Sabrina Artel Audio Stories
Voices of Young Black Men about HIV/AIDS

SUPPORTING EFFECTIVE INTERVENTIONS, ADVOCACY AND POLICY WORK ON BEHALF OF YOUNG BLACK MSM LEADERS

Kali Lindsey
6-15-15

Artel: The HIV epidemic is devastating black men who have sex with men. HIV prevalence is estimated at 32% among BMSM.

[00:00:09] A strategic convening with young black MSM leaders was held June 14-16, 2015, at the Columbia University Mailman School of Public Health in New York City.

[00:00:21] To give some background, in June of 2014, the M•A•C AIDS Fund supported the Mailman School of Public Health at Columbia University to conduct a desk review of the context of the HIV epidemic among black men who have sex with men (BMSM) in the United States. The review was based on interviews, analysis of research, and government philanthropic interventions. It indicated that there were particular leadership access and advocacy issues for young men aged 35 and younger. As a result of this review, a convening was held a year later, June 14-16, at the Mailman School of Public Health. The convening was a collaboration between 24 YBMSM leaders from throughout the United States, the M•A•C AIDS Fund, the Mailman School of Public Health at Columbia University, and The Foundation for AIDS Research (amFAR).

[00:01:12] I'm Sabrina Artel, and I spoke with some of the young leaders at the convening. The 24 young leaders all work on HIV/AIDS advocacy in some

capacity. This includes direct services provision, research, policy work, organizing, grants management, the arts, and faith-based work.

[00:01:30] Kali Lindsey is Deputy Director at the Foundation for AIDS Research (amFAR). Lindsey has spent more than a decade of his professional career in HIV/AIDS program development and advocacy, both at the federal and local levels. Lindsey is an appointed member of the CDC/HRSA Advisory Committee on HIV/AIDS, Hepatitis, and Sexually Transmitted Diseases, where he co-chaired an external review of youth sexual health programs at the Centers for Disease Control with the late Dr. Doug Kirby.

[00:01:59] Prior to joining AMFAR, Lindsey directed legislative and public affairs at the National Minority AIDS Council, where he led the development of the Declaration and Summit to End the HIV Epidemic in the U.S. He released the "Rise Proud Action Plan for Combating HIV – Vulnerability Among Black Gay and Bisexual Men."

[00:02:20] Lindsey also previously held senior positions at the Harlem United Community AIDS Center in New York City, and the former National Association of People with AIDS.

[00:02:27]

Lindsey: My name is Kali Lindsey, and I work with amFAR, The Foundation for AIDS Research.

Artel: Let's begin with the initiatives of your organization and the mission.

Lindsey: One of the things ... I'm an incredibly lucky individual because I work with an organization who has as its mission making AIDS history, and there's a little play

on the words there, right, because we're also try to talk about making AIDS history in terms of making a mark on ending the epidemic, as well as making AIDS go away so that people aren't continuously afflicted by this epidemic. So, I feel incredibly lucky to be in a position to work in a public policy office and address many of the programs that are providing key resources to help individuals provide services to people living with or at risk for HIV around the world.

[00:03:10]

Artel: And Kali, what are some of these key risk factors?

Lindsey: I think we know a lot more about HIV today than we did 30 years ago, and what we know today is that the main risk factors are unprotected sex and injection drug use, and particularly injection drug use through sharing needles. Fortunately, in the global epidemic, we've gone to this conversation around key populations that are recognized where the key drivers of the epidemic are, and a lot of global attention is being paid to focusing efforts on really driving resources and attention to those populations that are really behind where HIV is being transmitted.

[00:03:44] But the reality is that it's not only where the epidemic is being transmitted. Individuals that aren't necessarily transmitting it, like women, are also at risk for HIV because their partners might either get it from sex with another partner who has HIV, or they might get it from injection drug use. So, we're really focused in on really getting to those individuals with information about how it's transmitted, and also with new information about how they can protect themselves, which now has the benefit of having a pill that you could take every day that can help you avoid HIV infection.

[00:04:14]

Artel: In what ways are you providing outreach?

Lindsey: We provide outreach in a lot of different ways. We're not a direct service provider, so we're a global organization, so we don't necessarily have boots on the ground. But we do support through the resources that we raise through our foundation, we do support a lot of advocacy efforts, both domestically and around the world. We also have a very new initiative that's incredibly exciting. We're investing $100 million between now and 2020 in identifying a cure for HIV because we absolutely believe that we'll be there by 2020; we'll have the scientific foundation for a cure, and we'll be able to give a scientific solution to the epidemic around the world, and then when 2020 gets here we'll have to do the work to figure out how to get it to everybody that needs it.

[00:04:56] I think the impetus for kind of a redirection of how we're approaching this work really started with a very poignant statement made by President Obama when he released the National HIV/AIDS Strategy. He added a meeting on World AIDS Day in 2011, and he made the statement that, "At a time when we recognize that HIV infections among young black gay men increased by 48% between the years of 2006 and 2009, we need to do more to show black gay men that their lives matter." And I think that that's really what brings us into this room today, is to figure out what we can do collectively to carry out that vision – that bold statement that President Obama really gave the country when he was galvanizing all of our efforts behind the National HIV/AIDS Strategy.

[00:05:37] And I think it's very important that we recognize that not only have we gotten a supportive message from the person that's at the highest level of the federal government's response, but we're also in a time of unprecedented opportunity because of other recent events that have occurred at the same time that the president released the National HIV/AIDS Strategy. Those three things include the passage of the Affordable Care Act, which is unprecedentedly expanding access to care for individuals that are both at risk for HIV and

individuals that are living with HIV. Prior to the ACA, many people who were at risk for HIV found out that they couldn't access care because they were either not poor enough or sick enough to access Medicaid, and they couldn't access employer insurance if they didn't have a job to access that employer-provided insurance.

[00:06:21] So, with the ACA, we now have an ability to connect people to more of these opportunities, and those two opportunities that are really important for the healthcare environment are Pre-exposure Prophylaxis and Treatment as Prevention. They together provide a new strategy for us to address HIV incidence and prevalence, and really kind of drive the footprint of the HIV epidemic in the United States down by really providing a tool, which is a pill that HIV-negative individuals can take that will help them avoid acquiring the HIV virus. It's a daily pill; it's a combination of emtricitabine and tenofovir. If they take the pill every day they can avoid HIV infection.

[00:07:00] And then for HIV+ individuals, if we get them into care and get them on treatment and they're able to maintain the suppressed viral load, they have a 96% reduced likelihood that they will transmit HIV to their sexual partners.

[00:07:12] So, with these important developments and the call from President Obama to do more to demonstrate that the lives of black gay men matter, we're in this room today to figure out how we can carry out that mission by figuring out what's missing and what we can do better.

[00:07:26] So, when we look at the individuals that are not being helped by the Medicaid expansion, we're really talking about the individuals that find themselves at risk for HIV. All of those states that decided not to expand Medicaid are worsening our efforts, or impeding our efforts to really address the HIV epidemic in those areas, because we have to buy additional resources and pay for care, and to pay for testing, and to pay for all the necessary services to

keep people either safe from getting HIV or diagnosing them with HIV and get them into care so that they can control their virus and avoid passing the virus along to others.

Artel: What would you say are the needs, or what this movement to combat HIV and AIDS looks like right now?

[00:08:07]

Lindsey: Well, the first thing that it needs is a heavy injection of resources. But, being realistic, I recognize that we're not going to get a whole lot more money, and that we really need a heavy injection of resources because we have a lot of information right now that we can do a lot of good with. And if we had the resources to do something with it, we can really beef up our program and really beef up the CDC and HRSA, and we can expedite testing and we can expedite healthcare access to so many people; that would help us to drive down the numbers of who's being impacted by the epidemic, both domestically and globally. But unfortunately, we have to make the investment case. We're not necessarily marshaling the necessary resources, and we need everybody's help to make the case to Congress that we can do this – we are on the fast track to end the epidemic. If we marshal the resources, we can make an impact, and we can really kind of "make AIDS history," and that's where I think the movement needs to go. We need to make sure that people recognize that even though we have really effective treatment, far too few – only 12 million people have access to treatment, and 40 million people are living with HIV. That leaves a lot of individuals left without access to care and treatment that are potentially unwittingly transmitting the HIV virus.

[00:09:14] If we could do more to expedite resources to those areas and get testing and treatment to those individuals, we can do a really good thing for the HIV epidemic, both domestically and abroad.

[00:09:25] I would very much encourage everybody to take a good look at the recent research that's come out of the NIH respective to HIV, because we've learned a lot in the last 5 years, and it's really incredible and really exciting, because both Pre-exposure Prophylaxis and Treatment as Prevention were kind of proof-of-concept in 2010, at the same time that we passed the Affordable Care Act, and at the same time that we, for the first time, the president released a national HIV/AIDS strategy.

[00:09:52] So, there's these cooperative events that are happening in the environment all at the same time, and we really need to embrace them and figure out how to work them collectively to make an impact on the epidemic. If people look at the research, they'll really see that. They'll see that with Pre-exposure Prophylaxis coming out in 2010. They'll say, "Yeah, I get it ... I get why the Affordable Care Act is so important." They'll see Treatment as Prevention and say, "We need to do everything we can do to get people with HIV into care and get them access to treatment." They'll talk to people about it, and they'll probably be a little bit more kind to people with HIV because they'll understand that some of the things that put them at risk for it ... it can happen to anybody, and there are things that we can do, and there's no reason to be fearful ... or, there's no reason to shun someone that's living with HIV. You can help them. We have answers. Help them find the research; help them find access to care; help us help them in the epidemic.

[00:10:41]

Artel: And Kali, what you're also addressing is both the current needs with treatment and care and kindness and understanding, and you also talked about 2020 in terms of actually ending the epidemic. And I'm wondering if you can speak with us about this pill that you mentioned, about this year of 2020, and what is this convergence between right now, where the numbers are growing, and with populations that don't have access?

[00:11:10]

Lindsey: I would love to. The science behind pre-exposure Prophylaxis, which was first confirm in the iPrEx trial, which was a multi-national trial that took place in 5 countries around the world – it was really the first time that we proved that you can actually avoid HIV transmission with an HIV medicine that is given to individuals that are living with HIV, or have been diagnosed with HIV. So, there's a medicine called "emtricitabine" and "tenofovir" that, together in one tablet, if individuals take it daily and have unprotected sex or find exposure to HIV, it will actually make it unlikely that they will acquire HIV. And that's really exciting, because prior to that, the only thing we were able to tell people was, "Abstain from sex completely, or use condoms 100% of the time." And of course we all know that intimacy is somewhat inhibited when you have a barrier between the two individuals; or, if you want to procreate, the condom might not necessarily be the best tool. So, now we have a new tool in the toolbox that we can really help to keep people safe from HIV.

[00:12:12] At the same time, we also confirmed ... we've had an idea for a while that HIV treatment reduces the risk that you'll transmit the HIV virus. But in 2010 we actually had the HIV Prevention Trial Network 052 Study confirm that with steady access to HIV treatment adherence, if you're able to suppress your viral load and keep it suppressed, there's a 96% reduction in your likelihood that you'll transmit HIV to your partners. It's almost nil. There's almost no chance that an individual that has a suppressed viral load will transmit HIV to someone.

[00:12:45] So, if we're talking about really addressing HIV globally while we're preparing ourselves for the cure in 2020, we'll have to do a lot more work after 2020 to get the cure to individuals that are actually in the epidemic. But if we just help people understand that there's a pill that you can take to avoid HIV, there are also other things that you can use to prevent the likelihood that you'll acquire HIV. And if you find out you have HIV, we can get you access to care; we can get

you access to treatment; and we can make it really unlikely that you'll ever give HIV to someone else. That's the message that everybody needs to hear in every corner of the environment and every corner of the globe. Everybody needs to know that information.

[00:13:19] I think what's most important for us at amFAR right now is that we recognize the value of human rights around the world, both domestically and abroad, because when we continue to see that domestically the African American community is the most heavily impacted by the HIV epidemic, it's clear why that's happening in some respects, because we know that in those areas there's less access to healthcare. There's an issue around employment access which, of course, is the main gateway to access to healthcare for those communities. And we also know that many of the school systems and many of the areas where the epidemic is at its worst have issues with educating individuals with comprehensive sexuality education so that individuals understand fully what puts them at risk for HIV and what they can do to keep themselves safe.

[00:14:02] So, I think when you come to it with a human rights perspective and you start to respect everybody's humanity and not just try to focus people in on the kind of human being you want them to be, human rights really gives you the access to really give everybody the tools and the information and the access that they need to keep themselves knowledgeable and safe and protected from HIV, both domestically and abroad, whether that's freedom from criminalization because people recognize that you're gay, or whether it's freedom from prosecution because people recognize that you use drugs – particularly injection drugs, or that people have issues with you because you're involved in the sex worker movement or industry. All of these things are particularly things that individuals may be involved in, but it doesn't mean that they should not have access to comprehensive health information and comprehensive healthcare access.

[00:14:50] And I think the human rights conversation helps us recognize that everybody is worthy, and that we all must work together to make sure that everybody that's worthy has access ... that they need to be safe.

[00:14:58]

Artel: Kali, why did you become involved with this issue?

Lindsey: I actually didn't follow this issue very much at all in my earlier part of my years. I was born in 1979, right when the HIV epidemic was happening, so I wasn't awake for most of those years because I was a kid. I was growing up, being happy, and I was in school. And then one day, everything changed when I recognized my own sexuality was coming into development, and I recognized that I was at risk for HIV, and I had to learn something about how to keep myself safe.

[00:15:28] Unfortunately, I'm part of that community, because the information that was given to me didn't work for me.

[00:15:32] And later on ... So, I graduated from college and I found out that I had acquired HIV. I became mobilized to really do something about it – to help information get out to everybody that was not getting access to it in the same way that I hadn't gotten access to it, and I wanted to make sure that everybody had the tools that they needed to keep themselves safe; or, if they, like me, seroconverted – that they had the information that they needed to keep themselves healthy and safe and not transmit HIV to others.

Artel: Thank you for sharing that.

Lindsey: Thank you for having me today, and thank you for being open to this conversation.

[END OF INTERVIEW]