

## ***Intervals - Episode 19***

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### ***Introduction***

CHRISTOPHER BRICK: Hello everyone, I'm Christopher Brick. Welcome back to the *Intervals* podcast and to episode 19 -- our penultimate lecture of season 1 on the history of public health. *Intervals* is a public humanities initiative of the Organization of American Historians - OAH for short - and I'm joining you all today on behalf of the OAH's Committee on Marketing and Communications.

It's my pleasure and the committee's real honor to have Dr. Dan Royles with us to deliver this week's guest lecture. Dan's currently an assistant professor at Florida International University and his most recent book, *To Make the Wounded Whole*, examines the history of HIV/AIDS in the United

States as it was processed, experienced, and confronted by Black Americans - the subject of his lecture for us today.

As such, and by shifting the frame of reference away from a focus on white experiences, the course of events and even their beginning and end can look very different from the story we've come to expect or the narrative we might think we know. Take for example the point at which this talk opens, in the Old North section of St. Louis, Missouri in 1969 rather than the white gay enclaves of Los Angeles, San Francisco, or New York City in 1981 - locations each for the first of several clusters of AIDS-related opportunistic illness that helped epidemiologists identify men-who-have-sex-with-men as an at-risk population early in the HIV pandemic's history.

When they paid attention, mass media and American popular culture did their part as well to construe HIV as a condition that mostly afflicted white gay men, other disfavored groups like IV drug users, as well as a handful of other patient categories - like hemophiliacs - who contracted the virus via blood transfusion in the time before the blood supply was routinely screened for viral contamination.

HIV/AIDS was at the same time devastating Black America, yet Black Americans themselves neither factored prominently into the Reagan administration's anemic response to the crisis, nor

did their experiences gain much in the way of attention from the press or commensurate visibility within American public discourse or popular culture.

In his introduction for *To Make the Wounded Whole*, Dan explains that his work arose from a desire to explore what else made the African American struggle against HIV/AIDS historically distinctive, and that he spent years researching some of the answers to that question. The monograph study he produced in response has been getting noticed on this year's prize circuit, recently getting shortlisted for the very prestigious Museum of African American History Stone Book Award amongst other accolades.

And here he is, Prof. Dan Royles on HIV/AIDS and Black America.

### ***Lecture***

Forty years ago, in June 1981, doctors in cities like Los Angeles, San Francisco, and New York began to report something strange. They were seeing young gay men suddenly get sick with unusual infections like *Pneumocystis pneumonia* and Kaposi's sarcoma, a rare form of skin cancer. By all accounts, these men shouldn't have had diseases like these, which are mostly seen in the elderly and people with compromised immune systems. But by the end of 1981, over 330 such cases had been reported, and over a third of those had died.

Those rare infections would soon become recognized as symptoms of a new disease: acquired immune deficiency syndrome, or AIDS. Within a few years researchers would identify human immunodeficiency virus, or HIV, as the virus that causes AIDS. In the human body, HIV uses CD4 cells to make copies of itself, destroying them in the process. CD4 cells play an important role in our immune function, so as the virus destroys more and more of them, a person with HIV will see their immune system get weaker and weaker. Eventually, their immune system won't work at all, and they might develop the types of rare opportunistic infections that doctors began to see in large numbers in 1981. Of course, HIV and AIDS don't only affect gay men. HIV can be transmitted through sexual contact, shared needles, from mother to child in the womb or through breast feeding, and through blood transfusions, although this last mode of transmission is exceptionally rare today. Since 1981, AIDS has led to the deaths of more than 700,000 people in the United States and over 36 million people around the world, and over 37 million more are believed to be living with HIV today.

Over the last decade or so, we've seen lots of new attention to the history of AIDS in the United States as part of what AIDS scholar Ted Kerr calls the AIDS Crisis Revisitation. Here the story of AIDS in the US is most often told through the viewpoint of white gay men, in plays and TV movies like *The Normal Heart*, or the documentary *How to Survive a Plague*. As that story goes, gay men— who again, are almost always portrayed as white— began to get sick with a mysterious new disease in the early 1980s. Many were abandoned by their families because they were gay, or because they had AIDS, or

both. They suffered gruesome, painful infections that withered their bodies to almost nothing, and some were neglected and mistreated by hospital staff who refused to enter their rooms. A countless number of them died scared and alone, not knowing why their health had suddenly given out. And all the while, people in power and American society at large just didn't seem to care.

Now, this is all true. We have lots of eyewitness accounts of the ways that people with AIDS were treated— or mistreated— in hospitals, and the federal government was criminally slow to act while the number of cases and deaths grew. A deadly, sexually transmitted disease that seemed to mostly be killing gay men just wasn't a priority for the conservative Reagan administration. We know this because when a reporter asked White House Deputy Press Secretary Larry Speakes about AIDS in 1982, Speakes laughed and joked about it. We also know from records at the Reagan Presidential Library that social conservatives within the administration lobbied hard to make sure that any federal response to the disease would emphasize that "heterosexual sex within marriage is what most Americans, our laws and our traditions consider the proper focus of human sexuality."— that's from a 1987 memo by undersecretary for education Gary Bauer.

So, with little help coming from the federal government and most Americans unconcerned so long as AIDS didn't personally affect *them*, gay men and their allies got together to create programs that would care for those who were sick, educate those who were well, and remember those who had passed. They wrote safe sex guidelines to help others protect themselves at a time when almost no information about the disease was available. They

insisted on the dignity of people with AIDS, and that those who were sick should take an active role in deciding how they would be treated and cared for. And with that in mind, they demanded to be called people with AIDS rather than victims or patients, terms that they associated with powerlessness.

They also got *angry*. Groups like the AIDS Coalition to Unleash Power, or ACT UP, used direct action and civil disobedience to bring the urgency of the dying to people in power and the national news media. They held a controversial "die-in" at St. Patrick's Cathedral in New York City to protest the Catholic Church's stance against on condoms. They interrupted trading at the New York Stock Exchange to draw attention to price-gouging by pharmaceutical companies. And they marched on the Food and Drug Administration to demand changes to federal policy that would make more drugs to treat HIV available to more people, more quickly.

The work of ACT UP and other treatment activists helped to bring about a revolution in HIV treatment in the mid 1990s, with the advent of the multi-drug cocktail to treat the virus. Those advances have made HIV infection into a manageable condition for those with access to treatment, which is a far cry from the virtual death sentence it was less than thirty years ago. Further advances in treatment have also opened up new avenues for HIV prevention. We now know that people with HIV who achieve what is called viral suppression, meaning that they have undetectable levels of the virus in their system, can't pass it on to their sexual partners, and people who are HIV negative but at risk can take medication to keep them from contracting the virus in case of exposure.

This is the heroic story of our partial victory over HIV— and it's also true, but it leaves a lot out. The story of AIDS in the United States didn't end when the cocktail became available. The fact is that 1.2 million people are living with HIV in America today, and more than 35,000 become infected with the virus every year. And the fact is that a disproportionate number of them are Black.

African Americans account for around 13 percent of the US population, but 42 percent of people newly diagnosed with HIV. Of those, the majority of new infections are among Black gay and bisexual men. Black women are also overrepresented in the epidemic, accounting for 55 percent of new HIV diagnoses among women. A recent CDC report also found that almost two thirds of Black transgender women surveyed were living with HIV. Many of the cities with the highest rates of new HIV infections in the country are Southern cities with large Black populations, such as Baton Rouge, Memphis, and Atlanta.

This is not a new phenomenon. For as long as we've been keeping track, Black people have been overrepresented among people with HIV and AIDS in the United States. So why are our stories about AIDS so white, and what would it mean to put African Americans at center of our histories of AIDS in the US? On this podcast, I'll talk about three ways that looking closely at the history of AIDS in Black America changes how we think about the past, present, and future of the epidemic.

One, putting Black communities at the center of the story changes our timeline of AIDS in America. It starts us not in 1981, but in 1969 with Robert

Rayford, the first documented person with AIDS in the United States. It also makes clear that AIDS and AIDS activism aren't just history. While AIDS may no longer make front page news, the epidemic is certainly not over.

Two, putting Black communities at the center of the story helps us to see the epidemic through an intersectional lens. Here I'll talk about some of the experiences of Black gay men with AIDS, and how racial divisions in urban gay communities kept Black gay men from receiving life-saving information about AIDS prevention. I'll also talk about some of the ways that those same men crafted AIDS programs to speak to an intersectional Black gay identity.

Three, putting Black communities at the center of the story shows us that AIDS is not just a matter of individual choices or behaviors that expose us to HIV. In other words, Africans Americans aren't disproportionately affected by AIDS because they use drugs or have unprotected sex at higher rates than everyone else. Instead, our vulnerability to HIV is embedded in the weight of our history, our built environment, and policies enacted by people in power. Telling the story of AIDS in Black America helps us to see past an individualized view of health and lets us see some of the larger forces that make some of us more ill than others.

Although the first cases of AIDS were recognized in the United States in 1981, we know that HIV emerged decades earlier. Based on archival blood and tissue samples, we can determine that HIV appeared in humans sometime around the 1920s, in or near what is today the Democratic Republic of the Congo. This probably happened when a hunter who was cutting up

chimpanzee cut himself, exposing his own blood to infection with a variant of the simian immunodeficiency virus. In the upheaval of post-colonial Africa, the virus made its way to big cities, and then through routes of global trade and travel, to the United States, where it was circulating widely in gay sexual networks in big cities by the early 1970s.

But that doesn't explain the case of Robert Rayford, a Black teenager from St. Louis and the first person in the United States known to have died of complications from AIDS. Rayford passed away in 1969, twelve years before doctors reported on mysterious opportunistic infections in gay men in 1981. Rayford was just 15 years old when he checked in to City Hospital in St. Louis with swelling, fatigue, and shortness of breath. Doctors weren't sure what to make of his illness. Rayford had a case of chlamydia that had spread throughout his body, but his immune system didn't seem to be fighting the infection at all. He told doctors that his symptoms started not long after a sexual encounter with a girl in his neighborhood but didn't reveal much else about his personal life. Rayford's condition continued to deteriorate. After two years of illness, he succumbed to pneumonia on May 16, 1969. An autopsy found lesions from Kaposi's sarcoma on his skin and soft tissues.

Over a decade later, when Rayford's mysterious symptoms became recognized as signs of AIDS, doctors tested the teenager's blood and tissue samples, and found evidence of HIV. But how he contracted the virus remains a mystery. As far as anyone knows, Rayford had never traveled outside of St. Louis, never received a blood transfusion, and never injected drugs. Doctors speculated that

Rayford was gay, had been sexually abused by an older man, or had engaged in sex work, but all he told them was that he had been sexually active with a girl in his neighborhood. We'll probably never know how Rayford contracted HIV, but his story tells us that the virus was present in his community in St. Louis over a decade before AIDS would be recognized elsewhere. So why was AIDS recognized as a new disease in New York and California in 1981, rather than in St. Louis in 1969?

Rayford was from North St. Louis, a part of the city where most residents were Black. His neighbors there rented run-down rowhomes from absentee landlords, and were kept out of lucrative jobs by racist hiring practices. Even if they could afford to move to more affluent areas, North St. Louis residents were prevented from doing so by racial housing covenants, racist realtors, and outright violence. Over the course of his short lifetime, many of Rayford's neighbors were also displaced by "urban renewal" schemes that bulldozed Black neighborhoods to make room for freeways, parking lots, and, eventually, St. Louis' iconic arch. Some of the displaced ended up in the Pruitt-Igoe Apartments, a massive public housing complex just a few blocks from the Rayford family home. Pruitt-Igoe was completed in 1954, the year after Rayford was born. But project was both underfunded and understaffed, and buildings quickly fell into disrepair. Within a few years, the name Pruitt-Igoe became synonymous with urban misery. When Rayford died in 1969 the complex was half empty, and a few years after that it was demolished, to great fanfare.

I say all this because it speaks to how little Black lives and livelihoods in St. Louis mattered to the people in power, who were almost entirely white men. They didn't really care what would happen to Black residents who were displaced by urban renewal; they were more worried about protecting white property values. Nor did they care to make Pruitt-Igoe a livable place for its mostly Black inhabitants. To the St. Louis city fathers, Black residents were a problem to be contained, policed, and—ideally—removed. So why should they notice if some of those same residents died prematurely?

It might be something of a historical accident that we know about Rayford's case at all. One of his doctors recalled to *St. Louis Magazine* in 2007, "all of us were very young, just starting out and curious enough to make this case a challenge to all our diagnostic skills." Had Rayford been treated by someone else, we might not know about him. And if others in Rayford's community were sick but avoided the doctor, or had opportunistic infections that just seemed less weird, then their deaths may have seemed unremarkable. Or maybe they were driven elsewhere by urban renewal and the exodus from Pruitt-Igoe, which might have kept doctors from recognizing a cluster of cases like Rayford's. Either way, if there were others—and there almost certainly were—they made up what literary scholar Dagmawi Woubshet calls the "disprized dead," those whose lives are not seen as worth saving, and whose loss is not seen as worth mourning.

This helps us to make sense of why AIDS was recognized among white gay men in 1981 rather than in Black St. Louis in 1969: white death in the United States is remarkable in a way that Black

death is not. Of course, white gay men would soon find that they, too, were expendable. The Black gay writer Melvin Dixon addressed this discovery in his keynote at the 1992 OutWrite conference for gay and lesbian writers. He told the audience, "Some of you may have never before been treated like second-class citizens. Some of you have felt a certain privilege and protection in being white." And indeed, much of white gay men's writing and activism around AIDS betrays the sense that *this was not supposed to happen to them.*

It might be tempting to look at Rayford's case as a strange footnote to the history of AIDS in the United States. After all, it's an outlier, a story that doesn't fit neatly into the ways that we think about the story of AIDS in this country. But if Robert Rayford really was the first American to die of complications from AIDS, then he was also the first of so many young Black men in this country whose lives were cut short by the disease. His story also points to the ways in which AIDS in Black America has been made worse by public policies that devalue Black lives and inflict lasting trauma on Black communities.

Looking at AIDS through the lens of Black America not only shows us that the epidemic has been around for longer than we generally think, but it also underlines that AIDS is not over. That may seem like an obvious point to make, but over the last 25 years the epidemic *has* receded from public view as an ongoing crisis. Some of this owes to the effectiveness of the new treatments that became available in the mid 1990s. But those treatments haven't benefitted everyone equally.

In 1995, the year that new treatments started to become available, white Americans and African Americans made up roughly equal percentages of new AIDS diagnoses in the United States. Again, this was already evidence of a disparity, since African Americans made up around 13 of the US population that year, while whites made up over 70 percent. But by 2003, that disparity would widen even further, with new AIDS diagnoses among African Americans outpacing those among white Americans by almost 20 points. And today, African Americans with HIV are less likely to achieve viral suppression through treatment, which keeps people with HIV both from getting sick and from passing the virus on to others.

It's clear that AIDS has faded from public concern as it's become increasingly a Black disease. Even so, every now and then, a major event or news story will focus our attention on AIDS in the present day, if only for a moment. That was the case with Linda Villarosa's June 2017 cover story for *New York Times Magazine* on AIDS and Black gay men in the South. In the background of her piece are some truly shocking statistics. If current trends hold, one in two Black gay men will contract HIV in their lifetime. The problem is especially pronounced in predominantly Black cities in the deep South like Jackson, Mississippi, where 40 percent of gay and bisexual men are living with HIV.

To understand why, Villarosa followed a handful of Black gay men in Jackson, Mississippi, describing the specific ways that racism, homophobia, AIDS stigma, and neglect from people in power puts them at risk for HIV and AIDS. That brings us to the second way that centering Black communities changes the way we think about AIDS in the United States,

in that it shows us the epidemic through an intersectional lens.

The stories out of Jackson, Mississippi may have been new to readers of the *New York Times*, but they're not new in the history of AIDS in America. The same forces that Villarosa described have shaped the ways that Black gay men have encountered AIDS since the early 1980s. Looking closely at their stories shows us just how limited the narratives of the AIDS Crisis Revisitation are.

Many of the first AIDS organizations in the US emerged in cities like New York and San Francisco. These cities had well-established, identifiably gay neighborhoods, but Black gay men and other gay men of color experienced them as profoundly unwelcoming.

Take gay bars as an example. Historically, these were important spaces for fostering a certain kind of gay identity and community. But for Black gay men, going to the bars often meant coming face to face with the fact that many white gay men saw them as outsiders. Black gay men going to the bars would be asked for multiple forms of ID at the door while obviously younger white men entered freely, they were mistreated by bartenders, and many reported being either ignored or fetishized by white men looking for sex.

Importantly, the bars were also places that AIDS groups went to teach people how to protect themselves from HIV through safe sex, and to raise money to help those who were already sick. In short, the bars were one of the places where gay men came to see AIDS as an important issue that threatened their well-being. This mattered because

in the same way that many Black gay men felt excluded from the bars and the gay community they represented, Black gay men also saw themselves as being outside the community of people threatened by AIDS. Because early AIDS organizations grew out of the very communities from which Black gay men felt alienated, those same organizations had a hard time reaching Black gay men with information and services. In other words, racism in visible gay communities contributed to the idea, early on, that AIDS was a "white boy's disease." That idea would be hard to undo, and it would be harder still to convince some predominantly white gay organizations that targeted, specific outreach to Black gay men was needed.

At the same time, Black gay men had to contend with homophobia in Black communities as well. Some of the groups that rallied for AIDS prevention in Black communities were squeamish about working with gay men. Black churches, which had been so important to the Black Freedom Struggle, were often hostile to openly gay and lesbian members. And many Afrocentric thinkers, who were enjoying new popularity in the 1980s, argued that Blackness and gayness were incompatible.

In this context, groups like Gay Men of African Descent— or GMAD— in New York formed to give Black gay men a place to meet, talk, and share experiences. They saw Blackness and gayness as equally important parts of a holistic identity, and they understood that work on Black gay identity as part of the fight against HIV. They figured that Black gay men, having been shut out of both a gay community that was normatively white and a Black community that was normatively straight, needed to see themselves as worthy and whole before they

would take steps to practice safe sex and protect themselves from HIV.

To give members that sense of a positive Black gay identity, GMAD looked to Black history for evidence of queer desire. They designed workshops and discussion groups that highlighted the role of queer and gender non-conforming people in ancient Egypt and traditional Yoruba culture, as well as in the Harlem Renaissance and the Civil Rights Movement. By highlighting their presence in the Black past, GMAD claimed space for Black gay men in the present. And they argued that this work, more so than AIDS education programs designed with white gay or straight Black audiences in mind, would give Black gay men the tools to protect themselves and one another from HIV.

That work was notable for the way that it went beyond a model of HIV prevention rooted in changing people's individual behaviors. Don't get me wrong, groups like GMAD did want Black gay men to change their sexual behavior in ways that would protect them from the virus, such as by using condoms. But they also put those individual choices in the context of building community and a sense of collective identity that resisted all of the racist and homophobic baggage that Black gay men had been burdened with. They didn't take it for granted that Black gay men already saw their own lives as worth saving. Instead, they recognized that Black gay men confronted HIV and AIDS alongside psychological, social, and structural pressures that made them especially vulnerable to the disease.

It's that larger set of pressures that a history of AIDS with Black communities at the center helps us to see. AIDS arrived in Black communities on the

heels of a rapidly expanding system of mass incarceration, urban renewal programs, and the deliberate unraveling of the social safety net. These developments followed and built on histories of Jim Crow segregation, redlining, anti-black violence, the theft of Black wealth, medical racism, and centuries of enslavement. To borrow a phrase from Saidiya Hartman, AIDS is just one of the afterlives of slavery, and is shaped by all of the inequities in housing, healthcare, education, employment, policing, and incarceration that have followed.

Public health scholars use the phrase "social determinants of health" to describe how these inequities put some people at greater risk of illness, but I think this sounds too neutral and euphemistic. After all, we're talking about the ways that centuries of injustice are born out in people's bodies in the here and now; the ways that historical oppression feeds the visceral pain of illness in the present day. So instead, I'm going to borrow a phrase from Celeste Watkins-Hayes, a sociologist who has written about women living with HIV/AIDS, and refer instead to these as "injuries of inequality."

According to Watkins-Hayes, injuries of inequality encompass all of the ways that people suffering from inequity have a harder time protecting themselves from harm. In the context of AIDS, we might think about a woman in an abusive relationship who can't insist that her partner wear a condom for fear that he'll beat her up but can't leave him because she doesn't have enough money to survive on her own. We might think about how a racist War on Drugs crippled needle exchange programs that have been proven to save lives, or

how hunger and homelessness make protecting yourself from HIV through safe sex pale in comparison to needing a roof over your head or food on the table. We might ask ourselves what it means to protect yourself from a deadly disease in a society that tells you in so many ways that your life is not worth saving?

Since the early 1980s, African American AIDS activists have taken aim at the disease precisely through these injuries of inequality. BEBASHI, one of the first Black AIDS service organizations in the US, produced educational short films that addressed Black women's HIV risk in the context of physical abuse by husbands and boyfriends. SisterLove, a group in Atlanta that takes an explicitly intersectional approach to HIV prevention among Black women, has operated a housing facility for HIV-positive women since the mid 1990s. And groups like ACT UP Philadelphia, the Community HIV/AIDS Mobilization Project, and Women with a Vision have organized around the ways that mass incarceration and criminalization make Black communities vulnerable to HIV and AIDS.

This kind of perspective is important for how we think about the present and future of AIDS. It helps us see that vulnerability to HIV is about much more than what we do as individuals, and that approaches to the epidemic that rely solely on people's personal responsibility—whether to use condoms or clean needles, or to take their medication—will only take us so far. If we think about AIDS and, really, all racial health disparities as symptoms of the disease of inequality, then it becomes clear that the changes we need to make go much deeper.

We see the same kind of thing in the context of COVID-19, another epidemic that has disproportionately sickened and killed people who are marginalized in any number of ways. Racial disparities in COVID-19 became clear early on, particularly in the pandemic's effect on young people of color in the deep South. Mortality data for COVID-19 through November 2020 found that Black Americans were 3.6 times more likely to die of COVID-19 than their white counterparts.

The reasons for this are multiple. As a result of poverty and lack of access to quality health care, African Americans are more likely to develop serious complications from COVID-19. They're also overrepresented among "essential workers" and thus more likely to be exposed to COVID-19. The virus has also raced through jails and prisons, where a disproportionate number of the incarcerated are Black, and people get sick and die outside the sight and concern of most Americans.

We lead interconnected lives, and that means that we're all threatened by inequality, even if some of us are much more threatened than others. But we shouldn't have to see ourselves as personally at risk of death or disease before we can care about people who are suffering.

The stories that we tell about the past matter. Stories help us to understand and to empathize. They matter for the ways that we think about where we've been and where we're going as a country, and how we can make things better for all of us. Telling the history of AIDS in the US with Black communities at the center helps us see that story not as an exception to our history, but as deeply intertwined with it. It also reminds us that who

we've been as a country is not who we have to be.  
We can do better, and history can show us how.

### **Q+A**

[segue from lecture]

CHRISTOPHER BRICK: And just a quick note, Kariann Yokoto joined Dan and I for the Q&A, so there's three of us in the virtual jungle studio for this one. Enjoy.

[beginning of group conversation]

CHRISTOPHER BRICK: All right, Dan Royles. Welcome to the podcast!

DAN ROYLES: Thanks, thanks for having me.

CHRISTOPHER BRICK: Madam Chair, welcome back!

Kariann Yokota: Thanks, hi Chris, you're right. I'm really looking forward to today's podcast.

CHRISTOPHER BRICK: Thank you for spearheading the committee this past year and thank you again for joining me, because these conversations are always better when you're around. And Dan, thank you again for the wonderful talk

Is it fair to say that structural racism -- the structural racism you talk about in the book and in this talk that you call our attention to was itself -- is it unfair to think of that as an important vector for the transmission of HIV/AIDS among Black communities?

DAN ROYLES: I mean, it's definitely part of this story and in ways that I think makes it hard for folks to wrap their heads around. Because when you talk about something like housing inequality, it's easy to imagine how that might relate to tuberculosis transmission or kind of diseases or epidemic disease that has rodent or insect.

Vectors of transmission like those are things that I think we can understand pretty easily with something like HIV -- where the modes of transmission are different and also vary kind of personal and stigmatized.

We're talking about sex. We're talking about drug use -- things that a lot of people do but that we have a hard time talking about and we have a hard time understanding the ways that those things intersect with all these structural factors, but one thing that's very clear, especially in public health literature, is that all these things do play a really important role in shaping the environment in which people make these very personal choices about how to have sex with whom to have sex. Whether they're going to use drugs and under what conditions.

Things like housing, policing, crime policy, criminalization. And working conditions, like all these things can impact on those but, it's kind of hard for a lot of people to understand or imagine why that is. But if for example-- what one of the things that I think makes that really complicated is that, like HIV is a disease with such a that can

have a very long latency period. And for people thinking about their risk is very much a kind of like long term game or is like a long-term consideration.

Whereas things like housing, employment policing those are often like can be very kind of short term, immediate needs where so you know, like I say in the talk, if you are thinking about whether you're going to have a roof over your head tonight that concern can very easily supersede thinking about whether you're going to demand condom use from a partner or whether you're going to engage in sex work to make ends meet or what kind of decisions you're going to make about things like needle sharing and those--those decisions can also be, whether you have decisions to make about those things at all. Can be very easily shaped by these bigger concerns. So, one connection that I read about in public health literature very, but that made this very clear for me, was talking about the criminalization of drug use paraphernalia. So, in the 1980s, criminalizing, you're just having clean needles on you as evidence of drug use or intent to use drugs.

If you criminalize having clean needles, then people are much less likely to have clean needles and therefore much more likely to share clean to share needles, if they're injecting drugs. I mean and from everything that we know about addiction is like if you were addicted to heroin or opioids, you're not making these kinds of like rational long-term calculations about what risks is posing to your health, and so if you can't carry clean

needles, you're much more likely to share needles. I think that's a really good example of how the policy environment can really powerfully shape what kinds of choices people can make about what to do with their bodies that may or may not put them at a very high risk of contracting HIV.

CHRISTOPHER BRICK: You foreground in your talk, Robert Rayford. Who was he and why is he so important to your story? The story you tell in the book.

DAN ROYLES: Robert Rayford is, as far as we know, the first person in the United States to die of AIDS complications and he died in 1969. That's really significant because we're in the year 2021 right now. We're hearing a lot of the 40th anniversary of AIDS, and going into, I guess the 5th decade of AIDS now, kind of a lot of commemoration of that as an important date in the history of the epidemic.

But AIDS didn't start in 1981, and we know that. We've known that for some time. But recognizing that Robert Rayford died of AIDS complications in 1969, pushes us to kind of rethink that timeline of AIDS in this country, and Robert Raiford in particular for this story is very important because Robert Raiford was a poor Black teenager from Saint Louis. As I talk about, in the talk he lived at basically Ground Zero for several waves of displacement from urban renewal and the failures of public housing policy in Saint Louis in ways that we can imagine how that made him and other people in his community vulnerable to all kinds of ill

health effects, not just HIV, but all kinds of things.

One scholar who's been very important for me and a lot of other people I think in thinking about this is, Mindy Fullilove, who did some of the very, very early research with her husband Robert on the vulnerability of African American communities to HIV. They did a lot of groundbreaking research in San Francisco public housing projects at the in the kind of early years of the crack epidemic looking at the intersection of crack and HIV. But she more recently has written about the way that policies like urban renewal in displacing and fracturing communities makes them more vulnerable or less resilient when it comes to dealing with all kinds of long-term health effects.

So she has this idea of root shock as something that we can use to understand how these policies, like urban renewal, connect in very important ways, but maybe not always obvious ways to things like HIV-- in terms of having a community with social resources with psychological resources in terms of the trauma that that inflicts on communities. And how that impacts all kinds of that has all kinds of long-term health ramifications. HIV being one of them.

So, understanding Robert Rayford as the first person in the United States to die of AIDS complications draws our attention to that intersection of policy and HIV of racial injustice and HIV. Of the disempowerment of programs like Urban Renewal or mass incarceration and HIV. And it

is just one more example of how that avatar for AIDS in this country, while it has been since the beginning of the epidemic, white gay men, it really shows us that it's not just a matter of that the face of AIDS has changed, which is kind of terminology that you see come up a lot in reporting on the epidemic, the changing face of AIDS. It's not that the face of AIDS has changed because AIDS has always impacted Black America.

As long as it's been in this country. It's just a matter of recognition. And we just came to recognize that late because we were talking about a community that has historically very low access to things like health care. So, we just didn't see it there early on, but it certainly was there.

CHRISTOPHER BRICK: I use the term recognition, but it's also a bit about historicization, which is what you've shared with us. This wonderful piece of work that you've done and Madam Chair it looks like you have a follow up or some kind of comment so I want to get to you.

KARIANN YOKOTA: Yeah, thank you. So, my question or my first question really does connect to what you were just saying Dan. I was thinking that the listeners of our podcast and the readers of your book will be curious to know how you came to the perspective you did in your own research. So how did? I was just really impressed by how you re-centered the narrative, the historical narrative of this crisis, this public health crisis by talking about the experience of Robert Rayford, just him as a historical actor in this historiography. How did

you find that story? How, why, and how did you create a different narrative? Was it your experience in the archives? Is this a story that people know but we just don't write about? How did you come to center the African American experience when we are studying this very significant public health crisis?

DAN ROYLES: Yeah, I came to the Rayford story pretty late. I didn't, I didn't uncover the Rayford story. I want to be clear about that. In in putting that in this talk I was drawing on work by other people by Ted Kerr, who's an aide, scholar, and activist. In particular and the reference to Rayford is actually one that I didn't get to put in the book, so it's really grateful for the opportunity to put it into this talk. The reasons that I didn't put it in the book are, you know, just about how I wanted to kind of shape that narrative around the stories that I that I did tell in the chapters in the book, which are about different kind of grassroots activist responses to AIDS in Black America.

But I think for me, a really important piece of the research in shaping the way that I thought about these stories and in shaping my sense of an ethical commitment to tell these stories with as much empathy and understanding and nuance as I could was the practice of doing oral history. Because that was really kind of crucial to my methodology for this project because, while some material has been archived and there are really good collections for AIDS history at places like UC San Francisco and

the GLBT Historical Society in also in San Francisco.

I knew that there were some stories that I wanted to tell, for which there was not a lot of archived material, and so oral history is going to be very important just to being able to tell those stories. So, I think that was the kind of approach that I had at the beginning was just like that idea that I had to recover some material from the past. I had to kind of like fill archival gaps, but in the process of interviewing people, I think having those conversations or sitting down with people to listen to stories for hours at a time, really kind of changed the way that I thought about that piece of the project as not being so much about or as being--some of it was about recovery, but also.

There's a really important aspect of listening there, and I think that listening is really powerful, and that's the kind of thing that I came to understand through doing oral histories. What I'm is, what I'm trying to say, right? I think that gave me a much deeper and more grounded understanding of these stories, because archives are archives are great, archives are important. Archives are often what we have to tell stories about the past but being able to sit down and build connection and build empathy with the people that I was writing about really strengthened my sense of a commitment to do that in the best way that I could, and I think that it made the book better than it would have been otherwise.

Obviously, we do a lot of history without the benefit of oral history. That doesn't make it any less valuable as history, but oral history was so important to me in this project. Not just in a research way, just in shaping the way that I thought about. The work and the importance of doing it.

KARIANN YOKOTA: I was just hoping that in the course of our Q&A session. And you can tell or talk a little bit about what it means to look at this particular topic through an intersectional lens.

So, for those listeners who might not be really sure about what you mean by that, please tell us a little bit about the definition of that, and how it changes the way this important story is told.

DAN ROYLES: Yeah, so intersectionality is probably something a lot of people maybe have heard a lot about. Or maybe a lot of people have heard a little bit about lately. And I'll hazard a definition right now. But intersectionality looks at the ways that our different identities intersect to shape our life courses, our political visibility in any number of ways in a way that is more than just the sum of their parts, right? So, to take, maybe a very, I don't know newsworthy example right now. As we're recording this we're in kind of the first week of the Olympic Games, you know, Simone Biles withdrew from the all-around team competition. And there's been a lot of backlash to that, right?

Simone Biles is a Black female athlete and the response to her withdrawal has been particularly

nasty from some quarters and so we can look at that and think about how Simone Biles being not only a Black athlete or not only a female athlete, but a Black woman athlete? Produces a kind of very vociferous reaction. From some folks or shapes that narrative or that discourse in ways that make it like particularly toxic to borrow a term from some activists like they talk about misogynoir: a kind of portmanteau of misogyny, misogynoir to describe the particularly nasty ways that Black women get talked about in the public sphere. So that's one example. And maybe not even the best example of how the house intersectionality works in practice.

There's also important ways that intersectionality shapes the ways that different folks have encountered or experienced HIV and AIDS. So Black gay men is one example here because, in the context of HIV, at the time that it was recognized and in important ways still today. People unconsciously understand gayness as being a default white identity and blackness as being a default straight identity, so when you're talking about HIV prevention and you're talking about it in modes that--modes like kind of privilege, a white, white gay identity and straight Black identity, like where do you find Black gay men in that it's hard to do?

Arguably, Black gay men become invisible in some ways. In the context of both the history of the epidemic and then in the context of prevention. And so, it shouldn't surprise us that the numbers among Black and bisexual men are so much higher than in other parts of the population. I want to be clear

that it's not because Black gay men have unprotected sex or use drugs at like much higher rates than anybody else. From the data that we have. That's not true, so there's something else going on here that is concentrating HIV in those communities and really it is that we know that HIV is concentrated in those communities. So, if you were operating in a sexual network where HIV is very prevalent. You're just more likely to be exposed to it and there are lots of reasons that HIV is concentrated in those communities.

The lack of access to prevention tools like Prep is one, that's pre-exposure prophylaxis. The lack of treatment is one because we know that people with HIV who are on treatment, who are virally suppressed are basically cannot pass HIV along to their sexual partners. So, if we're talking about a community where HIV prevalence is very high where access to prevention is low and access to treatment is low, then it's no surprise that the numbers there are very high. That's kind of an example of how the invisibility of Black gay men at the intersection of those two identities has really profound consequences for the life chances of people in that community.

CHRISTOPHER BRICK: Your talk begins in 1969. It's about 52 [years ago]. That overlaps pretty closely with the -- you'd mentioned mass incarceration before -- with the intensification of both the war on drugs and prison-industrial complex expansion which would seem to bear some relevance to what the disease ecologies for HIV/AIDS were like in prison.

Is AIDS in prison something that gets discussed enough? I mean, what do we know about that history and how do you connect those two stories if I was going to ask you that?

DAN ROYLES: Yeah, so to the question of whether we know enough, we don't, so I'm really glad that some folks are working on that now. Emily Hobson in particular is working on the history of HIV and AIDS in the US prison system, so I'm really looking forward to the work that Emily is doing when it comes out.

There's a couple of things going on here. I mean, at a very macro level we can look at the rise of mass incarceration and the prison industrial complex alongside the intensification and immiseration around HIV and AIDS in Black America as just being kind of both, indices of the anti-blackness of U.S. policy during those periods. I mean we're talking about during the 1980s, the Reagan administration really repudiating just the Great Society, the civil rights movement, the war on poverty, all that in ways that make both of those things worse. Mass incarceration and HIV and AIDS in Black America.

But then there's all kinds of ways that the rise of mass incarceration actually makes HIV and AIDS much worse in communities that are affected by it. So, there's public health research on all kinds of things from the way that mass incarceration fractures communities who going back to idea of Mindy Fullilove's idea of root shock, but also like in very concrete ways. People have done

research about how the gender imbalance in communities that are affected by mass incarceration makes it harder for women to negotiate safe sex with their partners. Because if you know there's a lot more women than men in a community, then it's harder for women too to turn down sex with partners who won't use protection because the partner can say, well I can just go find somebody else to have sex with.

So, there's all kinds of things like from that, like very kind of specific or seemingly specific and granular. To know the interruption of treatment that happens when people go in or out of prison, which has all kinds of consequences for the efficacy of treatment. And then whether or not protection, condoms are available in prisons and jails. That's been the focus of some fights in places like Philadelphia or in particular Philadelphia, just to get condoms into prisons and jails, requires ongoing or long-term political campaign or political organizing.

We know that AIDS education and things like condom access have been the focus for prison organizers going back into the late 1980s, early 1990s. And yes, I mean there's all kinds of connections between those two stories. From the ways that mass incarceration makes HIV worse to the ways that prison organizers, people within carceral settings have organized around those kinds of issues around treatment, access around prevention access, in order to just advocate for the things that they need to stay healthy inside.

CHRISTOPHER BRICK: In the capacity of this work as it functions as medical humanities. I mean, what would you want people who are working in the public health field or working and let's say the Medical Academy or medical education training new physicians, what would you want them to take away from your work?

DAN ROYLES: Yeah, one of the things that is really important in the stories that I tell in the book is the idea of cultural competency in medicine and public health. So, delivering messages to communities in terms that make sense to them, that resonate with them, and using the right messengers to deliver that message. I don't think that's an idea that's new to lots of folks in public health, but I think is one that's worth coming back too. But it's also one that I think connects back to the importance of listening in all kinds of contexts.

But let's just say in the medical context, listening to folks, hearing not just what their symptoms are, but the everyday challenges they're facing. The everyday contexts that they're being ill or healthy, tells you a lot about that larger constellation of factors, that is shaping their ability to stay healthy, right?

So, I mean, that's just like the power of listening. It sounds it might even sound a little trite, but I think it's really, I think it really is powerful and important in all kinds of ways. In our politics, in our approaches to medicine and all kinds of things, so that is actually, I think is one thing that I would underline. And again, that's

like not a new point necessarily. It's one that's taken up by all kinds of other folks in fields like narrative medicine. But I think that the power of stories and of listening, listening with empathy, listening with curiosity, listening with compassion—really is important. That is, that is one thing I would underline.

CHRISTOPHER BRICK: I just want to say that I think anybody who's active in any of those fields would gain a lot of wonderful perspective from not just listening to the talk, but also reading the book.

KARIANN YOKOTA: Well, and I concur, as I usually and all, I guess I've always concurred with your views Chris. And during the course of giving our doing these podcasts. I wanted to close out my questions with just trying to link the work that you're doing on the HIV AIDS crisis, with the current pandemic, and you do this so very eloquently in your lecture. And I thought that, when you're talking about the power of empathic listening and the importance of that and the other lessons that you present to listeners in your lecture. They can really help us deal with the current crisis.

So, I just want to give you a chance to elaborate a bit on the connections between your research. And our current, the current crisis that we face today.

DAN ROYLES: I mean, one of the things that we see with HIV and AIDS is that it being such a stigmatized disease, it's hard for people to think outside of that is being just a function of

individuals making good or bad choices, and that's what makes you vulnerable to HIV. And that's a problem. And so, at the beginning of the COVID-19 pandemic in the United States. So, thinking back to like March 2020. I thought that maybe because of the ways of this disease is transmitted, they're much less stigmatized or not stigmatized because it spreads through the air that, maybe here is an opportunity for people to understand that being sick is so much more than that, than a kind of indication of how good or bad a person you are.

Which is so often how people talk about or understand HIV infection and that hope was of course very naive unfortunately. Very naive. Of course, as we know, the disease COVID-19 has hit communities who are disenfranchised so much harder than others. I mean what we have seen is much higher rates of infection among African Americans among Latino communities. And then higher rates of severe COVID and death among those communities as well.

We've seen the vulnerability of essential workers who tend to be come from Black and brown communities. I mean what we have seen is just a kind of another reiteration of like who is expendable in this country. If you're old, if you're disabled, I mean the context of COVID-19. It's like if you're old. If you're disabled, if you're out of sight and out of mind, i.e. If you work in the meatpacking industry, or if you're incarcerated. It's really astounding and troubling to see the kind of mental gymnastics that people will do to insulate themselves.

To consider themselves like insulated from risk and then to just kind of excuse the status quo. I mean the idea that we need to reopen, we needed to reopen the economy and that it was acceptable for people to die in order for us to do that, I mean. Probably should not be surprising but was and remains like deeply troubling and so. As folks have pointed out, it seemed like kind of at the point in which it became clear in COVID-19 that the folks who have the least were suffering the most. It seems like it kind of became OK to soldier on with returning to normal. Far before it was safe to do so.

So just kind of at a macro level—I just think we see in both of these epidemic stories, just further evidence of whose life matters in this country for people in power. And maybe even for the majority of Americans, and whose life does not. One thing that I do remain hopeful, for is that the experience of COVID-19 and the kind of fractures or fault lines in our society in terms of our vulnerabilities. Cause obviously it's exposed to a lot of fractures and fault lines, but I mean specifically in terms of our vulnerability around health and disease is that it will lead to much more widespread access to health care in this country.

I mean like just in terms of concrete policy. Things like that is step one, that's like even before step one, but it's such a such a basic thing. That I hope if anything comes out of this that it is that, because that will be such an important lifeline for people who have HIV. For

people who are vulnerable to HIV in terms of making them healthier in terms of making communities less vulnerable to HIV as well as just making all of us more healthier on a day-to-day level, but also making us more prepared and resilient for the next epidemic.

Because we know that it's going to come, it's just a matter of time. But the sooner that we recognize that we live in an interconnected society, and that making everybody healthier is better for everyone. The better off will be, and I really hope that if one thing comes out of this, it is that.

CHRISTOPHER BRICK: Could I ask you too right before we go: what's next for you?

DAN ROYLES: Oh, that's such a good question. OK, I might have to give two answers here.

My next book project is a social, intellectual and cultural biography of Claude Brown, who is the author of *Manchild of the Promised Land*, a book that came out in 1965, was really important in the emerging field of Black studies. It was a really well received book. It's been sold, I think millions of copies at this point, but this is an account of growing up in Harlem in the 1940s and 50s, and it was really hailed at the time that it was published for the kind of verité, the authenticity of this account of growing up in Harlem in the kind of shadow of the Great migration.

Claude Brown never really published another successful book. He published one other book that was not well received, but he became a kind of pundit and public speaker about issues of gangs and drugs and juvenile justice at that time that the system of mass incarceration was being put into place. And so, I'm really interested in his role in that ongoing conversation, as these conversations about gangs and drugs and super predators are kind of unfolding through the 70s, 80s, and 90s. I'm interested in his role in those, but I'm also interested just to kind of piece together an account of his life from other sources because the authenticity of *Manchild in the Promised Land* is so central to its influence. So that's my next book project.

My other next project is going to be--I'm going to start working on a 2 1/2-year study for the National Park Service on the history of anti-black violence in the United States and its territories from 1500 to the present, which is a massive project. So that's one that will be working on at FIU. I'm the principal investigator for a small team of folks, but some of the things that we're going to emphasize in that study are the histories of anti-Black violence, not only in the United States as it's currently constituted, or rather in the kind of New England colonies and then the United States as territorial expansion happens. But in the United States as it's currently constituted, going back to 1500. So, in parts of the country when they were New Spain or New France, so Puerto Rico going back to the transatlantic slave trade, Louisiana colony.

The parts of the southwest when they were New Spain and Mexico when they were like Alta California. So looking at all of that history in a way that helps that contributes to this developing rapidly, unfolding public conversation about the history of anti-Blackness in the United States and how we deal with that as a public as a polity, and how that figures into how we think and talk about and remember the past. So that that will be my immediate next project.

CHRISTOPHER BRICK: So, you're going to be busy, and we have more to look forward to. And you do great honor to this podcast and to the Organization of American historians by sharing some of your perspective and this wonderful work with us today. Madam Chair, you always do honor this podcast every time you're here. Thank you for joining us again today as well.

KARIANN YOKOTA: Thank you, it's been a pleasure to be here.

CHRISTOPHER BRICK: Dan Royles everybody.

### ***Conclusion***

CHRISTOPHER BRICK: And that is a wrap for episode 19. Thank you so much for joining us again this week. Come back next time for the season finale, we're already there, season finale, episode 20 with professor Cathy Choy from Berkeley. We'll catch you then.