

2018

Women of Color and Health: Issues and Solutions

June Cross

Columbia University School of Journalism, jcross@columbia.edu

Nia Weeks

Women With A Vision, Inc. (WWAV)

Kristen Underhill

Columbia Law School

Chloe Bootstaylor

Columbia Law School

Follow this and additional works at: https://scholarship.law.columbia.edu/faculty_scholarship



Part of the [Health Law and Policy Commons](#), [Law and Gender Commons](#), [Law and Race Commons](#), and the [Law and Society Commons](#)

Recommended Citation

June Cross, Nia Weeks, Kristen Underhill & Chloe Bootstaylor, *Women of Color and Health: Issues and Solutions*, 36 COLUM. J. GENDER & L. 21 (2018).

Available at: https://scholarship.law.columbia.edu/faculty_scholarship/2798

This Article is brought to you for free and open access by the Faculty Publications at Scholarship Archive. It has been accepted for inclusion in Faculty Scholarship by an authorized administrator of Scholarship Archive. For more information, please contact scholarshiparchive@law.columbia.edu.

WOMEN OF COLOR AND HEALTH: ISSUES AND SOLUTIONS

JUNE CROSS* & NIA WEEKS**

Moderated by KRISTEN UNDERHILL***

Introduction by CHLOE BOOTSTAYLOR****

Chloe Bootstaylor: Welcome to our second panel. This panel focuses on women of color in health, issues, and solutions. The session is inspired by Professor June Cross of the Columbia School of Journalism and her recent film, *Wilhemina's War*, which follows the story of Wilhemina Dixon and depicts the obstacles that Americans with HIV/AIDS face in accessing not only adequate healthcare but also financial, infrastructural, and social support in their communities.

This panel will consist of Professor Underhill and Nia Weeks. June Cross will join us a little later on. We will start with a clip from her film, and then our moderator and our panelists will take it away. So, here's a little bit of *Wilhemina's War*.

© 2018 Bootstaylor, Cross, Underhill, and Weeks. This is an open access article distributed under the terms of the Creative Commons Attribution License, which permits the user to copy, distribute, and transmit the work provided that the original author(s) and source are credited.

* June Cross is a filmmaker and Professor at the Columbia School of Journalism.

** Nia Weeks is the director of Policy and Advocacy at Women With A Vision, Inc. (WWAV). A native of New Orleans, Ms. Weeks has spent years fighting for the rights of women, children, and families. She graduated with a law degree from the Loyola School of Law in New Orleans in 2009. Ms. Weeks then served as a law clerk for Southeast Louisiana Legal Services, the Housing Authority of New Orleans, the Louisiana Public Defender Board, and Essence Music Festival. After passing the Louisiana Bar, Ms. Weeks served as a law clerk for the Honorable Judge Angelique Reed in First City Court in Orleans Parish and was the director of a supervised visitation center for victims of domestic violence named Harmony House. Before joining WWAV, she served as a public defender in Orleans Parish for two years.

*** Kristen Underhill is an Associate Professor of Law at Columbia Law School.

**** Chloe Bootstaylor, J.D. candidate 2018, served as 2016–2017 Vice President of Empowering Women of Color at Columbia Law School.

*Excerpt from Wilhemina's War.*¹

Governor Nikki Haley [NH]: *This is a great county. It's a great place to grow up. It's a great place to live. You should be incredibly proud of it.*

Representative Joe Neal [JN]: *Rural South Carolina is dying on the vine. Farming has failed. There's no industry.*

NH: *We need to handle South Carolina the way that we know that's best, not the way the President knows that's best.*

Wilhemina Dixon [WD]: *So, are you going to drink it or you want to just take it? All right.*

JN: *We have a county here, for example, Bamberg, that lost its hospital. There's not one doctor in the whole county.*

WD: *Every two months she goes to Columbia. That has been a burden on us because when gas got so high we didn't have the money to get gas to go into Columbia. And a lot of times the car be broke or something like that, but I just have to make sure I get her to Columbia.*

Vivian Clark-Armstead [VCA]: *This state right now is investing very little in saving the lives of African Americans affected by HIV/AIDS. And so, if you're waiting on the cavalry to come, you're waiting on somebody else to come and save us, and you think the government is coming, if you think help's coming, just think about Katrina. They ain't coming. So, we're going to have to save ourselves. We're going to have to save our children.*

Dayshal Dicks [DD]: *My name is Dayshal Dicks. I have HIV for fifteen years. All my life.*

WD: *Well, they just gave her to me for her to die. She was so little. And she had turned like . . . I say like if you got a chicken and you pick it, and it starts to turn kind of blueish. But she was so tiny.*

DD: *Oh, you HIV positive? You're going to die today or tomorrow.*

1 WILHEMINA'S WAR (June Cross 2015).

Ms. Phyllis: *HIV? You don't hear too much about that around here. Because if people got it, they're not going to tell you about it.*

Monique [M]: *What is this I hear that you have stopped taking your medicine for a while? What happened?*

DD: *Uh . . . I think it was stress.*

M: *Stress?*

DD: *Yeah.*

M: *You got depressed?*

DD: *Yeah.*

WD: *Any type of like depression, depression is the worst thing you can have with it. How can you get yourself straightened out if you have no home to go to, to sleep at night? Just in the streets. They might as well let everybody that's got HIV die.*

Kristen Underhill [KU]: Thank you so much having us. So, after seeing the preview, I'm sure there's no additional encouragement that you need to see this movie. We watched it last night here at the law school, and it's incredibly moving, and it's really a striking illustration of some of the systemic and structural disadvantages that people face when they're trying to access treatment for HIV, in a healthcare system, in a state that has not expanded Medicaid, with all these different layers of disadvantage, marginalization, and poverty.

So, the film tells the stories of Wilhemina Dixon; Toni Dicks, her daughter; and Dayshal Dicks, her granddaughter. Toni and Dayshal are both HIV-positive, and the movie discusses how this affects their everyday lives, and how they're able (or unable) to get access to healthcare. So, this movie exposes some of the changes in the nature of the HIV epidemic here in the United States, and particularly its new concentration among men and women of color.

Just as some background information, 12% of the nation's population is

African American.² About 40% of people living with HIV, and 45% of new HIV diagnoses, are among African American men and women.³ Of the nearly 3,400 people who died of HIV in 2015, 52% of them were African American.⁴ And of African American people who are diagnosed with HIV, only about 50% are in care and have a suppressed viral load, which means that the virus is at such a low level in the bloodstream that it is considered to be undetectable.⁵ So, the lifetime risk of HIV and AIDS are vastly higher for African American people compared to white people in the United States. For example, the risk of HIV is 16 times higher for African American women compared to white women.⁶

For men, the lifetime risk of HIV is almost 8 times higher for African American men compared to white men, with African American men having the highest risk of HIV infection overall, at about 1 in 20 men being infected over the course of his lifetime.⁷ The disparity is more extreme for men who have sex with men, which is the group at primary risk of HIV infection in the United States. 50% of black men who have sex with men, and 25% of Latino men who have sex with men, are projected to be diagnosed with HIV, compared to 10% of white men who have sex with men.⁸ So, really very striking disparities here.

HIV risk also varies along geographical axes. And the trailer is correct that the areas with the highest risk are in the rural South. Alabama, Delaware, North and South Carolina, and Mississippi are among the states with the highest incidence of HIV.⁹ Of these, only Delaware has adopted the Medicaid expansion under the

2 *HIV Among African Americans*, CDC (Feb. 14, 2018), <https://www.cdc.gov/hiv/group/raciaethnic/africanamericans/index.html> [perma.cc/FT9L-S3VU] [hereinafter *HIV Among African Americans*].

3 *CDC Fact Sheet: HIV Among African Americans*, CDC (Feb. 2017), <https://www.cdc.gov/nchhstp/newsroom/docs/factsheets/cdc-hiv-aa-508.pdf> [perma.cc/VE8S-KCMY] [hereinafter *CDC Fact Sheet*].

4 *HIV Among African Americans*, *supra* note 2.

5 *Id.*

6 *CDC Fact Sheet*, *supra* note 3.

7 *Id.*

8 *Lifetime Risk of HIV Diagnosis*, CDC (Feb. 23, 2016), <https://www.cdc.gov/nchhstp/newsroom/2016/croi-press-release-risk.html> [perma.cc/KPR8-TH6P].

9 *HIV in the United States by Geography*, CDC (Nov. 2017), <https://www.cdc.gov/hiv/pdf/statistics/cdc-hiv-geographic-distribution.pdf> [perma.cc/XF43-YXE7].

Affordable Care Act.¹⁰ So, there are major structural disadvantages to getting care in these places.

These disparities in HIV incidence are really just one window on disparities in health generally, and in healthcare. Both infectious and chronic diseases break in the United States along what Paul Farmer has called “social fault lines.”¹¹ Disease is disproportionately experienced by people who experience social and economic disadvantage and exclusion. We see these disparities show up in three different places. We see it in the incidence and burden of disease; in access to the care system; and in the quality of care for people who are actually in the system and who are able to make it into the doctor’s office. I’ll talk about each of these briefly in turn.

First, disparities in the incidence and severity of disease. Some of the social determinants of health include discrimination and stigma due to factors like race and gender, disability, illness, poverty, and age. If you’re familiar with an intersectionality framework, this is the idea that people who experience multiple sources of discrimination are even further disadvantaged by those overlapping layers of stigma and discrimination. HIV stigma, as shown in this movie, is one source of discrimination, but it functions as a double or even triple stigma. With HIV, you are perceived as not only ill, but also dangerous, and as somebody who engages in socially unacceptable practices. So, this triple stigma really makes it very difficult to access care, to talk about care, and to engage in prevention and public health programming.

Additional social determinants of health we see in this movie, and that we can talk about, include neighborhood experiences of poverty; lack of safe spaces for recreation and social participation; lack of employment and educational opportunities; lack of prevention funds. Public funds for public health programming are always in tension with other priorities, but these tradeoffs are really acute, and especially damaging in poor geographical areas. The disparities in the geographic distribution of care are really very considerable, with access to doctors and pharmacies being extremely limited in some areas.

10 *Affordable Care Act Medicaid Expansion*, NAT’L CONFERENCE OF STATE LEGISLATURES (Nov. 1, 2017), <http://www.ncsl.org/research/health/affordable-care-act-expansion.aspx> [perma.cc/QMQ5-6787].

11 PAUL FARMER, *INFECTIONS AND INEQUALITIES: THE MODERN PLAGUES* 5 (1999).

Physiological experiences of stress, including things like minority stress and internalized stigma, can also further increase the odds of both infectious and chronic disease.

Finally, there's effects of local epidemiology. When you have a local area with a higher prevalence of infectious disease, the same kind of behavior that you can engage in anywhere becomes riskier here, because disease is already more prevalent here. So, you're more likely to be exposed to an infectious disease like HIV.

I should also add that law itself can be very hostile. So, when we talk about law in the HIV space, we talk about penalties for prostitution. We talk about the effects of the criminal justice system generally in its tendency to disrupt lives and to expose people even further to socio-economic marginalization. And, of course, restrictions on programs like needle exchanges and reduced access to Medicaid are particularly important.

All of these contribute to what have been called "syndemics." These are overlapping and mutually reinforcing experiences of illness, stigma, mental health burdens, and stress-related coping that includes problems like substance use. And all of these are present in this movie, and all of these contribute to the cumulative effect of social disadvantage. We see disparities in the care system. So, all of those are problems that can disproportionately increase the incidence and the burden of disease.

Second, once you have disease, there are also disparities in access to care. We have no constitutional right to good health in this country, and no constitutional right to healthcare. There are some human rights claims that we could make to these rights, but they are generally unenforceable here. Instead, what we have is a highly fragmented system of access to care that's built on employment-based health insurance, with some statutory rights to public insurance. But, of course, access to public insurance depends on public financing. The ACA tried to address some of this with subsidized private insurance and the Medicaid expansion, but that expansion is optional and did not happen in South Carolina and many other states. Doctors in hospitals have no duties to treat non-paying patients, with the exception of a statutory right to emergency care. But even that depends on having a hospital nearby, which wasn't present for this community. Discrimination in care and refusals on the basis of a preexisting condition like HIV were permissible up

until the Affordable Care Act. Discrimination on the basis of race and gender is also barred under the Affordable Care Act and Title VI. However, that depends on whether a healthcare provider is receiving federal funding, and statutory bans on discrimination don't reach refusals of care due to poverty.

Third and finally, once you're in the healthcare system, there continue to be disparities in the quality of care that people receive. There are major problems with cultural competence in care; systemic problems in part due to poverty and type of insurance. Depending on the type of insurance you have, it can be difficult for you to access certain types of treatments. There's also implicit and explicit bias on the basis of race, gender, sexual orientation, HIV status, and a lot of other different characteristics in care. These problems exacerbate issues like medical mistrust and difficulties disclosing information to doctors, which further impairs care quality, and has health consequences.

Wilhemina's War deals with all of these different themes. And Nia Weeks is one of the crusaders who is working to advocate for better healthcare, better access to healthcare, with her work with Women With A Vision (WWAV). Nia, we would love to hear more about your work, and how you're tackling some of these disparities.

Nia Weeks [NW]: My name is Nia Weeks. I come from New Orleans, Louisiana. I work for an organization called Women With A Vision. WWAV is a twenty-seven-year-old grassroots organization in New Orleans that advocates with and for marginalized black feminine communities across the city, the state, and the South. We utilize an intersectional framework, so the women that we work with are women living and surviving with HIV; we do work with sex workers; we work with women who are currently and formerly incarcerated; we work with the LGBTQ community.

We do racial justice; we do gender justice, gender-based violence, reproductive justice, the whole kit and caboodle. We use a harm reduction model. So just to give you a little background on WWAV, WWAV was founded twenty-seven years ago by eight black women who were social workers, and it was a direct response to the AIDS/HIV epidemic that was happening in New Orleans. The ability for black women who were living with HIV to receive care was very limited.

And so, what they did was they would take their time off, and they would go to the projects, and they'd sit on the corner where the sex workers were. And

they wouldn't tell them not to do sex work, they would say, "Baby, are you being safe?" "Let me show you how to put a condom in your mouth so that you can keep yourself safe." "You need some condoms? Give you some extra condoms." "Needle exchange, I got you. Here's some clean needles. Give me your old ones." And that harm reduction model is actually being utilized currently across the country.

That was twenty-seven years ago. The organization has grown. And so, we do direct services, and we do policy and advocacy work. My position at WWAV is the Director of Policy and Advocacy, and I have to say it is probably the biggest privilege that I've had post-law school. When I graduated from law school, I clerked for a judge for a year, and I ran a shelter for victims of domestic violence for a year. I did public defense for three years.

My mom passed a year and a half ago, and my mom was my personal crusader. She was the one that let me know that no matter what skin and what body I was in, that everything that was available to everybody else was available to me, too.

And so, losing her . . . I was in court, and I was advocating for my clients, and they would tell me their stories, and I'd go up to the judge, and I'd say, "Oh, judge, you can't believe what happened." I thought, you can't advocate like that. So, I literally sent my supervising attorney a text message, and I said I can't do this anymore. And they gave me a two-month leave, and in that time this amazing job came into my lap, and now I get to work with proximity, and push real policy for the communities that I love and care for so much.

It's really interesting because I'm watching the trailer, and just watching poor black mothers and daughters navigating that space like that was triggering. And I'm going to give you all a little bit of background on some other things, and explain to you why that particular issue is triggering for me personally. The reason why we utilize an intersectional framework to tackle the issues of the spread of HIV is that all of these things contribute to how people become infected, and what happens once they are infected.

The ability to navigate this world in a black feminine body is difficult for me. And I carry a bag full of privilege, everywhere I walk. When I walk into a room full of formerly-incarcerated women, that's not my experience. I don't live with the PTSD associated with that. So, I walk into that space with privilege, and I have to recognize that on a consistent basis. We utilize the intersectional framework

because all of these things are all-encompassing.

I'll start with breaking down each community. I'm going to start with incarcerated women. The criminal justice system, specifically in the South, in Louisiana, the laws related to HIV are so draconian. In Louisiana, you can get charged with intentional exposure to HIV for spitting at someone. Or women who are charged with prostitution, if they're found to be HIV positive, will subsequently be charged with intentional exposure to HIV, with no other evidence presented, except for the fact that they were engaged in prostitution, and that they are HIV positive.

We talk about sex work. There are multiple reasons why people choose sex work, and there's this national, international space that conflates trafficking with sex work. I have four children. I was talking to my two youngest daughters, and they said they didn't want to go to camp one day. And I said, "Well, then you can go be a policy director." And they said, "Okay." And I said, "I'm going to talk to the City Council about the conflation of sex trafficking." And my nine-year-old, she goes, "That's easy. Sex work is when you choose, and trafficking is when you're forced. Duh." I'm thinking, okay, well, not to everybody duh, but, you know. And it's true, right?

But there's this conflation of sex work and trafficking that happens all the time, and there's this idea that we have to save women from sex work and what have you. But people actually come and choose sex work for a variety of reasons. The onus is not on us to judge, or to maneuver them out of the space. Because we'll stigmatize and create policy to try to maneuver them in a moral ideology that we want them to have, but we're not there to pay their light bill. We're not there when their children are hungry. We're not there when they're about to get convicted. We don't have the capacity to maneuver and morally structure everybody's life.

I remember I had one client who was engaged in sex work. I'm bringing in Louisiana law because Louisiana is the incarceration capital of the world, New Orleans specifically. And the second highest incarceration state is Mississippi, and Louisiana has twice as many people incarcerated than Mississippi. So, we're really, really bad. And a lot of it has to do with the laws that are there.

We have a habitual offender law that allows people to receive a life sentence for any felony, regardless of what that felony is. So, if you get more than one

drug charge—and the drug charge could be marijuana, and it's not gradated—you can receive life for a fourth offense marijuana charge. And the way our District Attorney in New Orleans interacts with our community, and pushes for his ADAs to prosecute cases in an aggressive manner. And so, like I say, the women are arrested for sex work, and they're charged with intentional exposure to HIV.

So, that's one piece of the criminal justice system that grabs them in. But then, when they're incarcerated, they don't have the ability to access all their medication. And we know that a suppressed viral load reduces the risk of HIV spreading. But our criminal justice system doesn't even think that while someone's incarcerated we should actually give them their medication if they're HIV positive. They use their HIV positive status to push them into a more unhealthy space.

You have that piece, and then you have the stigmatization piece put on top of all of that. And I'm using sex work because it's a community that we work with, but it's not the only community that's affected by this. You have a woman who has been engaging in prostitution, for whatever reason she's chosen to engage in prostitution, she's HIV positive, she's not receiving her medication, and then there's also that stigmatization if she says she's HIV positive So, if she tries to advocate for her medication, she might get charged with something else. A felony. Not going to say anything, right? Which puts her at further risk, and puts the community at further risk. So, that's how all these things kind of come intertwined, and that's why you have to utilize the intersectional ideology and the harm reduction model when you're working with these particular communities.

There's also a lot of stigmatization when it comes to our trans men and women. Even going to the doctor, for a trans man or woman, is a difficult process. Because you have to find a doctor that's going to have that right conversation with you. Tell you all the things about your body. Tell you all the risks associated, all the medicine you need to take, the right food to eat.

We had some reproductive justice roundtables at our office, and we engaged black women around the entire state. And we would just sit down and say, let's talk black women's health. And what we realized is that the conversations that black women are having with their doctors are very different than the conversations white women are having with their doctors. The treatment process that is described and laid out is very different for women of color and women who are not. And we've done little studies. So, we've had black community members going to Planned

Parenthood and see what they were told. And then we had white community members who are allies go in and see what they were told. And the breadth of information, the time that was spent with women who have had law degree and medical degrees, even doctors. We didn't tell the physician that's what they were. But these well-educated women were not given appropriate information about their own body.

So, you can imagine, if you are a marginalized individual, the lack of information that's given to you because all the stigma, all the negativity that's associated with living in that body, is woven through. And it can be a difficult conversation sometimes, because people don't like to admit that those biases are interwoven.

But I was talking to somebody else earlier. In New Orleans, we have a black sheriff. We've had a black mayor for years. We have a black sheriff, a black police chief, but we still have racist interactions. Our police force is considered the most racist police force in the South. And so that shows you that racism, sexism, it's interwoven into policies that surpass, sometimes, even our recognition on its face. I'm going to give Professor Cross the mike, but I did want to thank you for your amazing movie first.

KU: We watched the trailer, and we would love to hear more, just as a starting point, about your process of making this movie, and what are the most significant barriers to healthcare access that you saw.

June Cross [JC]: Well, racism is the most significant access to healthcare barrier. David Williams, a professor at Harvard's School of Public Health, discussed studies on unconscious bias, in which they got data from the UCLA Medical Center, where patients presented in emergency rooms with broken bones.¹² The white folks were given pain medication immediately, while black patients and Latino patients were given pain medication significantly less often. This happened even though they were able to figure out a way to account for variances in language understanding and communication.

When this data was presented to the doctors, they didn't want to believe it,

¹² *Scholars Address Wide Impact of Unconscious Bias at America Healing Conference*, W.K. KELLOGG FOUNDATION (Apr. 26, 2012), <https://www.wkkf.org/news-and-media/article/2012/04/scholars-address-wide-impact-of-unconscious-bias-at-america-healing-conference> [perma.cc/GUY2-7N4Y].

because they all take a Hippocratic Oath that says they're supposed to treat patients regardless of skin color, ethnicity, language, or whatever. But there, the data was inescapable that there was something unconscious in their minds that they just felt like folks who look different than them don't have pain, or don't experience pain in the same way. So, they've been doing a lot of work up there trying to figure out how do we erase this, or how do we at least make ourselves more aware of it.

When you talk about HIV, it's a process, because the first step is being aware that you have it. And then you have to act on the awareness in some way, in an active way. Like asking your patient, "How much pain are you in?" And believing them when they give you an answer back, and not dismissing them because they speak with what my aunt used to call a thick-tongued accent, or speak in a way that you don't quite understand, or somehow present themselves in a way that makes you think that they're less than. Even in a subconscious manner. We all have these unconscious biases.

They've also done an analysis of three million data points of reportorial writing, and looked at the words black, white, male, and female, and looked at the stereotypical way in which we as reporters reinforce the stereotyping of people. I went to a conference at the Association of Black Journalists, maybe four or five years ago when I was first beginning the film that became *Wilhemina's War*, and it began to occur to me that we never hear from the patients on the end of this. We never hear from those people about their experiences of the public health system. Whenever reporters approach public health stories we use data, and we talk to public health officials, and we talk to doctors, and we talk to researchers. The patient is the last person reporters talk to, as a little example of whatever it is we're trying to show.

So my effort with *Wilhemina's War* was really to have Wilhemina's analysis of how she thought the public health system was working for her, from her vantage point as an uneducated, underemployed black woman living in the rural South. So, when you talk about barriers to access, there's a whole bunch of things that start with, how do I get to the hospital? How do I get to a doctor? How do I get to a doctor that I think cares about me? Instead of being reliant on the community health service that the state—a hostile sort of Tea Party state—runs.

The people who work in the community health service, Wilhemina says, more often than not act like they're taking trouble and time out of their lives to treat

you. But even that is forty-five minutes away. If she wants anything more than that, she has to drive an hour and a half to get to Columbia. There's no public transportation in the state of South Carolina. This isn't unusual, actually. There's no public transportation in most of the southern states. Once you leave New York City, you're in another world.

So first, you start with, how do I get to a doctor? Then, will the doctor listen to me when I'm describing what's going on? Will they be responsive? Can they be responsive, given the governmental structures that underemployed and poor—I don't even like to use that word anymore, I like to use underemployed or unemployed, because that connotes being poor. Poor is the word that reporters most often use in conjunction with the word black, so I've started trying to eliminate that from my vocabulary. If I had a job I wouldn't be poor. If I wasn't underemployed I would have more wealth.

KU: What do you see as some of the biggest misconceptions or stereotypes about women of color in the healthcare system?

NW: I think you brought up the huge issue of believability. The information that's given to us when we go to a healthcare provider is structurally different than the information given to our white counterparts. And there's also this space of believability when a black woman comes in and says "I'm depressed." Or "I have this ache" or "I have this pain." "I have this concern." It is often dismissed, unless you go to the right facility. And there's a structural difference between women and family members who live in the rural South and in the city. In New Orleans, it is still difficult for me to access good quality healthcare, and I have friends that are physicians.

But it's different for someone who's living in the rural South; they're limited in who they have access to, how they get that access to that individual, and the ability to be self-informed. I can hop on a computer and I can figure out ways to maneuver myself through.

Unfortunately, a colleague at Women With A Vision found out in July that she had breast cancer. In an organization that advocates the way we do for women's health, it was really interesting to watch her maneuver through this process. And she had to do so much research for herself. And really figure it out, to the point where now, she says when she goes into her doctor's office, she tells the doctor

what she wants, and what the treatment is she wants, because that's the only way she's going to get the appropriate treatment for her body. And you would think that the doctor would be the one to tell her.

She goes on forums with white women who have survived breast cancer, and finds out what their treatment plans are, and then structures hers out of the information that she wasn't given from those spaces. So, I think the way doctors interact with black female community members across the whole spectrum when it comes to healthcare, and that believability factor, is a major issue.

JC: I would second that. And then just a lot of misconceptions and old wives' tales, especially when you're dealing with a rural southern population. How do you understand things? Do you understand things? Do you understand what the doctor is saying when they come back to you? At one point in the production, at the tail end of the process, I took Wilhemina to this conference held by an organization called the Positive Women's Network, which is women of color who are living with HIV, living their lives out loud, as they say. They do a lot of grassroots organizing. So, I took Wilhemina to this conference, and they were doing all these presentations on the latest medical updates on HIV, and PrEP, and all these things. And they're using all these sort of twenty-dollar words.

And Mina's sitting next to me, and she would keep leaning over, and she says, "What that they talking about? What they talking about? What they talking about?" And I would translate it for her, and she understood the concepts perfectly, she just couldn't understand the words. And she trusts me, so she's willing to ask me what do they mean, but if you're dealing with a doctor it's different. I have had this happen to myself. I recently had to go to a doctor for a problem, and it was for a pain I had, and it's the same thing, you know. She looks at me, and she says, "Oh, well, did you bend and reach for something, or come down hard on your foot?" And I say, "Uh, yeah. That's what feet are for. Right?" And she responds, "Well, no, you have a bunion or something," and so she said it was some kind of inflammation.

And so, she put me on some medication for two weeks, so I go back. She said, "So did you stop reaching for things, or bending, or jumping, or stepping hard on your foot?" And I respond, "Girlfriend, I live by myself. Do you understand that toes are made for reaching up on things? That's what they were designed for. If I

have a problem that I can't stand on my tippy toes, I have a bigger problem than whatever it is you're treating me for."

She sort of smiled at that and had to step back and re-explain it to me, but that really takes a level of assertiveness that is different for most people who are not educated. In this case, Wilhemina can't even read. She barely knows how to sign her name. So, if you feel intimidated when faced by educated, higher status persons, you can't come back like that unless you're really, really, really angry about something.

NW: As we sit in the spaces that we do, there are so many community members that are navigating with nothing. With no hope. Think about when you're taking your exams, you're hoping to pass, right? And the idea that you can get a top grade, that feels good.

And you have no hope of getting food. No hope for getting lifesaving medication. No hope for your child to get lifesaving medication. And knowing that it's just a lack of money. A lack of access. That no one did anything wrong except live and exist. There are thousands of girls, there are thousands of women, for whom surviving would be a prayer. That would be an answered prayer.

And so, when we talk about privilege and the ability to maneuver and access, the privilege that we have that we're able to even have a conversation about it. We have to remember that we're having a conversation about community members who aren't even represented in this group. We don't have anybody, that I know of, here who is living like this. And so, we have to keep those persons here as we maneuver through, and when we have the ability to say something, do something, push something different, the onus is on us to do so.

KU: What is the advocacy work being done politically? At their town hall meetings, a lot of politicians are under pressure to make some changes. What advocacy work is happening in this space?

JC: Well, it's really state-to-state and city-to-city, which is sort of unfortunate. I think one of the obstacles that the HIV advocacy organizations face is that, largely because of stigma, there hasn't been an intersectional grassroots response, so the people who are working around issues of using, and food insecurity, and minimum wages, aren't joined with the people that are working in HIV advocacy, because

we're all in our little silos around our issues. Unless you're joining hands with other likeminded people, you don't have the political power to do anything in the state.

And then in order to do anything, you have to be willing to be public. And that level of stigma is a barrier. I remember we showed *Wilhemina's War* in Atlanta, and I almost pulled the film at one point because I could hear somebody sobbing. This was not like crying silently, there were wracking sobs. When the film ended and I saw who it was, it turned out that she was a federal employee, and she'd been living HIV positive for four years and nobody in her family knows. She wasn't a low-level federal employee, and this is in Atlanta. When she saw Wilhemina's granddaughter, that scene where Wilhemina's granddaughter died, she could see herself.

We walk around New York and we have all these signs saying, I'm loving safe, and I'm with my partner, I have condoms and PrEP, and all this stuff. They just barely even heard of PrEP down there. It's hard to overstate how different the attitudes are, I mean this is the Bible Belt. They teach abstinence only. Even in most of the state laws, the sex education doesn't even have to be scientifically accurate. If you go to the CDC, to the sexually transmitted diseases meetings, the things you hear are mindboggling because there's just such a high level of ignorance.

The kids are not going to stop being kids just because somebody told them not to do the do. We all got here because our parents did the do, but for some reason we don't want to talk about it with our kids. Kids are going to find ways to at least do something. Because that's where you are when you're a teenager. Those hormones are strong. And it's very hard to talk about.

NW: I want to talk a little bit about the advocacy work that's going on in New Orleans and Louisiana. I always say you can't change policy until you change the policymaker, because policy comes from an idea. It's an idea of how a group of people should interact and react to the world. Until that person sees everybody as a valid human being, you're going to have policies that are detrimental to certain community members across the board. And so, at Women With A Vision, we do voter engagement with low-propensity black feminine communities in the Fourth, Fifth, Sixth, and Seventh Wards. We do door knocking.

Last presidential election we engaged 3,000 low-propensity black feminine voters. And the numbers in Louisiana are actually such that we are not a red state, we are purple. And if we engage the right people, and push the right issues, we can actually turn the tide. I left a meeting right before I came here on clusters where there had been no unopposed Republicans, and the clusters of black women that live in those areas, and engaging them. In Louisiana, one district hadn't had a black representative for thirty-five years. Last year they got two, and it is because of that voter engagement that we did.

So, I'm organizing a reproductive justice black women's advocacy day in Baton Rouge on April 26. I'm bringing up 300 black women from around the state, and we're coming together. And I'm bringing everybody. I'm bringing my members, and my Jack and Jill members, and I'm bringing my sex workers, and my formerly incarcerated, and my trans women too. And that's—

JC: And positive women?

NW: Oh, yeah, we have quite a few people in the Positive Women's Network. And we're bringing them all to the Capitol, and we're advocating for everybody. And everybody is talking about voter engagement, access to healthcare, criminal justice reform. We're doing a voter call. We have a national reproductive justice policy brief that we're introducing. We're introducing a resolution in the city and in the state on reproductive justice. We're doing an administrative equity bill.

As we're garnering all of that political power and engaging voters that way, we're also putting together a black woman's super PAC. So, we're leveraging our political and economic power, and pushing that through so that we can change the tide of what's happening. This election cycle we have two black women running for mayor. Baton Rouge got their first black woman mayor. We have a judicial race that's happening on Saturday. Every single candidate is a black woman.

Higher Heights is engaged strategically in putting together the right analysis. And we're pushing the issues, and centering black women's issues and women's issues in every single race. None of this means anything until you're organized and strategic. I keep saying I'm a Trojan horse femme like nobody's business. I see your game. I see what you're trying to do. So, I've got to get the right people to change in there, so that things can change.

Audience: Thank you so much for being here and speaking with us. It means a lot, and it's truly inspiring. You've spoken to it a little bit, but I'm wondering what your vision is for how to change the stigma around these issues, especially dealing with the fact that individuals who are largely affected are already marginalized. What is your vision for changing that?

NW: So, along with legislative education and advocacy, you have to have community education and advocacy. Legislators listen to what community pushes, but community has to have the right understanding, knowledge, and framework in order to push it. I'll give you an example. When I was in court, in public defense, I didn't want the judge to say "victim." I wanted to use the phrase, "complaining witness."

The judges and the DAs always kept saying "victim," but I kept saying "complaining witness." And after a while, that terminology changed. And I'm in court the other day, and the judge said "complaining witness." I think, "yeah, a win for me!" But I had to educate the judge on why I want him to use that term, why it was important. I know that's not in the same framework, but I'm utilizing that to show that education and consistency when it comes to community. Community engagement is very different than legislative engagement: when you're educating a legislator, then you really have to do your homework and understand the political structure of your community.

So, when I go to the Capitol, I have a grading system. You're either a red, green or yellow. If you are a red, you're a lost cause. If you're green, thank you so much, I appreciate your support, here's some more information. If it's yellow, those are ones I spend my time with, because those are ones that are on the fence and need the most education. And then I gradate the bills that I'm advocating as level one through four, and I engage on that. That's the legislative piece; you have some that need personal stories for them to push the policy pieces that are important to you. One thing especially that grassroots organizations have a problem doing is that when there's an issue that's specific to a community, they leave out the community and put faces in there that legislators care about. And so it's desensitized legislators into thinking that these community members don't exist. You have to put those people in their face.

There are a lot of women, especially women who live in stigmatized spaces, who aren't always willing to come forward. So, you have to allow them to do what

they know to do best, give them the education in how to be self-advocates, and then help them structure their space around that. So, like I said, I'm bringing some transgender women up to Baton Rouge. Not all of my transgender women that I work with want to come. They don't want to do it like that. So how do you want to do it? Do you want to do the phone calls to the legislator? Because then they don't know that you're trans. They have no idea. There's no face to go with it. So, you can advocate for yourself like this. If I'm writing a piece for a newspaper, or if I'm going on a radio show, they don't know your face. We can do a fake name. But we can advocate with you like this.

And so, there's a way to use your privilege to help marginalized community members navigate the way they know how, and the way they want to. Giving them the space and the pieces helps break down community stigma too, because it allows community members to see them as they are: fully human and capable human beings.

JC: I would agree with that. I just think too often Northerners and educated people, but particularly Northern advocates, go to the South and try to tell them how to act, and our ways of being up here just won't work down there. You can't be in somebody's face in the South like you can up here. There's a whole different set of protocols. And so, the sessions that I've attended, particularly with Positive Women's Network, when they show the film, and then ask the women "how do you feel," I literally just step back and let the women have their own conversation.

It's hard, because I'm a professor. I'm used to leading the class. But you have to find the strength within to step back. This goes all the way back to the Civil Rights Movement. I mean, this is just organizing and grassroots work 101. You got to let the people do their thing without telling them how it should be done. Even if that means that they're going to make mistakes and you can see the train coming. You just got to let it go, because they got to do it their way. Folks have got to do it in the way that works best for their culture.

KU: I know there were so many good questions that we didn't have time to get to, but thank you so much, both Nia and June. It was wonderful to have you both here.