

AJPH Podcast—July 2021

CONSISTENT GRASSROOT VOICES ON THE WAY TO END THE HIV-AIDS EPIDEMIC
Alfredo Morabia

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GA If we're convening policy-setting tables or if we're developing programs, the people who should be leading those conversations are people living with HIV and who shoulder disproportionate risk for HIV.

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[musical interlude]

AM Hello and welcome! This is the July 2021 podcast of the American Journal of Public Health. In 1981, 40 years ago, HIV was a game changer. Society was transformed in many ways, some for the better as communities most affected such as the gay community would stand up for their rights; but society was also transformed for the worse, as some communities were slashed by the epidemic, and the threat of the disabling and often deadly infection would cancel the naivete of the sexual liberation years of the 60s and the 70s. In 40 years, HIV/AIDS has infected 76 million people in the world and killed 43% of them. HIV/AIDS still infects about 1.7 million persons every year. In this issue, Deputy Editor Farzana Kapadia and Associate Editors Stewart Landers and Lisa Bowleg have assembled articles reviewing the record of the HIV/AIDS epidemic and

emphasizing what's need to further control and eradicate this persisting pandemic.

Today with my guests, representing voices from the LGBTQ, Latinas, and Black women communities. We discuss what they see as the top priority now to finally end the HIV epidemic.

GA My name is George Ayala; I'm the Deputy Director of the Alameda County Public Health Department.

AM Thank you, George. Hortensia?

HA I'm Hortensia Amaro, Distinguished University Professor at Florida International University.

AM Thank you, and Dàzon?

DD I am Dàzon Dixon Diallo, Founder and President of Sister Love in Atlanta, Georgia and Johannesburg in South Africa.

AM Alright, so 40 years ago, there were the first clusters of diseases—pneumocystis carinii pneumonia and Kaposi's sarcoma—and here we are, 40 years later, in this HIV/AIDS pandemic; and I'd like to review the situation for several communities in particular that have been heavily impacted by this pandemic. And I'd like to start with you, Dàzon, because you use the Sankofa symbol. So, tell us about this paradox and why you use it as a symbol of the current state of the pandemic.

DD So, you know, in the African tradition, the Sankofa symbol really means you have to know where you've been but you're facing forward while you're looking backwards. So, that means you're learning from your past as we move forward. And there's this other part of the symbol that protects an egg on the back of that same bird, right? So that bird is looking backwards, moving forwards, but protecting that which represents in-between.

And that is how I see women, especially women of African descent, cis gender women, and women in all of our identities—transgender, gender non-conforming, and especially those assigned female at birth, right, is that we have been a part of this epidemic from the very beginning, whether it's been in contribution, science, in the community organizing. As people living with HIV, we remain invisible in so many different contexts; but the real thing here with why the Sankofa paradox is so important is because if we don't capture what we've learned from excluding any population over the course of the 40 years of this epidemic, we will never reach the end. And my second part to that is it's probably the people who have been overlooked the most who are most likely to lead us to the end, and that's really why the Sankofa paradox is the best symbolism I have for when talking about the state of Black women in particular but women in general in the overall HIV epidemic over 40 years.

AM So, Dàzon, how do we involve practically women of color and under a group that have been hit by the AIDS epidemic. So, I've got three things: One, of course, we have to practice full inclusion. That's the most important thing. We have to make sure that women's lived experiences, our knowledge, our skill base, our leadership capabilities that we have to bring are included. Second, we also want to make sure that we are actually elevating the role that community plays. So, community engagement needs to be up-ended. Community engagement belongs in community. It doesn't necessarily only belong with the providers of services or the researchers or the principle investigators at sites; but community engagement belongs with the community, and the community deserves a full equal partnership in all aspects of the HIV response. So, really lifting up even community research, right, lifting up every part of the community's engagement and its

value. And then the third thing, I think, which is probably the most is making sure that all of our HIV services—education, prevention, treatment, care, advocacy as well as support—are provided where people seek their care the most. A lot of folks are still stigmatized by going to HIV-only specific care; but for about 70% of the women in the United States primarily seek their health care through their reproductive health providers. And if the HIV and STI services are not there, then we're missing us. We're missing large opportunities for engagement as well as for increasing our outcomes with regard to achieving viral suppression, complete prevention, and of course the end of HIV.

AM Thank you. And so, Hortensia and George, how does this sound with respect to your perspective in other communities?

HA Early when I was involved, there was a lot of focus on HIV prevention and how to get people to use a condom, and it wasn't until some of us wrote articles [to] say, wait a minute, women don't use condoms, their task is really different, they gotta talk a man into using a condom, and now that's a whole different behavioral challenge, and you haven't taken into account issues of power, gender roles, and trauma and abuse, and so really when we started writing about that, it helped to shift the prevention approaches to be more focused on how the qualities of these relationships really impact women's risk. So, we need to learn from the past, and we could probably cite many examples. You know, the CDC criteria early on did not include women, and it wasn't until women came forward and said wait a minute, because it meant that their HIV care wouldn't be paid for and they couldn't receive it because it was not listed under the criteria.

AM George, what's your perspective?

GA Ken Horn who was a gay sex worker became the first person diagnosed with AIDS, and preceding that was Robert Rayford. Robert was a Black young man from Old North neighborhood of St. Louis, and he died of pneumonia in 1969 after enduring severe chlamydia infection and Kaposi's sarcoma. Post-mortem testing on Rayford's tissue samples confirmed HIV infection. And so, as we reflect over the last 40 years, we have to remember how HIV is happening; HIV is not equally distributed in the general population. It concentrates itself in vulnerable populations—women and girls, especially in southern eastern Africa, and gay and bisexual men, sex workers, people who use drugs, transgender women everywhere else in the world, we have to be talking about concentrated epidemics and we have to be talking about the ways that we organize HIV responses.

[musical interlude]

AM Hortensia, in your editorial, you draw a picture of the situation, for Latinas, lack of research, communication, access—so why have we reached this situation for this community?

HA Well, with Latino populations and all its diversity, it's really the largest minority population, and that there's just still this invisibility when it comes to HIV but also research in general including public health prevention, so it's very consistent about really needing to make the response specifically relevant to the populations you're trying to reach. So, we continue to have obstacles related to language, the culture, the stigma, the lack of health insurance, barriers to care add up; and we see similar barriers in substance use treatment where Latinas, for example, the opioid epidemic, are greatly underrepresented, have greater obstacles to care. So, why? Well, because we continue to

have great disparities in our society and in health care, and we tend to not understand or bother to know the history of how structural racism has occurred in the US in different populations, how it's played out differently, and how the consequences are different. So, we're becoming more aware of Black [life] health disparities when people are beginning to recognize some of the root causes, but people rarely know when the US took over Puerto Rico and Cuba how it set certain economic and politic disenfranchisement for people in the island or along the US/Mexico border and how people were disenfranchised when whole communities were taken. People couldn't vote, couldn't own land, et cetera. So, we really need to understand more broadly how racism has impacted and manifested in communities differently.

DD Hortensia, I think when reviewing and reading both yours and your editorial, George, it's sort of like we were sitting in the same room having a conversation while we were writing our papers. And so, I'm loving the symbiosis and the synching of what we're doing, and the synergy itself. One thing that I think is pointed out most throughout all of this conversation is the power of recognizing, acknowledging, and doing the work at the intersections, right? Intersectionality not only allows us to see the whole persons, and in some instances the whole populations, that are most impacted, but it also gives us a different opportunity to work differently, to work together, to work across issues, and to build a different kind of response to HIV that, while we're tailoring to specific people by using people-centered programming or human-centered design, at the same time we can look at the historical structures as well as the contemporary frameworks in which all of the silos are working against us. And I think the bigger the silo, the more invisible a population can be, and so that's where I really hear, Hortensia, is the bigger role the

intersectionality and recognizing it and incorporating it, because people live intersectional lives, so the HIV response should have intersectional responses.

GA Yeah, I completely agree with that, and we have to swim further upstream to really understand and address what's happening with HIV, not only here in the US but around the world. Sex between men, for example, is criminalized in 68 countries, and 89 countries criminalize HIV transmission, exposure, and non-disclosure. And here in the US, 37 states still criminalize people living with HIV, laws that disproportionately affect economically poor people, Black and brown people, and gay men. How do we lift up HIV programming under those conditions, under horrendous human rights conditions here in the US and around the world?

AM And I think all of you are stressing the fact that to find the solution we must integrate the people that are first affected by the disease and without their voices it's impossible to be effective.

[musical interlude]

AM George, something you raised in your editorial, you mentioned that the advance of therapies, treatment for AIDS and HIV, which is a great achievement in itself, also tended to disenfranchise the communities that had been so active in taking care of their own in the 80s and 90s. Can you explain to us how can an effective therapy have paradoxically negative impact on the progression of the epidemic?

GA You know, biomedical prevention and treatment of HIV began in 1996 with the introduction of antiretroviral medications. And although that was heralded as a hard-fought win by activists, HIV responses that are singularly focused on biomedical interventions overlook persistent social drivers of HIV, and it also keeps people most

affected by HIV in narrowly defined roles. For example, we think about community folks only as outreach workers or only as members of community advisory boards or only as peer educators. This is because biomedicalized HIV response situates power with the clinician and the trained professional. As a result, community members are often the lowest paid but hardest working and the last hired and first fired. They are also the last involved in decision-making, and that's what makes for entrenched power differentials between those who determine what services and programs are needed and those who use them. The HIV sector has become beholden to clinics and their funders as funding shifts away from community-authored and community-led responses; and ironically, access to culturally appropriate health care remains difficult for people living with and disproportionately affected by HIV, especially for gay men, transgender women of color, and people of color, here in the US and around the world.

AM Last year, I interviewed Admiral Giroir who was Assistant Secretary then and in charge of the End the HIV Epidemic, and he was genuinely concerned by these issues and integrating Latinos and African Americans. So, what's the recommendation to people who currently are running the End the HIV Epidemic program in order to be successful?

GA We've all implied the solution here which is if we're convening policy-setting tables or if we're developing programs, the people who should be leading those conversations are people living with HIV and who shoulder disproportionate risk for HIV. That's really quite key to me. It's not that our communities are not welcoming the biomedical interventions; we need to figure out how to weave them into the other things that our communities know how to do to take care of themselves. So, for me, it's really about putting communities first; it's about taking a human rights approach to the HIV response

and marrying a human rights approach to biomedical interventions and community-led and community-authored programs.

HA The beginning of the epidemic, many of us who were involved at the grassroots and onward were affected populations in one way or another, and so it was, you know, you're talking about when I think of the work that we did with Act Up and then women bringing their voices forward, my brother died of AIDS at 29 very early in the epidemic, so I was very aware of how that affected him and all his friends, and then I worked with women who were injection drug users and sex workers. So, we came with this inherent knowledge of what was needed on the ground, and then a lot of people came in as investigators in the AIDS epidemic and that was good. We came up with important solutions, but then the voice, the people affected, were more minimized. So, what I would say to people who appoint those leaders is that [we] really need to have those voices within the leadership. Secondly, also recognizing that biomedical interventions only get us so far, and we see that with most other diseases, and unless you address root causes, you're always pulling people out of the river. And biomedical researchers, I think, tend to overlook the behavioral challenges of getting broad adoption at a population level of these kinds of interventions.

DD So, I could have easily just said ditto and hit the mute button, right, because everything that George and Hortensia said are, you're speaking my language, and what I would add to that, there's a couple of things and thoughts. One, obviously supporting a rights-based approach that is justice centered, so it's not enough to win the rights of something that not everybody has equal access to, for example. And we can talk about PrEP in that regard, abortion in that regard, we can talk about a whole bunch of different things. And

so, the other message that would have, of course, is to really give more power, and I'm talking about an actual p-value-type power but also real robust recognition and acknowledgement of what the lived experience or the indigenous expertise of people who are living in the face of HIV whether they are living with HIV in their bodies or in their lives or working hard to not have HIV in their bodies and their lives, that these are the folks who have the stories that get us the solutions, right? And then, be willing and bold and courageous enough to transform the systems that aren't working. It is interesting that one of the things we know just from the data, for example, is that for people who have no other means to cover their HIV care or their medications, they're eligible for the Ryan White program, right? What I know, not only about how robust the program is because of its health care delivery system that's very localized, but because it also recognizes all of the other facilitative and ancillary services and needs, meeting the needs that actually help keep people engaged in the biomedical context—so, all of the other social safety nets that are needed. And what we've shown is that for people who are in the Ryan White care system they actually are achieving greater successes with viral suppression and reducing HIV incidence and transmissions, and it's not only that, but that system is also locally designed. It is decided by people in that community what their priorities are and how that money should be spent and on who needs it the most. That should be the way our entire health care system works from a prevention standpoint and being willing to transform systems to require community partnership in all aspects of biomedical research, treatment care prevention, being able to say that what we have with our current health system is not adopting the best of what we know in the HIV health system and vice versa. Those are the kinds of things I think at the level of an Assistant Secretary or

the Secretary or ODP office or the National AIDS Policy office, any of those—the acceleration of getting to the end of the epidemic, whether it’s using the End the Epidemic plan or whether it’s using a revised, revamped, and rebirthed national strategy, is that if we’re not working on changing systems, we’re still going to be at this very slow pace of trying to tackle an epidemic that requires rights-based, people-centered, human-centered, and indigenous expertise design in the midst of all the other models that we have.

[musical interlude]

AM Alright, there is a clear and consistent message coming out of this conversation. Even though my guests access the HIV/AIDS epidemic from different perspectives, they all converge to say that what’s needed now is more power to the LGBTQ, to Latinas, to women of African descent, to Native Americans, and other heavily impacted communities, power over the residual steps required to eliminate the epidemic. The biomedical response consisting in treatment and prophylactic therapy, PrEP, has not sufficed and will not suffice. In the January 2020 podcast when I interviewed Admiral Brett Giroir, the former Assistant Secretary of Health, the accent was placed on the need for federal funding, standardization, and guidance. This remains true, but my guests today insisted that it won’t work if the federal guidance is not combined with an effective local control of the interventions by the targeted communities themselves.

[musical interlude]

AM I am grateful to all the members of the panel for taking the time to share and discuss their ideas. I’d also like to thank Michelle Irving and Michael C. Constanza for edits on an earlier version of this podcast. Anthony Bansie is the student producer for today’s

episode. Francis Jacob chose to paraphrase the 1993 soundtrack of one of the first mainstream movies about living with HIV/AIDS. The papers discussed in this podcast are available on the Journal website. For more podcasts including podcasts in Chinese, visit us at www.ajph.org or subscribe to it on your usual podcast app. A full transcript of the podcast is available on our website for persons with hearing disabilities. This Alfredo Morabia at AJPH. That's it, thank you for listening!

[musical postlude]