Structural Stigma in Public Health: From HIV to Monkeypox

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Learning Goals

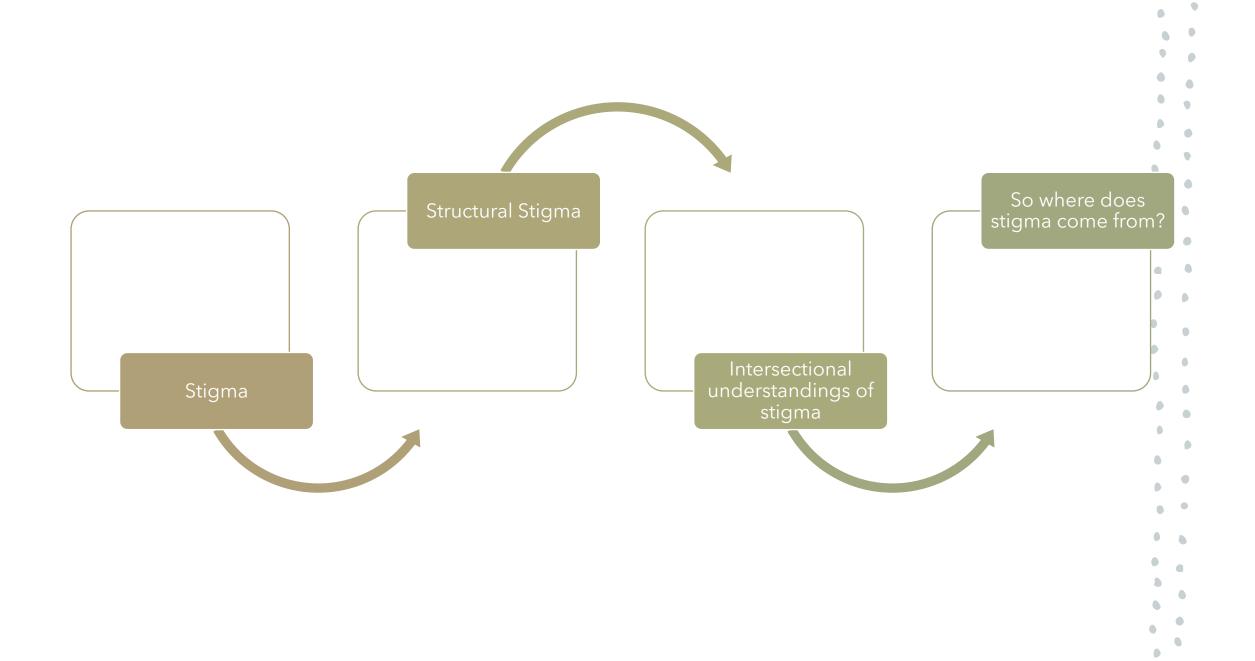
- 1. Understand stigma as social and institutional practice
- 2. Develop an intersectional and structural understanding of stigma
- 3. Consider how stigma is mitigated or perpetuated in public health and clinical responses to the monkeypox outbreak

Disclosures/Conflict of Interest

- None to declare
- An insider/outsider perspective



Understanding Stigma



Remember dictionaries?

stig•n /ˈstigmə/	na	
: stigma; plu	ral noun: stig	gmas; plural noun: stigmata
		ated with a particular circumstance, quality, or person. e to prison will always be with me"
Similar: si	hame dis	sgrace dishonor stain taint blot 🗸
		ks corresponding to those left on Jesus' body by the Crucifixion, said to divine favor on the bodies of St. Francis of Assisi and others.
MEDICINE a visible sigr	n or character	istic of a disease.
 a mark or 	spot on the sk	kin.
BOTANY (in a flower)	the part of a p	pistil that receives the pollen during pollination.
n		
REEK	LATIN	
igma rk made pointed iment, a		
dot		late 16th century
	ENGLISH	ate four contary
	stick —	
	/'stigmə/ stigma; plu a mark of dis "the stigma of Similar: s (in Christian have been in MEDICINE a visible sign • a mark or BOTANY (in a flower) N REEK gma k made pointed ment, a	stigma; plural noun: stig a mark of disgrace associ "the stigma of having gond Similar: shame dis (in Christian tradition) mar have been impressed by of MEDICINE a visible sign or character • a mark or spot on the sk BOTANY (in a flower) the part of a p n REEK LATIN gma k made pointed ment, a dot ENGLISH

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Stigma: Ingroups and Outgroups

- Othering
- Ingroups ('normal')
- Outgroups ('deviant')

Is stigma just discrimination?





Structural stigma – exclusion prom social & economic life

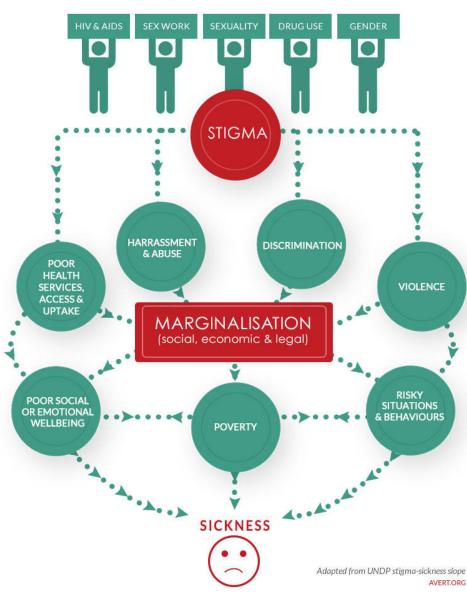
"In health care, structural stigma occurs when laws, policies, and practices result in the unfair treatment of people with lived experience."

" Societal-level conditions, cultural norms, and institutional policies that constrain the opportunities, resources, and wellbeing of the stigmatized."

https://mentalhealthcommission.ca/structural-stigma/ Hatzenbuehler ML, Link BG. Soc Sci Med. 2014 (103):1-6

HOW STIGMA LEADS TO SICKNESS

Many of the people most vulnerable to HIV face stigma, prejudice and discrimination in their daily lives. This pushes them to the margins of society, where poverty and fear make accessing healthcare and HIV services difficult.



Stigma has real health effects

- Access to care
- Treatment in healthcare spaces
- Adherence
- Disclosure
- Intimate partner violence
- Mental Health
- Substance Use
- Housing/employment/Food security

Stigma & Intersectionality: A layered understanding

Understanding intersectionality

Multiple social categories (e.g. race, ethnicity, gender, sexual orientation, socioeconomic status) intersect at the micro-level of individual experience to reflect multiple interlocking systems of privilege and oppression at the macro, social-structural level (e.g., racism, sexism, heterosexism).



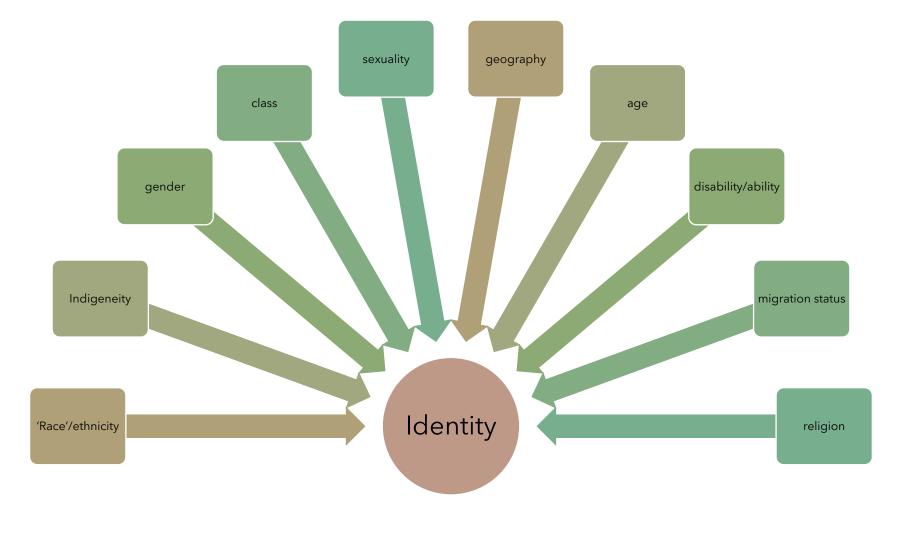
Kimberlé Crenshaw



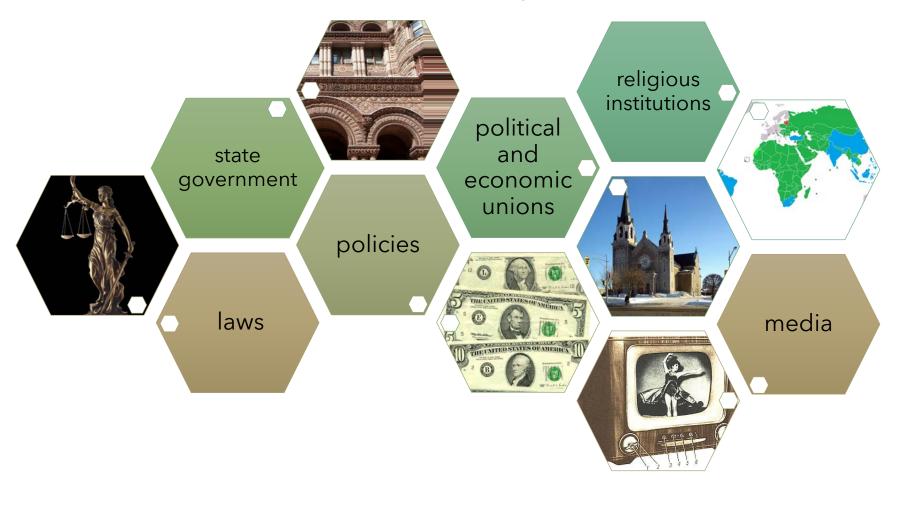
Patricia Hill Collins

Bowleg L. American Journal of Public Health 2012;102(7):1267-73; Hankivsky, O. (2014) Institute for Intersectionality Research & Policy, SFU.

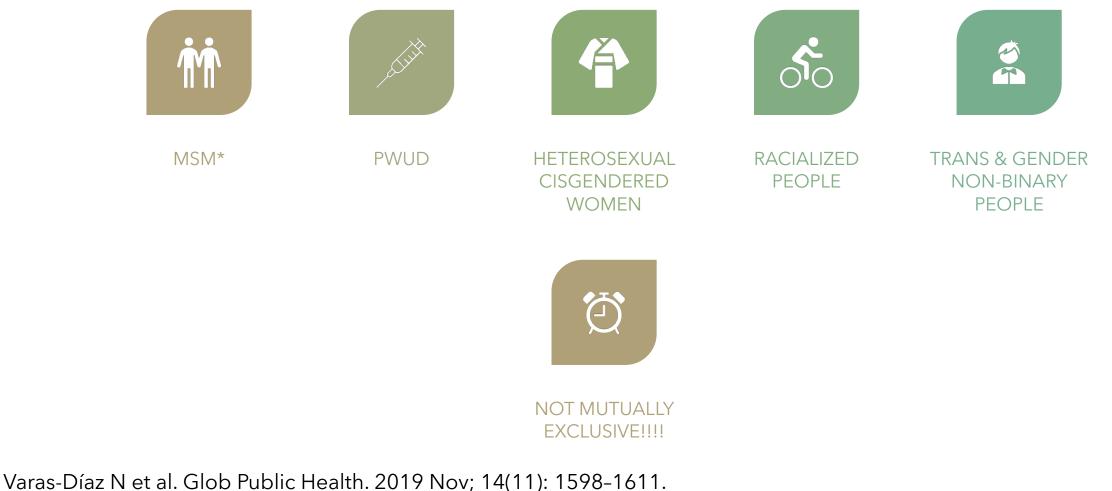
Social Locations



Systems & Structures of Power



Intersectionality is essential to understanding how stigma is experienced



Aggleton & Parker. (Am J Public Health. 2015;105:1552–1558.

Stigma & Intersectionality

RESEARCH ARTICLE

Open Access

Stigma and intersectionality: a systematic review of systematic reviews across HIV/ AIDS, mental illness, and physical disability

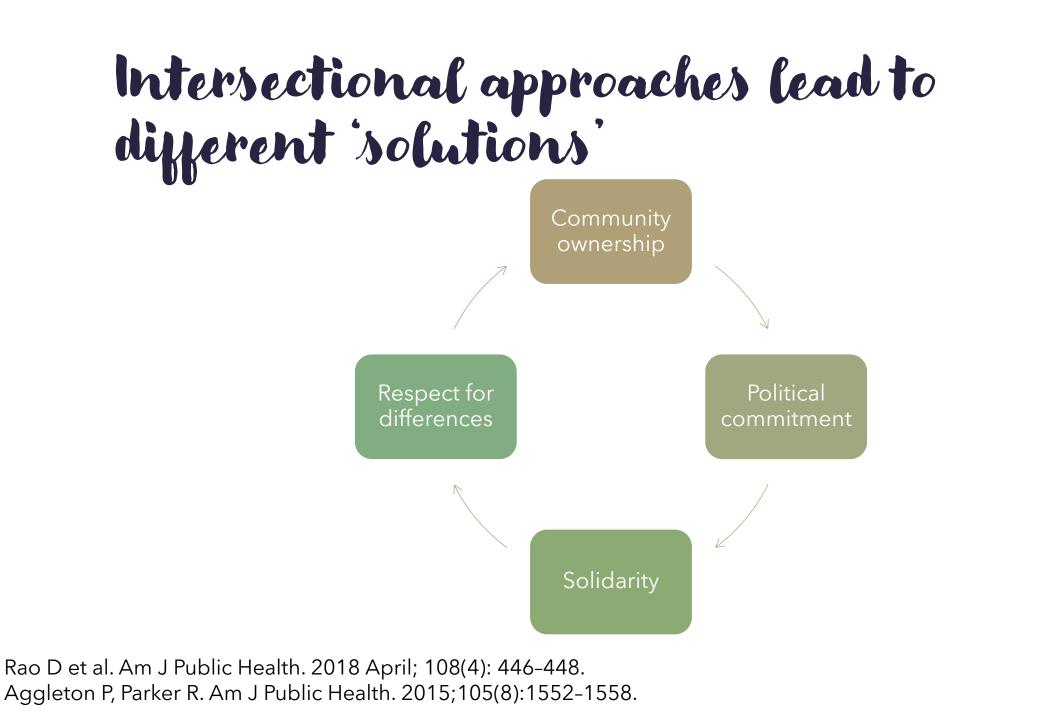
Fatimah Jackson-Best^{1*} and Nancy Edwards²

HIV/AIDS and intersectional stigmas: Examining stigma related behaviours among medical students during service delivery

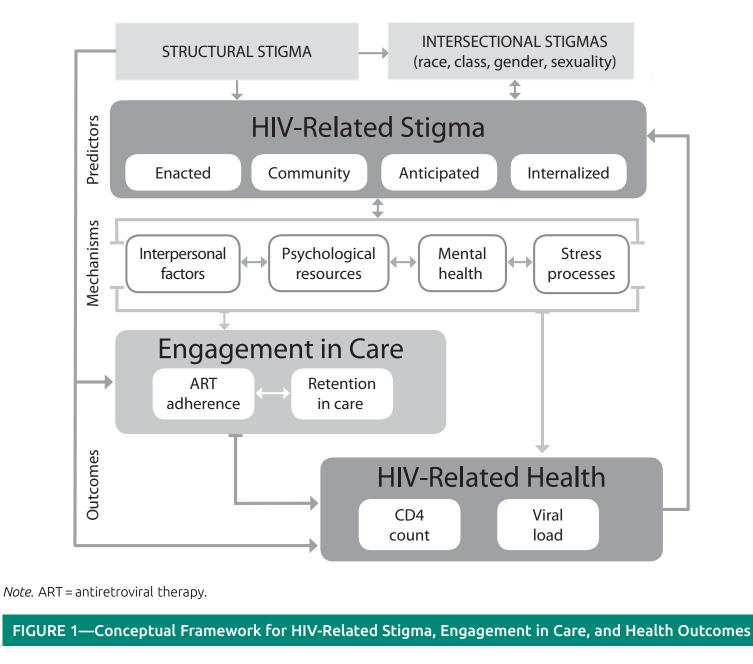
Nelson Varas-Díaz, Eliut Rivera-Segarra, Torsten B. Neilands, Yasmín Pedrogo, Paola Carminelli-Corretjer, Nelmit Tollinchi, Estefanía Torres, Yanira Soto Del Valle, Marinilda Rivera Díaz & Nerian Ortiz HIV Stigma Among Black Women in the United States: Intersectionality, Support, Resilience

Moving Beyond Biomedicalization in the HIV Response: Implications for Community Involvement and Community Leadership Among Men Who Have Sex with Men and Transgender People

Peter Aggleton, PhD, and Richard Parker, PhD



Making the connections



Turan B et al. Am J Public Health. 2017 Jun;107(6):863-869.

What if the call is coming from inside the house?

Healthcare providers, institutions, & stigma

Healthcare providers and Stigma

It starts with how we're trained...

The students showed a high-but declining-degree of willingness to care for patients infected with HIV or at high risk of infection. Homophobic attitudes decreased, but so did the students' intentions to follow infection-control guidelines. The students who expressed a career interest in surgery specialties indicated less willingness to provide care for HIV-infected patients, presumably because these students felt that they would be at a higher risk of exposure. Conclusion. Overall, the students' responses indicated that over the two years of the study they became more restrictive in their attitudes toward HIV-positive patients, felt less personal obligation toward caring for these patients, and were less likely to use appropriate infection-control methods to ensure their own safety. Acad. Med. 68(1993): 377 - 379.

Do Words Matter? Stigmatizing Language and the Transmission of Bias in the Medical Record

Anna P. Goddu, MSc¹, Katie J. O'Conor, BA¹, Sophie Lanzkron, MD, MHS², Mustapha O. Saheed, MD³, Somnath Saha, MD, MPH^{4,5}, Monica E. Peek, MD, MPH, MSc⁶, Carlton Haywood, Jr., PhD, MA², and Mary Catherine Beach, MD, MPH¹

¹Johns Hopkins University School of Medicine, Baltimore, MD, USA; ²Division of Hematology, Johns Hopkins University School of Medicine, Baltimore, MD, USA; ³Department of Emergency Medicine, Johns Hopkins University School of Medicine, Baltimore, MD, USA; ⁴Section of General Internal Medicine, VA Portland Health Care System, Portland, OR, USA; ⁵Division of General Internal Medicine and Geriatrics, Oregon Health and Science University, Portland, OR, USA; ⁶Section of General Internal Medicine, The University of Chicago, IL, USA.
 Table 1 Text Employed in the Vignettes

note	Neutral language chart note	Stigmatizing language chart note
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Section 1

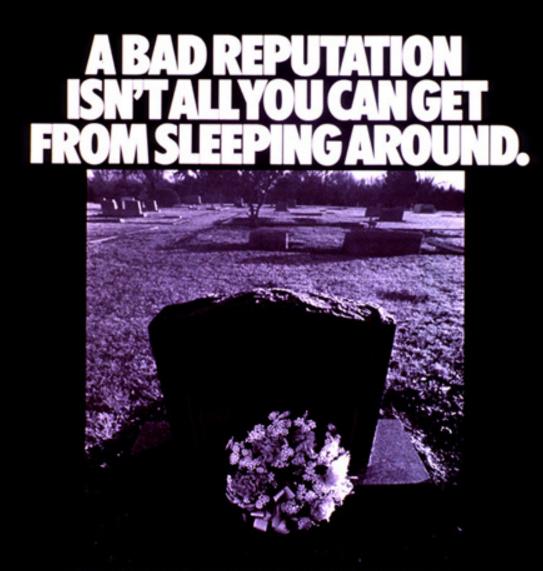
Mr. R is a 28-year old man with sickle cell disease and chronic left hip osteomyelitis who comes to the ED with 10/10 pain in his arms and legs. He has about 8–10 pain crises per year, for which he typically requires opioid pain medication in the ED. At home. he takes 100 mg OxyContin BID and oxycodone 5 mg for breakthrough pain. Over the past few days, he has taken 2 tabs every 4-6 hours. About 3 months ago, he moved to a new apartment and now has to wheel himself in a manual wheelchair up 3 blocks from the bus stop.

He spent yesterday afternoon with friends and wheeled himself around more than usual, which caused dehydration due to the heat. He believes that this, along with recent stress, precipitated his current crisis. The pain is aching in quality, severe (10/10), and not alleviated by his home pain medication regimen.

On physical exam, he is in obvious distress. He has no fever and his pulse ox is 96% on RA. The rest of the physical exam is normal other than tenderness to palpation on the left hip. Mr. R is a 28-year old sickle cell patient with chronic left hip osteomyelitis who comes to the ED stating he has 10/10 pain "all up in my arms and legs." He is narcotic dependent and in our ED frequently. At home he reportedly takes 100 mg OxyContin BID and oxycodone 5 mg for breakthrough pain. Over the past few days, he says that he has taken 2 tabs every 4–6 hours. About 3 months ago, patient states that the housing authority moved him to a new neighborhood and he now has to wheel himself in a manual wheelchair up 3 blocks from the bus stop.

Yesterday afternoon, he was hanging out with friends outside McDonald's where he wheeled himself around more than usual and got dehydrated due to the heat. He believes that this, along with some "stressful situations," has precipitated his current crisis. Pain is aching in quality, severe (10/10), and has not been helped by any of the narcotic medications he says he has already taken.

On physical exam, he appears to be in distress. He has no fever and his pulse ox is 96% on RA. The rest of the physical exam is normal although he reports tenderness to palpation on the left hip.



Public Health Stigma & Moral Judgment

Think about it, When you skeep with someone, you're sleeping with everyone he And if someone along the line had the AIDS virus, you would have been exposed.

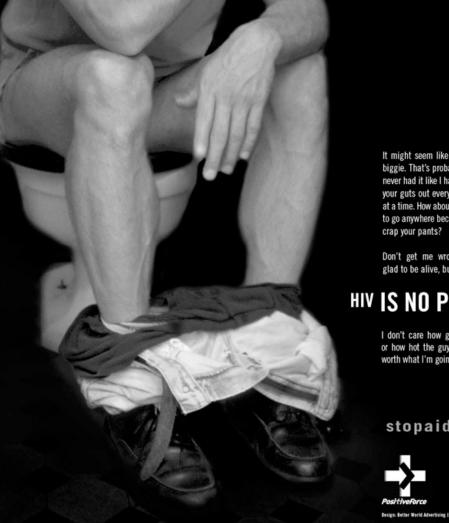
Unfortunately, there is no known cure for AIDS. Everyone who gets it dies, But AIDS can be presented. By saying The point is, if you're going to have sex,

no to sex. And by saying no to needle drugs. you should do it responsibly. Don't let it embarrass you to death. Get Don't fool around with your life. Find out or she has dept with for the past eight years. all the facts about AIDS, and talk about them more about how AIDS is transmitted, and with your girlfriend or boyfriend. Then if how you can protect yourself. Call the Dalas true choose to have sex, stick to one partner. County Health Department, (240.353-4335, And use a condom, properly, every time. It's one of the best defenses against AIDS.

All calls are strictly confidential.



DIARRHEA



Public Health Stigma & Fear

It might seem like diarrhea is no biggie. That's probably 'cause you never had it like I have. Try shitting your guts out every day for weeks at a time. How about being terrified to go anywhere because you might

Don't get me wrong, I'm really glad to be alive, but

HIV IS NO PICNIC

I don't care how good the sex is or how hot the guy is, nothing is worth what I'm going through now.

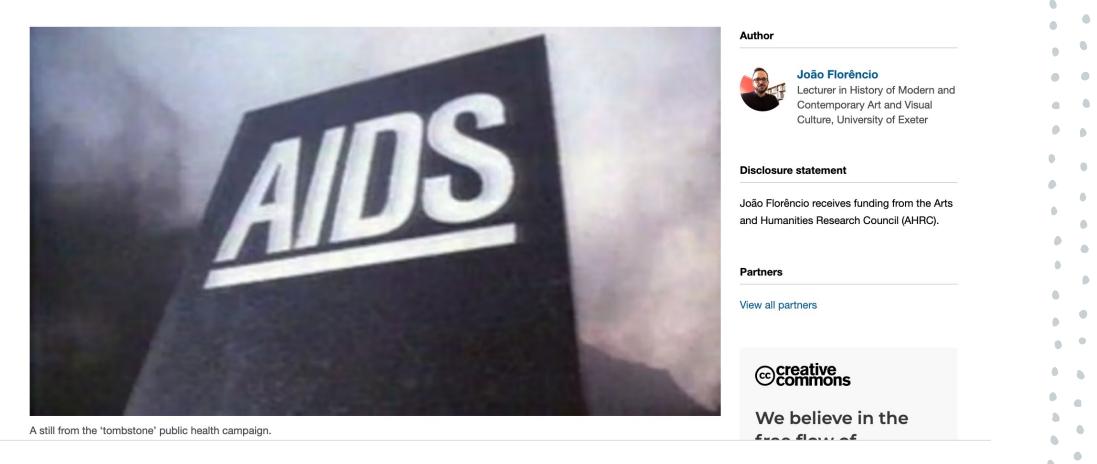
stopaids.org



Fairchild AL et al. (Am J Public Health. 2018;108:1180–1186.

AIDS: homophobic and moralistic images of 1980s still haunt our view of HIV – that must change

Published: November 27, 2018 9.30am EST



https://theconversation.com/aids-homophobic-and-moralistic-images-of-1980s-still-haunt-our-view-of-hiv-that-must-change-106580



Reflecting on ourselves is an important starting point...

- Our own social locations
- Our own beliefs & biases
- Our own privilege
 - What do I never have to think about?
 - What do I take for granted?
 - "That never occurred to me"
- What are the locations/beliefs/biases/privileges of those at decision-making tables?



But reflecting on the nature of our institutions is key

• What are the

locations/beliefs/biases/privileges of those at decision-making tables?

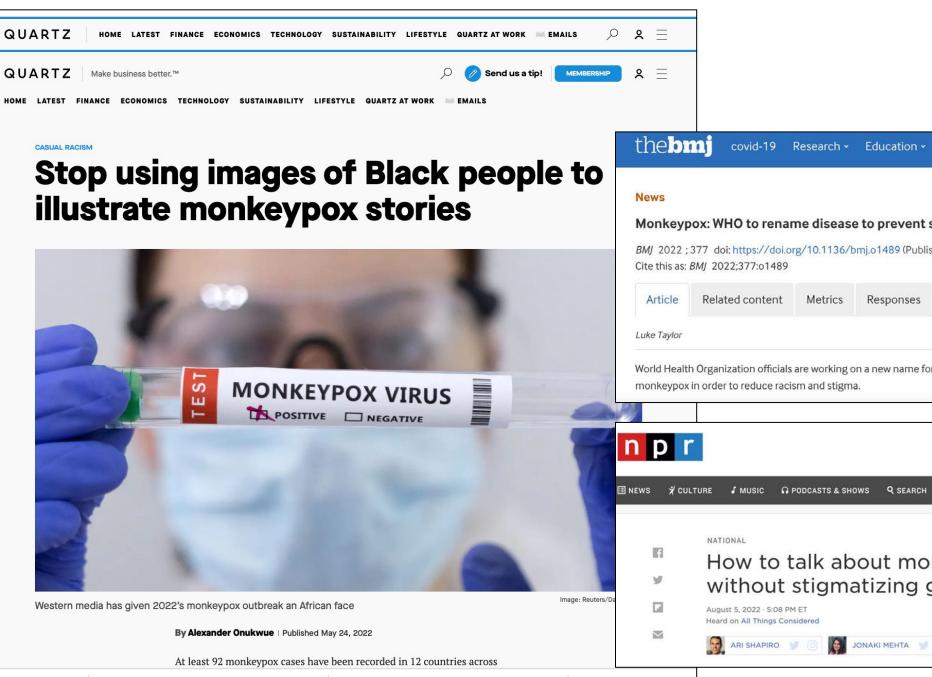
- Whose voices are missing?
- Where do we get our information?
 Who is considered the expert?
- To whom are we accountable?

Moving to Monkeypox

Monkeypox & Stigma

 Most discussions of monkeypox & stigma have centered on interpersonal or social stigma

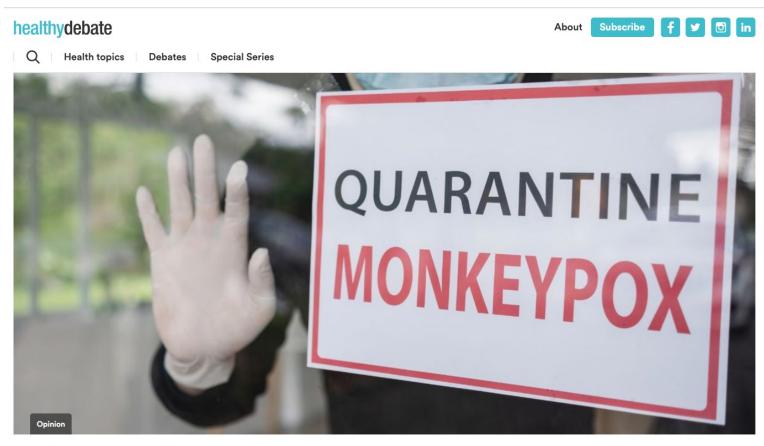
- RACE
- GENDER
- SEXUAL ORIENTATION



Research - Education - News & Views - Campaigns -Jobs ~ Monkeypox: WHO to rename disease to prevent stigma BMJ 2022 ; 377 doi: https://doi.org/10.1136/bmj.o1489 (Published 16 June 2022) World Health Organization officials are working on a new name for the virus and disease commonly known as **SIGN IN** NPR SHOP DONATE How to talk about monkeypox effectively, without stigmatizing gay men 100 CHRISTOPHER INTAGLIATA

Monkeypox & Structural stigma

Structural stigma poses major threats to the health, safety, and well-being of many people affected by monkeypox



Aug 24, 2022 by Malika Sharma, Nanky Rai

Pandemics as portals: What monkeypox teaches us about medical apartheid and resistance



Infectious disease outbreaks can tell us a lot about ourselves.

Monkeypox has been declared a global emergency by the World Health Organization. Spread through close contact that can include but is not limited to sexual activity, labelling monkeypox a sexually transmitted infection has been politically charged - not only for scientific reasons, but also because of the potential political and legal ramifications for 2SLGBTQIA+ people who are actively being targeted and vilified by some right-wing politicians.

There is justifiable concern that focusing attention on queer communities will further entrench stigma and subject them to harm. But it is essential to look upstream at the factors and conditions that make such scenarios possible. How does the scapegoating of 2SLGBTQIA+ communities connect to contemporary neoliberal agendas? How is science and public health communication subverted to fit these agendas? And most importantly, how can communities simultaneously respond to a

AUTHORS



Malika Sharma Contributor

Malika Sharma is a feminist writer, educator, and an infectious disease and HIV physician in Toronto.

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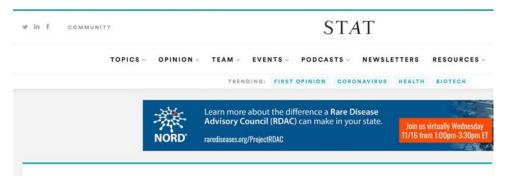


Nanky Rai Contributor

Challenges for Public Health

- How to talk about sexual transmission without putting LGBTQ2SIIA people at risk of discrimination, harassment, or violence?
- What are the legal and political ramifications for how this disease is classified?
- How is public health connected to the broader climate of injustice?
- How to target resources and interventions to affected communities without condemning, vilifying, or scapegoating?
- How to address our own bordered understandings of infection?

Public Health – which public?

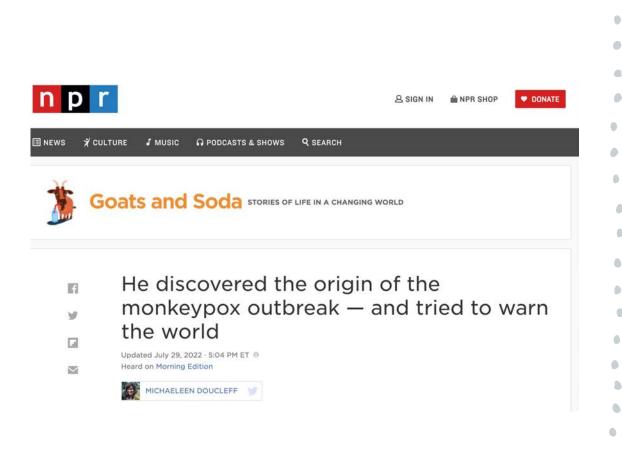


HEALTH

Warning signs ahead of monkeypox outbreak went unheeded, experts say



Reprints



What we say, matters

1983

National AIDS Hotline: HIV and AIDS Information Service Through a Toll-Free Telephone System

ROBERT R. WALLER, DDS, MPH LYNN W. LISELLA, MS

The authors are with the National AIDS Information and Education Program (NAIEP), Office of the Deputy Director (HIV), Centers for Disease Control (CDC). Dr. Waller is the Project Officer for the National AIDS Hotline. Ms. Lisella is the Chief of Communications Services and Assistance. Tearsheet requests to Dr. Waller, Centers for Disease Control,

NAIEP, Mailstop E-25, 1600 Clifton Road, Atlanta, GA 30333.

Synopsis

The National AIDS Hotline (NAH), a service of

hotline service. NAH has received an average of more than 1.4 million calls per year since October 1987. Services of NAH include responding to the public's questions about HIV and AIDS and providing referrals to State and local resources. All services, including HIV and AIDS publications, are provided free of charge.

The public contacts NAH 24 hours a day, 7 days a week, through a toll-free telephone system. Services are available to English-speaking, Spanishspeaking, and deaf populations. Each service has its own telephone number—English-speaking, 1-800-342-2437; Spanish-speaking, 1-800-344-7432; TTY service for the deaf, 1-800-243-7889.

NAH employs approximately 170 information specialists to answer calls. The facility uses modern telecommunications technology to effectively manage and direct calls to 43 work stations. Each work station is supported by a personal computer that

- CDC establishes the National AIDS Hotline to respond to public inquiries about the disease.
- January 7: Report of AIDS in female sexual partners of males with AIDS.
 » Link to report of AIDS in female sexual partners of males with AIDS

O March 4: CDC announces most cases of AIDS have been among homosexual men, injection drug users, Haitians, and people with hemophilia.

» MMWR suggests that AIDS may be caused by an infectious agent that is transmitted sexually or through exposure to blood or blood products and issues recommendations for preventing transmission. Link to report of most cases of AIDS have been among homosexual men, injection drug users, Haitians, and people with hemophilia





Today, the World Health Organization declared monkeypox a health emergency and emphasized the focus on men who have sex with men. Given the climate in the US, this will lead to a dark place with rampant homophobia resulting from this. We have learned nothing from HIV/AIDS.

10:51 AM · Jul 23, 2022 · Twitter for Android

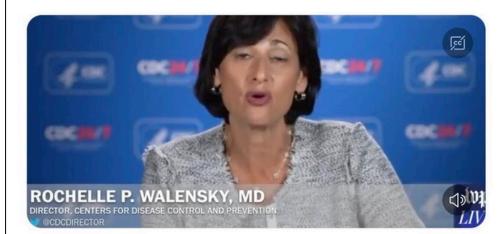


...



Rep. Marjorie Taylor Greene SepMTG

If Monkeypox is a sexually transmitted disease, why are kids getting it?



247K views

6:22 PM · 7/23/22 · Twitter for iPhone

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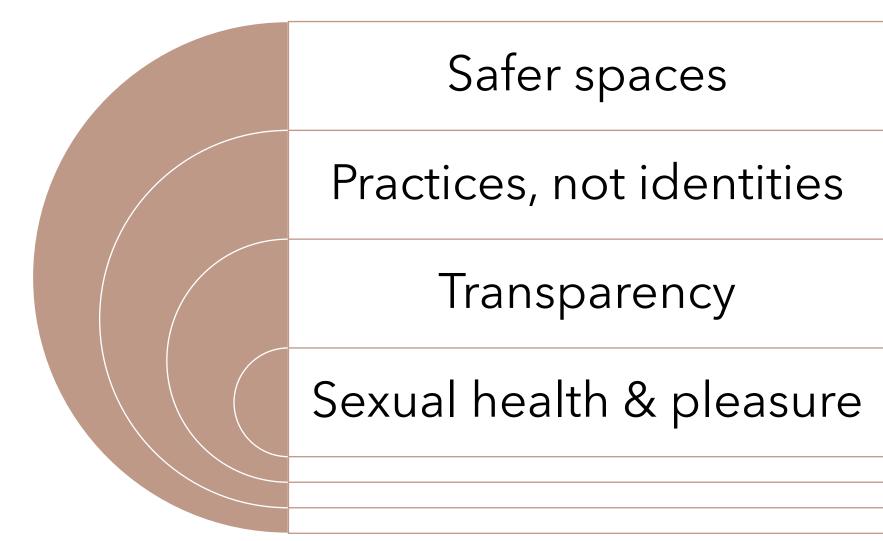
How can providers & practitioners address stigma?

First, a recognition

Of social and societal power

Of our words holding weight, historical legacy, and future ramifications

In the clinical space



CDC's Suggestions for Public Health

Describe

legitimate health issuerelevant to all people

Educate

- Modes of transmission with specificity
- Focus on action, not identity
- Clinical manifestations
- Infectivity

Frame

- Inclusive language ('us' and 'we')
- Non-sensationalistic language and images (positive, diverse, and credible)

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- Language that resonates with audience; concepts that the audience will be receptive to hearing or reading
- Emphasize prevention strategies, symptom recognition, and the treatable nature of monkeypox to minimize fear, promote action and a sense of personal agency

https://www.cdc.gov/poxvirus/monkeypox/resources/reducing-stigma.html adapting from Hood & Friedman, Sexual Health 2010 (7):1-12.

Prevent the SPREAD OF MONKEYPOX





spaces, when possible

Clean your hands often

Consider limiting close contacts, including sex partners



Clean & disinfect frequently touched surfaces often



care provider

Get vaccinated, if eligible



Monkeypox Vaccine Clinic

Hassle Free Clinic 66 Gerrard St East, 2nd floor Sunday, November 6 11 a.m. - 5 p.m.

Walk in only • No OHIP or ID needed Free 1st & 2nd doses for eligible people

2nd dose is a full dose exactly like the 1st

• You can get vaccinated even if you recently got a COVID-19 vaccine • Speak with a clinic nurse if you recently got another vaccine



TORONTO Public Health

toronto.ca/health

DI TORONTO Public Health

6 Ways we can have safer sex in the time of monkeypox

Stop going to places with lots of sexual activity

It might be time **temporarily** to hang up the group sex and saunas until we all get two shots of the vaccine. A soon as *fall 2022*, we hope to have enough vaccines for all who want it!

Slutty summer? Hold off for a monkeypox-free cider donut anal autumn!

Use sex "pods"

Similar to how to how people established pods to make socialization safer from COVID-19, try a sex pod! Pod members monitor for symptoms for a few days after last exposure and limit sexual partners to pod members.

Open & honest communication with sex partners

Before meeting up with a partner, discuss if you or they have had any other recent sex partners or had prolonged skin-to-skin contact with others. Discuss your health and whether you have any sores or other side effects.

Condom use

Although the hallmark monkeypox rash or pox can appear anywhere, they are commonly reported on the genitals and perianal area. Condom use won't fully protect against monkeypox, but it could help **reduce the risk of skin-to-skin contact** with any lesions in these areas (including internal lesions!)

More clothing

Monkeypox being mostly spread through skin-to-skin contact, anything you can do to reduce the amount of skin you have in contact with others makes riskier spaces—like bars or circuit parties—easier to manage!

T-shirt at a circuit party? Long sleeves at the Eagle? Break out the fetish gear! If Kim K can do it, you can too.

Take care of yourself and others

If you do test positive for monkeypox, or if you have flulike symptoms or a new rash, please stay home, get tested, and try to get TPOXX—a safe and likely effective antiviral treatment for monkeypox—if you can.

adapted from the Poz.com article "Six Ways We Can Have Safer Sex in the Time of Monkeypox" by Nicholas Diamond, Joe Osmundson and Grant Roth

FENWAY **EII** HEALTH

How does stigma relate to monkeypox?

Stigma is discrimination against an identifiable group of people, a place, or a nation. Stigma is associated with a lack of knowledge. Stigma hurts everyone by creating more fear or anger toward people instead of focusing on the disease that is causing the problem.

Stigma can

also make people more likely to:

- Hide symptoms or illness
- Keep them from seeking health care immediately
- Prevent individuals from adopting healthy behaviors.

In the current outbreak of monkeypox, gay and bisexual men and African immigrants may experience stigma. It is important that we educate communities about this public health concern without making stigma worse for groups that already experience discrimination and bias.

How can I

stigma?

- help increase knowledge and reduce
- Educate yourself on the facts and share them
- Correct negative language that can cause stigma by sharing accurate information about how the virus spreads

adapted f



Fast but thoughtful action

CANNOT

• sacrifice thoughtfulness for speed

MUST

 Recognize that what we put out there can be used against already stigmatized people and communities

Resource allocation

Focused on people and communities most affected WHILE anticipating and pre-empting stigma & scapegoating

> Must also ask - who is being rendered invisible, and potentially not getting the resources they need?

Think (and act) bigger

Focus is often on individual behaviour modification rather than systemic issues like:

- Robust vaccination policies
- Access to testing
- Access to preventive health care
- Access to structural supports to allow for safe isolation like adequate housing and workplace protections.
- HIV criminalization



In the United States, where organized abandonment has happened throughout the country... we see that as people have lost the ability to keep their individual selves, their households, and their communities together with adequate income, clean water, reasonable air, reliable shelter, and transportation and communication infrastructure... what's risen up in the crevices of this cracked foundation of security has been policing and prison."

– Ruth Wilson Gilmore

https://twitter.com/aboutfreedominc/status/1293281743940845568 https://www.democracynow.org/2020/5/5/ruth_wilson_gilmore_abolition_coronavirus

Listen to & partner with communities

People exist in community, and are often the first to recognize new threats to their health and wellbeing

Structurally oppressed communities often bear the burden of infectious complications of structural violence AND have led the way in creating solutions and practicing collective care models.



Aggleton & Parker. (Am J Public Health. 2015;105:1552-1558.

Recognize the tensions in this relationship

"Sometimes, administrators and bureaucrats were seen as pushing a line that rode rough-shod over **personal dignity, respect, and rights, all of which had been hard-won community values.** We need to have effective forms of prevention, treatment, and care, but those most affected by the epidemic should be involved, not as docile "partners" in program development and design, but as the leaders of what they know best: **how to work with and for heavily affected communities."**

Aggleton & Parker. (Am J Public Health. 2015;105:1552-1558.

Incredible examples of the people's public health

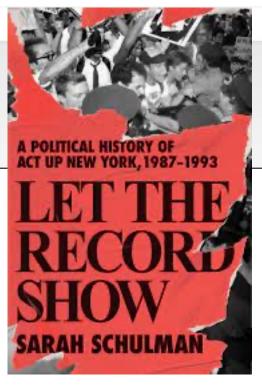


Sylvia Rivera (center) with other Street Transvestite Action Revolutionaries (S.T.A.R.). [From Coene Out (No. 7, p. 9)] Photographer Ellen Bedoz. Reprinted, by permission, from National History Archives of the Leshian, Gay, Bisexual & Transgender Community Center.

Zoë Dodd & Alexander McClelland

Taking Risks is A Path to Survival

Underground Naloxone Access The Crack Pipe Train VANDU Working with Drug Dealers Undermining State Surveillance Rule Breaking as Ethical



https://theanarchistlibrary.org/library/zoe-dodd-alexander-mcclelland-taking-risks-is-a-path-to-survival?v=1632271529 https://www.vice.com/en/article/z3enva/star-house-sylvia-rivera-marsha-p-johnson

Center in the Margins

- Shifting knowledge production to the concerns of the most marginalized, and privileging their voices in our discourses.
- Go beyond documenting inequities to analyze and take action against power differentials and privilege that create and perpetuate such inequities

Ford, C. L. and C. O. Airhihenbuwa. Soc Sci Med 2010;71 (8): 1390-1398.

So to summarize

- We have institutional & societal power
- We must use it wisely, recognizing the impact of our choices in priorities and language
- Our attempts to address stigma must be structural achieved through upstream interventions, community orientation & collaboration

Thank you!

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