and my sneakers that I want to wear, or you gotta wear panties, you can’t wear boxers in a women’s jail...I was a turtle out of my shell.”

Fear: Food

Cafeteria: Watched & Rushed

They're [COs] like, "I I don't see you eatin'. You can't be eatin' if you're talking. Get up, let's go! You got 5 minutes!"

You've got like your 15 minutes to eat and 50 COs standing over you and telling you to hurry.

Lack of access to clean drinking water.

PP: The water here is awful. It smells like mold. Everything. Like soon as you get...well me, when I get to the water and I turn it on, right? I just get sick, I'm like, oh no, I can't do this. But the water over here, like if they give you ice, it tastes totally different. Like clean or something like, um, I don't know, but I just don't drink the water at all. I just stay away from it.

PP: Like the water be brown. Like the water be brown or dirty looking and they'd be like, oh no, it's the same water. And I'm like, uh, it's not like, are you in the cells with us? Do you come in there? Like do you know what it's like to be in there. It's not the same water at all.

Alternatives: Juice, Milk, Boiled Water

Fear: Toilet

- **Peeing on self when verbally assaulted by staff.**
- **Get ticket if removing clothes to use toilet when COs walk by cell.**
 - *A girl was getting up off the toilet, pulling her pants up and they gave her a Class A ticket and stuck her in Seg cause uh, the CO was offended.*
- **Unable to pee on demand for drug test = dirty urine**

Fear: Gender Expression

Belligerent and incessant gaze of correctional officers. Jealousy.

- *Drew: 35 yo, White/Puerto Rican, they/them, lesbian and straight, transgender man*
“We had a list of guards among us who, especially if you were on the more masculine side, you’d stay away from...You stick out like a sore thumb so...It gives them a target to, kinda, know that they’re gonna reach their goal of being able to enforce some kind of rule.”

Attention, wanted and unwanted from peers. Complicated.

- *Jaden: 20 yo, Multiracial/Asian/Caribbean/Hispanic, he/him, transgender man*
“I had people try to run into my room, asking...to get in the shower with me...They just had to remove me from the situation.”

Institutional Legitimacy

You are **so hungry** when you're first coming in [to prison]. Especially when you are coming off drugs and now you have been running on the streets for months or years and you haven't been eating . . .

I used to get hungry where I was shaking, I would almost feel like I was going to pass out. But they don't care.

No bread . . . but they'd give you cake, cake . . . You get it almost every morning for breakfast, a piece of cake with your oatmeal, a piece of cake with your freno, a piece of cake with your eggs, a piece of cake with everything. But, you can't have bread. **I just can't understand the logic behind the menu.**



HIV Care & Prevention Starts with Me

HEAR ME, SEE ME, AND UNDERSTAND ME:
FINDING OUR PURPOSE



LOS ANGELES LGBT CENTER

1 in 4 people in the U.S. living with HIV is a woman.

Get tested today and ask your doctor about PrEP.



lgbtcenter.org/audrelorde

Protect Your
#BlackGirlMagic

Get Tested. Get in Care.

HIV rates for Black women are among the highest in the nation. On National Women and Girls HIV/AIDS Awareness Day, explore your treatment and prevention options. And don't forget to ask about PrEP. Protect your shine.

#NWGHAAD | March 10



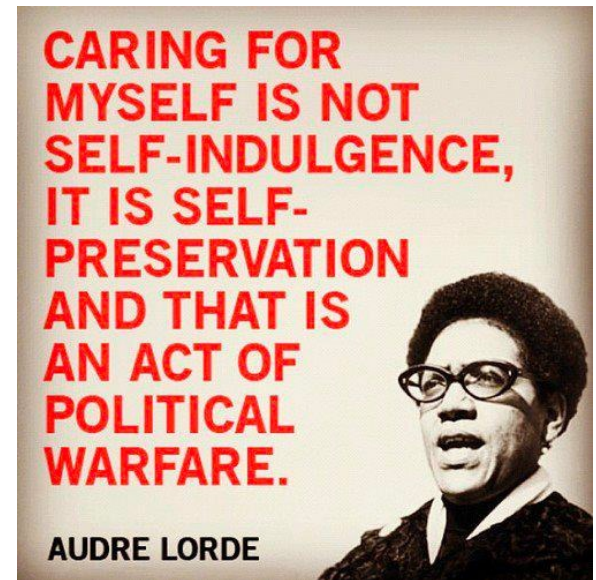
How can we harness the power of micro-activities?



Positive: Relationships with Self

FOOD

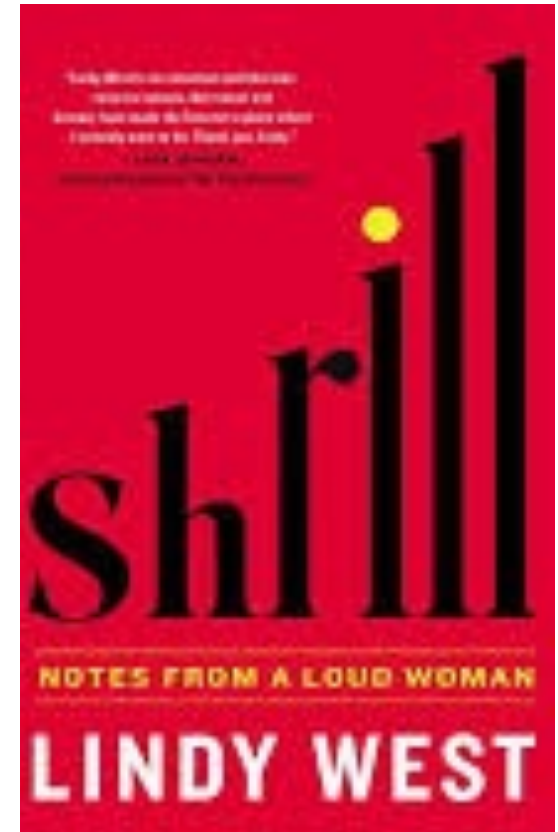
“I notice a lot of girls say when they get out they want to have McDonald’s ... but for me, I was concerned with eating the right thing. And I don’t know if it’s because I, it [prison] is a life-changing experience, and for me it was and I did the best I could there, and I want to change, and I want to, I’m starting to learn to love myself because that was what, what brought me there, was that I had no respect or love for myself. And now I do and I want to be healthy and I want to eat healthy.”



Smoyer, A.B. (2014). Good & Healthy: Foodways and construction of identity in a women’s prison. *The Howard Journal of Criminal Justice*, 53 (5), 525-541. doi: 10.1111/hojo.12097.

Body Acceptance & Wellness

The truth is, my discomfort with my period didn't have anything to do with the thing itself – it was just part of the lifelong, pervasive alienation from my body that every woman absorbs to some extent. Your body is never yours. Your body is your enemy. Your body is gross. Your body is wrong. Your body is broken. Your body isn't what men like... Yeah, well, my name is Lindy West and I'm fat and I bleed out of my hole sometimes. My body is mine now.



Positive: Peer Relationships

TOILET

She would not use the bathroom until I was sitting in a corner or facing a corner and I told her, “*Listen, you got like 20 years. You're going to have to get used to it.*” You know what I mean? I don't know what to tell you. You at least get used to having somebody sitting in a chair that's literally less than three feet, three steps away from you. Cause that's what you're going to get. (Laura)

Smoyer, A. B., *Schwarz, P., Camenga, D., & Rickey, L. (*in press, June 2023*). Negotiating toilet access: A qualitative exploration of women's incarceration. *The Prison Journal*.

Positive: Peer Relationships

FOOD

“You might see somebody you know and get to communicate, shoot the shit, as they say. Make you feel a little, at home. Or just, someone that you know very well that you can sit and laugh and eat with. Or, when I was there, we had a group that would eat together every day...We sat together and that was our little communication, get together time, because we were all on different tiers...people from Hartford, New Haven...just started talking and a lot of us were doing the same thing at the time before we got busted. Before we got arrested and incarcerated. We were running, getting high. And making a dollar the best way we can to get our drugs. And we just clicked.”

Smoyer, A.B. (2014). Feeding relationships: Food and social networks in a women's prison. *Affilia: Journal of Women and Social Work*. doi: 10.1177/0886109914537490

Positive: Relationships with Staff

FOOD

- Participants reported that COs would purposely leave food behind after eating, allowing the inmates to consume their scraps:
 - Say I'm eating right here and I'm a CO. I'd put it like right there and just walk away. Like, you know, I didn't give it to you. That's what a lot of them did."
 - They [COs] used to give me some...They'd be just like, here [First Name], you want this? And it's like, Yeah, real food, yeah!"

TOILET

Discussion about toilet paper: TP given out by institution is hard and balls up. Higher quality TP can be bought on commissary, but expensive.

PT 106: Now lately they've been given out good stuff. It's not really as hard as they used to be...the tissue.

PT 101: A lot of things have changed since we got this new warden. Um, she's changed a lot. She's changed a lot of the rules when it comes to staff members doing their tours also.

Women, Prison, HIV

While evidence-based interventions are used to provide trauma informed, gender sensitive programming for incarcerated women, women's daily interactions, behaviors, and habits may not align with this programming.

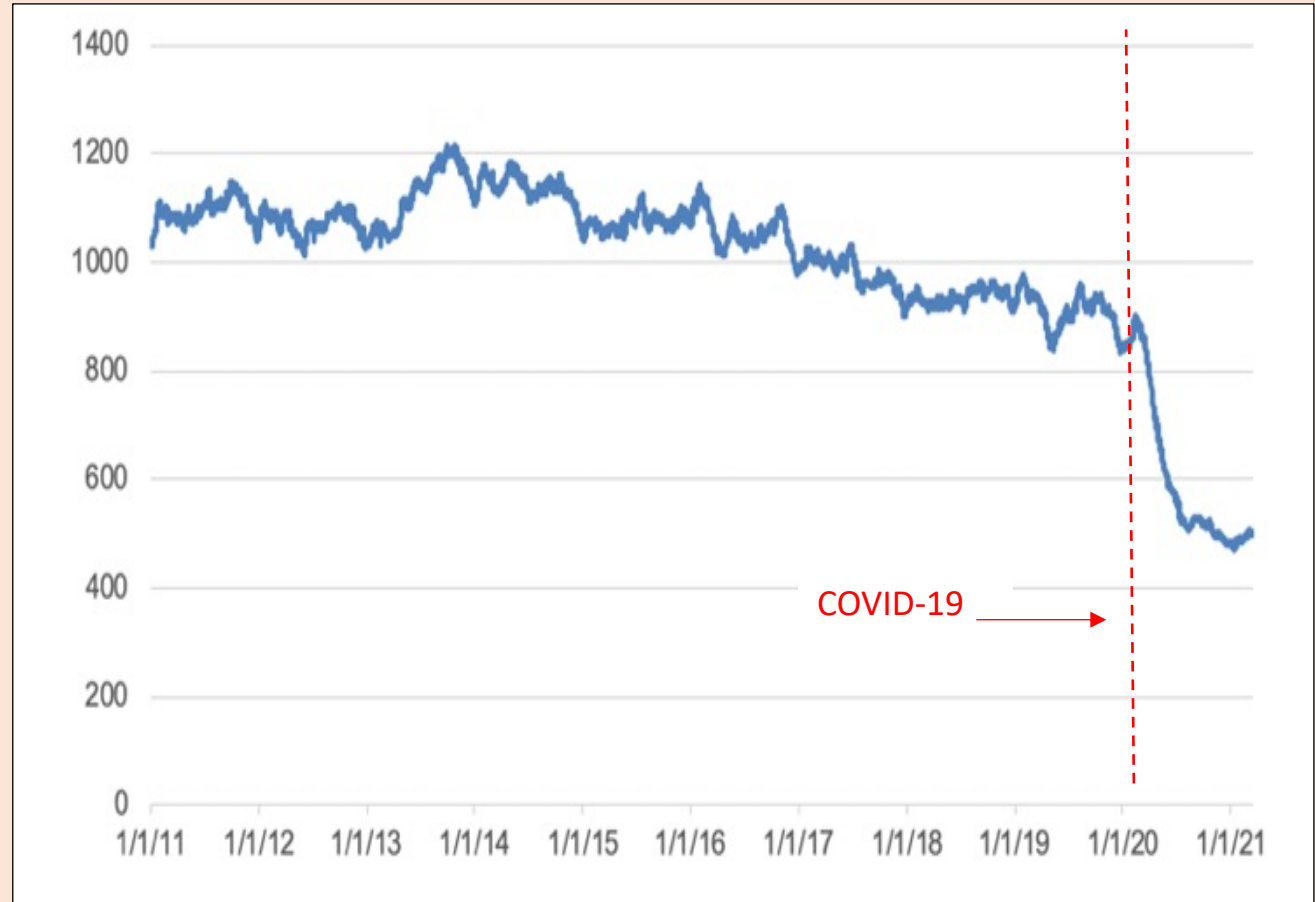
Institutional commitment to gender-responsive trauma-informed care must consider food & toilet, clothing & work assignments, interpersonal communication.

Outcomes related to HIV care and prevention improve when women are encouraged to notice what they are feeling and authority figures validate and respond to these reports.

Encourage women to listen to and trust their own bodies:

- EAT when you are hungry.
- PEE when your bladder feels full.
- TRUST sexual orientation and gender identity.
- BELIEVE women.





Incarcerated women in CT, 2011-2021

Group Discussion + Q&A



Thank you!



More information?

- smoyera1@southernct.edu
- www.amysmoyer.com
- www.theshawnproject.com

