Not Lost

The new Office of National AIDS Policy director seeks structural change and an end to the HIV epidemic.

November 15, 2021 By Heather Boerner

People tell Harold Phillips, MRP, that he's an extrovert. But he's not so sure, especially when it comes to "the work"—his life's work advocating for people affected by HIV and making policy in state and federal government agencies.

Harold PhillipsCourtesy of OIDP

"I've always just been doing the work, doing what looks and feels like it's the right thing to do," he says. "And here I am."

Here he is, indeed. Phillips, who has a master's degree in regional planning, has worked with the Ryan White Program, served as chief operating officer of the Ending the HIV Epidemic initiative and in June became the ninth director of the Office of National AIDS Policy (ONAP), a position also known as the U.S. "AIDS czar."

When he accepted the role, the United States hadn't had an AIDS czar since 2016. This interview has been edited for length and clarity.

How did you become involved in the HIV community and policy making?

I was always involved in tracking issues around the disability community and women's reproductive rights. Then, I got involved in AIDS work and was part of those groups of people who would march on Washington, DC, and do the candlelight marches and volunteer at organizations.

In graduate school in North Carolina, I was studying urban planning; I was going to do community development work. We were seeing the beginnings of the HIV housing crisis. When I learned that folks were coming home sometimes to die with loved ones [and about] those who were struggling between food and rent and medication, [I decided to do a class project on it].

I was doing the research and writing a paper as the HOPWA [Housing Opportunities for People with AIDS] program was starting. The AIDS director for the state of North Carolina at the time called and said, "Hey, we've heard you've written this paper. We've applied to HUD [the Department of Housing and Urban Development] for some funding for people with HIV and don't know a thing about what to do. They're going to send us $2 million. Can you meet with us and talk about what we might do as a state?" As a graduate student, I was like, "Sure!"

So I helped the state think through rental assistance for people living with HIV and adult day care [to relieve their caregivers], who were stressed out, exhausted and needing the assistance of someone to watch their loved ones. This was in 1992 or 1993. I was going around to different AIDS providers as well as housing coalitions to get them to understand the issues but also meeting with folks who were in that situation.

How are things going in your new role?

Having the support to bring together different departments—HUD, the Department of Agriculture—and thinking about educational settings and ensuring that we have a diversity of programs and a diversity of voices that are helping to influence policy has been great.

We're looking to revise the National HIV/AIDS Strategy by World AIDS Day, so some of the meetings that we have had with the departments [have been about] getting them to think strategically about how we do this work. We've had some initial conversations with them about some of the factors that put individuals at risk for HIV as well as some of the challenges that individuals have when it comes to maintaining the connection to medical care and taking medication and the life circumstances that get in the way. While [many programs in other departments] may not be HIV specific, we can use them to increase awareness at the community

level of enrollment in HIV care and eligibility for care.

One of the things that I think we've struggled with is that by the time someone becomes HIV positive and reaches our clinic doors, there's a host of things we could have done to keep that individual from becoming sick. So if we had worked on the housing issues, if we had worked on the employment issues...

I forgot to mention the Department of Labor has also been a great partner to have at the table lately, thinking about HIV and employment and income inequality issues. It's been exciting to be able to have those conversations and have a group at the table that understands these things and is looking at ways for a greater partnership with our traditional HIV stakeholders.

You are a Black gay man living with HIV. How does that inform your policy work?

I have been fortunate to be able, especially among respected colleagues, to not only talk and speak from what's happening at a population or community level but also to add my personal experience. One time when I thought that was important and I saw a powerful change happen was around the messaging for U=U [Undetectable Equals Untransmittable]. I was working in the Ryan White Program, and we were talking about what we might or might not say about U=U. Should we put out additional guidance to Ryan White recipients and the community around this?

Being a person in that room living with HIV, I shared my personal experience that, even with everything that I know, I still have that small piece of internalized stigma. I shared with them a story of chopping vegetables with my nieces. I accidentally cut my finger, and I just freaked out. They wanted to help me put a bandage on it. And I was like, "Girls, get away. I'm fine."

In that moment, you didn't feel like you could let your nieces kiss your boo-boo?

Exactly. I ran off to the bathroom to clean up the blood quickly. I realized my reaction scared them more than the actual cut. I had to sit down with them and talk them through it and explain to them that I was fine and that I think I overreacted: "And look, I got a bandage. It's OK. Let's go back in and finish dinner."

Because you were undetectable?

Yes. It made no sense, but I had to acknowledge that fear. If it's happening to me—somebody who's undetectable and knows there's no chance of transmitting the virus—then we need to begin messaging this differently.

I told this story to colleagues, and I said that every person living with HIV has that fear. If we can do something to alleviate that stigma, we need to do it. So we put together a work group and worked on what that guidance would be, which would go out to providers and to people living with HIV, endorsing the message.

I don't know if we would have moved as quickly and in the direction that we did if I hadn't been

there sharing my painful experience.

What was the message you sent out?

We reiterated the data. We talked about the importance of viral suppression and not being able to pass the virus on to others, especially your sexual partners. We also talked about the importance for health care workers to deliver this message and to use it both as an incentive to get individuals into care and to help them stay in care and remain undetectable.

What would you say to your younger self about what's possible for you as a person with HIV?

It's not lost on me when I'm running around the White House campus that I'm in a place that was built by slaves.

When I run into the Eisenhower Building, I know that the Eisenhower administration had the executive order about "sexual perversion," [classifying gay people as] a national security threat. They drummed out a lot of federal civil servants who were gay.

So it's not lost on me when I stand there sometimes. I just take it all in and just think, "You're doing this."

That I have the opportunity to try to make our country a better country—it's not lost on me, and I do not take it lightly.

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