P+A
POSITIVELY AWARE
HIV TREATMENT, PREVENTION AND HEALTH FROM **TPAN**
SPRING 2022

‘WHY ARE YOU HERE?’
All researchers need to be scholar-activists

SUPPORTING BLACK LEADERSHIP IN HIV
Models of advice, guidance, and experience

GENDER INCLUSIVENESS
Five points organizations should consider

BLACK AND LATINO MSM
Creating new strategies for prevention

ARTIFICIAL INTELLIGENCE
Can we trust the data?

> ‘I felt like, because of sh-- that was put on me, I was not worthy of happiness, of love, of success. And I believed those lies. Until I decided not to, and changed my life, and affirmed every day that not only am I worthy, but that I matter, that my presence matters, that my voice matters.’
>
> —DOMINIC COLÓN

ALL IN
We all have a stake in overcoming disparities in HIV treatment and care

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TWO COVERS, ONE FOCUS
Dominic Colón and Dr. Tonia Poteat are featured on individual covers of this special issue.
COLÓN: WILBER POLANCO
POTEAT: GILLINGS SCHOOL OF PUBLIC HEALTH, UNC

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TPAN was founded in 1987 in Chicago as Test Positive Aware Network, when 17 individuals living with HIV gathered in a living room to share information and support in response to the HIV/AIDS epidemic. POSITIVELY AWARE is the expression of TPAN's mission to share accurate, reliable, and timely treatment information with anyone affected by HIV.

NOTE FROM THE GUEST EDITOR

CANDACE Y.A. MONTAGUE
@urbanbushwoman9

No more bystanders

DEI: three small letters with big potential. When I first started hearing about diversity, equity, and inclusion being packaged into one campaign I thought, *Meh. This sounds like something to alleviate white guilt.* Maybe it was and still is. But I think it's okay to capitalize on this moment. It's way past time to start focusing on people. And by "people" I don't just mean marginalized people. I'm talking about the people who are silently corroborating instead of speaking out.

The killing of George Floyd was a wake up call for some but a reminder for others. What did you do when you saw the video? Ignore it? Post an article about it on social media? Black and Latinx people have known for decades how dangerous the world is when ignorance and fear reign. With the emergence of COVID-19, we were reminded of how marginalized populations get hit faster and harder than most in emergency situations. But after the shit hits the proverbial fan, it seems like people do what they've always done: turn to survival mode and, like the early days of HIV, look out for themselves.

So, who is left to speak out about the gross neglect that has left minority populations vulnerable?

From my perspective, one of the best ways to fight for equity is for people to call out *inequity* whenever possible. And by people, I mean white people. Shaking your head and shaming the offenders in your private social circles does nothing to combat discrimination. White people calling each other out hits differently from when people of color do it.

Calls for diversity are great and should continue for as long as it takes to truly achieve it. But I wonder what diversity looks like to some people. I wonder if they look at things such as disability, religion, and age. I wonder if they consider economic backgrounds and political allegiances.

Inclusion should be at the top of everyone's list when planning anything, whether you are restructuring an organization or planning a focus group. No more press releases that tell how you stand with marginalized populations. Show us how you do it. What does your management team look like? Who is making decisions? What kind of assessment will you employ to ensure that you're doing this right?

If you get nothing else from this issue, I hope that you will be motivated to do something on behalf of those whose voices are often muted. The contributors and I have included some noteworthy action items in this issue that can help fight stigma, ableism, homophobia, ageism, and most of all, white supremacy.

You will read about how inclusion is not just doctrinaire language but a gold standard. In Olivia Ford's article about how to incorporate transgender, gender nonconforming, and nonbinary people, you hear the voices of people who live this life every day and know the change they want to see. Listen to them and then do something about it.

Charles Stephens wrote a powerful opinion piece that discusses how you can support Black leaders in the HIV justice movement without yielding to fear or becoming an unwitting facilitator of white supremacy. Ever hear of a ***gatekeeper***? You may think differently about that word when you read his musings.

Not everyone can organize a protest or make great speeches. But it's time to do something.

Sannisha K. Dale, PhD, EdM, wrote the following in her personal essay on HIV researchers becoming scholar activists: "Addressing the HIV epidemic demands an approach rooted in social justice and intersectionality given that HIV inequities are driven by interlocking systems of oppression inclusive of racism, heterosexism, cisgenderism, sexism, ethnocentrism, poverty, and more." What does research have to do with social justice you might ask? She explains the connection in her piece.

Not everyone can organize a protest or make great speeches. But it's time to do something. This won't go away. Finding your voice in writing or theater or photography or whatever works for you makes a difference. You can help make DEI a required part of planning and execution of HIV treatment, care, and prevention. Find your way and do it.

No more bystanding.

Candace

CANDACE Y.A. MONTAGUE (*she, her*) is an award-winning, independent journalist based in Washington, D.C. She covers health, gender equality, and social justice topics for several local and national publications. She has been covering HIV and AIDS news since 2008.

WILDPIXEL -ISTOCK

‘Why are you here?’

Addressing HIV demands more than scholarship. All HIV researchers need to be scholar-activists

BY **SANNISHA K. DALE, PHD, EDM**

Why are you here? **is a question that a comrade living with HIV asked when I first approached her many years ago to collaborate on work among women living with HIV. In varied forms (e.g., *why are you interested?*) she has asked this question over the years to candidates applying to work with our team, including research coordinators, graduate students, and postdoctoral fellows. In some instances, she has explicitly stated that if you are here simply aiming to build your resumé, get a degree, or advance your career, there is no need to continue. For her, their potential contribution to the work is limited if advocating for, uplifting, and improving the daily lives of people living with HIV is not their core reason. I agree, and strongly believe that all HIV researchers should be scholar-activists.**

Scholar-activist combines two terms to describe academics who simultaneously engage in scholarship (academic study or achievement) and activism to promote social justice and improve lives. Addressing the HIV epidemic demands an approach rooted in social justice and intersectionality given that HIV inequities are driven by interlocking systems of oppression inclusive of racism, heterosexism, cisgenderism, sexism, ethnocentrism, poverty, and more. Everyone in the field, especially researchers with privilege and access to resources, ought to ensure that their research questions, process, findings, and dissemination help to improve the lives of PLWH and challenge the drivers of inequities.

Problems with current trends

SCHOLARS ENTER HIV research for various reasons. Some enter because of a genuine desire to make a difference in the lives of people impacted, create a personal narrative, and/or establish a proximity to people living with HIV (PLWH) and communities most impacted. Others enter because they find it interesting, and it is, or was, an area of work being conducted by a mentor. Their entry points can be problematic if young scholars are nurtured to merely approach HIV research from the angle of what is “interesting” to them. PLWH and the impact of HIV should not be reduced to a thesis or dissertation question that will not have a positive impact on the lives of PLWH. Further, research questions should never be arrived at in a vacuum and without being informed by PLWH. As harmful as this is, some scholars enter the HIV field because of perceived opportunities to launch their careers and secure grants by reiterating the HIV inequities affecting minoritized communities. The extent of their work may involve minimal contact with PLWH beyond the intellectualization of factors and issues impacting the lives of PLWH. In 2021, Dr. Elle Lett coined the term “health equity tourists” to describe the phenomenon of scholars who lack adequate knowledge and commitment to advancing health equity, jumping onto the bandwagon of applying for equity-focused grants and negatively affecting funding and publishing opportunities from minoritized scholars with the necessary expertise in health equity research. The term immediately resonated with me because of the parallel behaviors I have witnessed HIV scholars engage in.

The reason why a scholar initially entered HIV research does not need to remain the same throughout the

decades of their involvement, but I have witnessed that many HIV researchers have settled into the narrative of HIV research being what they do for their career, be it via research projects, publications, presentations, or leadership roles. This is wrong and harmful as it relegates PLWH to individuals to study and use for career gains, rather than a community fighting for the full range of their humanity in the context of stigma, who we as scholars should fight alongside.

Becoming or improving as an HIV scholar-activist

IT IS IMPORTANT to clarify that scholar-activism is not limited to HIV social and behavioral researchers whose content focus may include the study of social factors. Everyone who benefits from HIV research funding has an obligation to utilize their scholarship in advocating for the well-being of PLWH. Whether you are a basic researcher examining factors relating to HIV at the cellular level or a neuroscientist examining the impact of HIV on the brain, you can and should be a scholar-activist. There are HIV researchers who are and have been scholar-activists throughout the decades, but they remain an exception and instead should be the norm. There are no constraints on how to be an HIV researcher *and* a scholar-activist, but below are several questions for HIV researchers to reflect on and make concrete changes.

Everyone who benefits from HIV research funding has an obligation to utilize their scholarship in advocating for the well-being of people living with HIV.

- Are you partnering with PLWH and community-based organizations to arrive at research questions, determine how the research will be carried out, and decide on how to best disseminate findings beyond academic spaces?
- If you are partnering with PLWH and community-based organizations, is an equitable proportion of your research budget going to community partners and PLWH?
- On your research team, how many members are PLWH or members of communities placed most at risk for HIV? What are their roles on your team, and is there a pathway to advancement? If they are only delegated to recruitment roles (while being essential), without opportunities for training and advancement, that is problematic.
- In the face of institutional hiring policies (e.g., rejection based on incarceration and substance use histories, credit checks) that often penalize PLWH for the very consequences of the oppression (e.g., racism, heterosexism) they face, what are you doing to advocate with human resources to ensure the hiring of PLWH?
- When you recruit and interview trainees to mentor, does your selection process value lived expertise and the candidates' long-term commitment to positively impact the lives of PLWH or those placed most at risk?
- In mentoring PLWH and people placed at risk, do you view them as an extension of your work, or are you mentoring them to chart their own journey and one day replace you as they become established investigators equipped with both the lived and academic expertise needed to end the HIV epidemic?
- How often do you engage with PLWH and people placed at risk outside of academic institutions? Is this equivalent to how much time you spend giving talks about PLWH to other academics?
- When you are invited to give talks, sit on panels, or be interviewed, do you insist that the organizers meaningfully include PLWH, and offer payment?
- If you occupy leadership roles in centers for HIV research, do you utilize your voice to ensure that adequate monetary resources are directed to community engagement efforts? In addition, what are the roles occupied by PLWH, and are their voices impacting the allocation of resources? If PLWH are primarily on a community advisory board that is treated passively without their insights driving leadership decisions, this is not meaningful engagement.
- How responsive are you to community advocates when they ask for support that is not linked to one of your research aims or outcomes?
- Are you lending your voice to advocate against policies, laws, and practices entrenched in racism, heterosexism, cisgenderism, and ethnocentrism impacting the lives of PLWH and those placed most at risk?

SANNISHA K. DALE, PhD, EdM, (*she, her*) is an assistant professor of psychology at the University of Miami and a licensed clinical psychologist specializing in conducting research on the intersection of mental and physical health and developing interventions.

'We declare that research on transgender people must benefit transgender people'

THAT'S THE last line of a letter to *The Lancet*, written by transgender advocates Brian Minalga, Cecilia Chung, J D Davids, Aleks Martin, Nicole Lynn Perry, and Alic Shook expressing their concerns about research involving transgender people.

The letter was published in the February 12 issue of *The Lancet*, written in response to articles previously published in the British medical journal, and to the frequent study of transgender people as objects of intrigue rather than as people. The letter states that rather than simply studying transgender people, they should be consulted and listened to. It also addresses how too often trans people are studied out of curiosity, rather than out of a desire to benefit the trans community. Citing recent conclusions made in the field of public health stating that transgender women partner with cisgender, heterosexual men, the letter illustrates how this kind of trans research can directly harm transgender people. These conclusions were arrived at through the use of HIV-molecular analyses and phylodynamic analyses, both of which "are reported to have alarming limitations, questionable ethics, and potentially harmful consequences." In addition, they note that the finding might be "astonishing to the dominant research establishment," but is well known in the community. The research also fuels transphobia.

The letter asks researchers studying transgender people to consider who this research is meant to benefit, and why it is being done. The main reason transgender people should be studied is to improve their lives and address their needs, the letter reasons. Existing knowledge held by the trans community can be accessed through communication instead of stigmatizing methods of analysis. Rather than conducting research on trans people which will harm them, research regarding trans people needs to support the community and its needs.

—**JACK REDING** (*they, them*)

Learning from experience

How to support Black leadership in the HIV movement

BY **CHARLES STEPHENS**

When I founded the Counter Narrative Project (CNP) nearly eight years ago, there was so much I did not understand about navigating whiteness as a Black executive director of an organization situated within the HIV movement. Certainly, I had experienced racism in my daily life, both structural and at times interpersonally. But through the process of founding and leading an organization, navigating racism felt far more public and more visible. I believed at the time that how I responded would be judged on a different scale, a larger scale, by friends and adversaries alike, than the times I've had to grapple with racism before. I felt really exposed and vulnerable. My experience as a Black leader has at times felt like an improvisational performance. To sustain my work, and maintain my emotional wellness, I sought to create theories and models of leadership. This has led me to reflect on the many lessons I've learned and am still learning. Lessons that I would like to share in hopes that others will share with me.

Being afraid is all right, it eventually passes

It may be scary taking on powerful institutions even in the name of a righteous cause. Whether you are meeting with key individuals, issuing a public statement, collecting signatures for a sign-on letter demanding change, or organizing a full-scale protest, the necessary and critical work of challenging racism can be utterly terrifying at first. But I can honestly say looking back, that every time I challenged racism, whether I'm addressing singular individuals or multi-million-dollar organizations, I've never regretted it. My regrets, if I have any, are the battles I chose not to take.

Don't become their secret weapon

I'm not sure if it's the lure of power or the unchecked and unrecognized internalized racism that so many of us carry into our movement work, but one of the most effective ways that white supremacy works against us is when we, as Black leaders, are weaponized against each other. Let us not forget the legacy of COINTELPRO, birthed by the FBI, which would surveil and infiltrate groups, such as the Black Panther Party, cooking up conflicts and creating dissension for the sole purpose of destroying the organizations and the leaders involved. In 2022, perhaps we may not have FBI informants whispering into our ear, but there may be forces, folks clearly seeing the power we hold, and are threatened by it. We may need to bring discussions such as this more fully into the HIV movement space. The palace intrigue, rampant in many bureaucracies, including HIV organizations, might lead one to believe that success and treachery are one and the same. We must be on guard against the temptation to harm each other for our personal gain, and the external forces cheering us on to do that. That is not to say we can't hold each other accountable, but accountability must not be confused with sabotage at the behest of white patrons.

ILLUSTRATION: ROBIN OLIMB-ISTOCKPHOTO

Allies don't check boxes, they share resources

If there is ever a white supremacist trap that well-meaning, anti-racist white allies fall into, it's the lure of being the great white gatekeeper. No matter what good you hope to do in that role, gatekeeping, even among the most well-intentioned white folks, are the tracks that white supremacy runs on. When anti-racist white allies are approached by other white people in the media or funders or elected officials, to help them find Black people for splashy news features or grant opportunities or policy formulation, they have to be courageous enough to resist that role, with few exceptions. You should be very careful about putting yourself in situations where you alone can wield the power, unchecked, to determine the destiny of Black leadership.

There are those who might suggest that struggle is universal for all leaders. But there are vulnerabilities for marginalized communities that make the texture and consequences of those challenges different. To respond to those challenges two things that we should consider advancing are:

- Mentorship programs for new Black executive directors and organizational founders coupled with peer support networks.
- More research around Black founders of organizations in the HIV movement to offer best practices around sustainability.

My hope is that Black leaders and other leaders of color are willing to share our lessons learned with each other, not just to provide advice and guidance, but to share experiences so that we know that we are not alone. This will not solve racism, but not feeling alone gives us the strength and the fuel to fight another day.

CHARLES STEPHENS (*he, him*) is the founder and executive director of the Counter Narrative Project (CNP). His writings have appeared in *The Atlanta Journal-Constitution*, *Atlanta* magazine, *The Advocate*, POSITIVELY AWARE, and *Georgia Voice*.

Perspectives on gender inclusiveness

Five points for organizations to consider

BY **OLIVIA G. FORD**

GILLINGS SCHOOL OF PUBLIC HEALTH, UNC

“For a long time, we as trans, gender nonbinary, and intersex (TGNBI)* individuals have been asking for organizations and institutions to be inclusive and understanding of our community,” summed up veteran community leader Bamby Salcedo in a recent conversation. “It has been a long struggle.”

In recent years, there has been more widespread attention to the disproportionate burden of HIV in trans communities—a recent meta-analysis found that trans women are 66 times more likely, and trans men almost seven times more likely, to be living with HIV than the general population of adults worldwide. Not only these stunning numbers, but also the conditions of social exclusion and constantly looming physical and structural violence that increase vulnerability to HIV among TGNBI communities, are also more widely known. However, the volume of groups providing authentically affirming, appropriate services for and with people of trans experience has not nearly kept pace with the magnitude of need for such spaces, nor have funds to support their creation.

POSITIVELY AWARE asked six stakeholders holding a range of roles—from training to cutting-edge research to grassroots organizational development and broader queer and women’s community leadership—for their thoughts on what organizations ought to consider, and often overlook, in approaching inclusion of transgender, gender nonconforming, and nonbinary clients and staff.

* ***A note about language:*** *Slight differences in the ways interviewees refer to communities of transgender/gender nonconforming experience remain as they stated them, without being edited for consistency throughout this article. Acronyms are included at times for brevity.*

Investing in community expertise

TORI COOPER Director of Community Engagement for the Transgender Justice Initiative, Human Rights Campaign, Washington, D.C.: “I believe the single most important point is to have trans people at the center of the work: in decision-making, implementation and, when appropriate, evaluation processes. This starts by employing trans people to do ‘trans work.’

“Being the ‘first’ or ‘only’ comes with a certain level of tokenism in itself. It is the responsibility of the individual to open doors for others. But it should also be the priority of every institution to increase diversity in myriad ways."

TONIA POTEAT, PHD, MPH, PAC Associate Professor of Social Medicine at University of North Carolina System, Durham, North Carolina: "Promoting and supporting trans/nonbinary [TNB] leadership within and outside the organization is important for equitable partnerships. Hiring TNB people into meaningful positions in the organization is important and may require identifying existing barriers to employment [e.g., unnecessary background checks or educational requirements] and removing those barriers."

BAMBY SALCEDO Cofounder, President and CEO of Translatin@ Coalition and the Center for Violence Prevention and Transgender Wellness, Los Angeles: "Even some of us who are employed at organizations that have programs specifically dedicated for trans people are also limited by, for one, not necessarily having decision-making power [in the organization].

"Although there are some organizations that do understand the struggle and experience of TGNBI people, we as a community have also realized that we have to create our own organizations."

HEIDI BREAUX, DWS, LCSW-R Founder, Heidi Breaux Consulting, LLC, New Orleans, Louisiana: "TNB people should be on every board and every executive team of every organization that is LGBTQIA+ serving. It is long past time we stop defining people by their educational experience and credentials.

"We have existed in a community of TNB elders that have survived unimaginable oppression by always pooling our resources, learning information, and supporting each other. Therefore, we have expertise on many topics—which shouldn't be given away for free to help cis people excel in career paths that we are excluded from.

"Putting cisgender expectations on TNB people's work experience is a mistake. The life experience of TNB people provides qualifications that are unmatched by any university, program, or degree."

WENDI MOORE-O'NEAL, Co-Director, Southerners on New Ground, New Orleans, Louisiana: "I came out in Atlanta in the '90s, as a 19-year-old. At that time, most of the organizations that were organized in public were organized around addressing HIV/AIDS. So many of the people who I knew, and connected to, and associated with around queer justice were people who were connected to, or starting, organizations that addressed HIV—and so many of those folks were trans.

"Whatever we are doing in [the] queer movement, we should know that we are following behind trans people—we are the beneficiaries of things that trans people have already done."

Understanding and respecting lived experiences

SALCEDO "The needs of our community are very complex. Organizations that are not trans-led don't necessarily understand the root of the issues and the struggles of the community, nor support communities the way they need to be supported."

POTEAT "It's important for organizations to take the time to really understand the lived experiences of transgender people with whom they seek to work. Take the time to engage with existing community leaders [formal and informal]. Understand what is already being done by the members of TNB communities, then collaborate to facilitate addressing community priorities."

KATIE ADSILA WILLINGHAM Co-Chair of the Alabama Chapter of the Positive Women's Network-USA; Community Advisory Board member and blogger for The Well Project; Alabama: "[At the first women living with HIV event I attended, in 2016], the women completely respected me and treated me like I wasn't a stranger. They respected me for who I was, and it was like it was nothing to them. That was the first time I had experienced that, especially being from Alabama. That really meant a lot to me, to feel that respected and that affirmed. The affirmation and support that I felt were among the biggest reasons why I got into advocacy.

"I've been really happy with the organizations I have been fortunate enough to come in contact with and be a part of."

Acknowledging intersections (and disconnections)

BREAUX "More organizations should take into consideration the diversity of the TNB community. Having one trans client two years ago, one trans person on staff, multiple masculine-centered white nonbinary clients, is not doing the work.

"To provide affirmative services to the TNB community, in addition to best practices for inclusiveness with gender, you also have to create a safe space that welcomes BIPOC (Black, indigenous, and other people of color) folx, immigrants including undocumented people, formerly and wrongfully arrested and incarcerated people, non- or limited-English speakers, neurodiverse people, family,

FROM TOP LEFT: **WENDY SING, HEIDI BREAUX, TORI COOPER,** AND **BAMBY SALCEDO**

youth, elders, housing insecure people, long-term HIV survivors, and so much more. This *is* the TNB community."

COOPER "It is often easier to hire a Harvard-trained person of trans experience than it is to hire a Black trans person who lives in the same ZIP code as your organization. [Yet] simply being Black or trans does not automatically mean your employee is connected to the community. ... Often, the most impactful and meaningful work will come from people who more closely align with the work."

MOORE-O'NEAL "All trans people are not challenging transphobia or committed to transforming patriarchy (which in my mind is the root of the issue), or capitalism, or white supremacy. ... While visibility matters, and representation matters, [a person's] politics, and agenda, and commitments, matter even more."

Integrating individual and cultural transformation

POTEAT "Organizations often overlook the need for internal change. Aspects of existing organizational culture may need to change in order to truly meet the needs of their clients. Organizations may need to fundamentally rethink how they conduct business to ensure that their organization and the services provided are truly welcoming, inclusive, acceptable, and appropriate."

MOORE-O'NEAL "We had a trans woman at our last in-person membership meeting say: *What's happening here? How is the work with Black trans women in particular in this region being supported by SONG* [Southerners on New Ground, which has supported queer and trans community organizing in the U.S. South since 1993]*?* That was a really valid question, and I think they were able to ask that question because SONG has been asking those questions of itself, as a space where the leadership takes those questions seriously."

SALCEDO "The root of the problem is the structure that has marginalized and discriminated against us. What needs to happen [in organizations] is setting policies that are non-discriminatory, and non-biased, and also providing cultural transformation to employees to change the culture that has been created to not understand, include, or even validate TGNCI people.

"Cultural transformation is not capacity building—it is transforming the culture within institutions, to then transform the broader culture of society."

MOORE-O'NEAL "Yes, I've internalized white supremacy, homophobia, patriarchy, capitalism, transphobia ... I have a commitment to fighting transphobia, but that doesn't erase the ways I have internalized these notions. I'm not trying to pretend it's not there; I'm trying to have a kind of hygiene about it. Just as you have to brush your teeth, and floss, and have a daily regimen for maintaining oral hygiene—how I see it is, what are my practices that help me to maintain my *liberatory* hygiene? And those [times when my hygiene might need improvement] are actually valuable for me to be able to reflect on and grow, putting into practice what I have learned."

Honoring commitments—or facing consequences

WILLINGHAM "It helps to not treat trans individuals like 'trans individuals'—just treating us the same as anyone else, to me, is a big thing."

BREAUX "It's nice to have all-gender bathrooms, but how is staff held accountable when they misgender someone at the front door? How are workers who oppress TNB people in the workplace [intentionally or unintentionally] receiving consequences?"

SALCEDO "What oftentimes happens is that policies are created, but then individuals don't even know or understand them, and they still do the same things. There needs to be an accountability process for organizations and leaders when [exclusionary] situations happen. They should not continue to get funding to do this work if they are not capable of doing it ... and individuals who don't follow the values of the organization should no longer be there."

OLIVIA G. FORD (*she, her; they, their*) is a freelance editor/writer and editorial director for The Well Project, an online information, support and advocacy resource serving women living with HIV across the gender spectrum. Her work has appeared in *Black AIDS Weekly*, POSITIVELY AWARE, *POZ*, *Rewire*, and *TheBody/TheBodyPro*, among other outlets. She has worked primarily in HIV-related media since 2007.

New approaches

Creating more effective strategies to reduce new HIV rates among Black and Latino MSM

BY **MARK FISCHER**

We know that pre-exposure prophylaxis (PrEP) and viral suppression have achieved the most success in reducing new diagnoses of HIV and advancing the end of the epidemic. While PrEP prevents an HIV negative person from acquiring the virus, being virally suppressed means that someone living with HIV cannot pass along the virus. Together, the two trap HIV where it is and block its spread.

Drops in new HIV diagnoses among Black and Latino MSM (men who have sex with men) are lagging behind those for white MSM. How effective are the current prevention efforts in reaching Black MSM and Latino MSM? Why are current efforts failing? And what changes will increase success?

New infections dropped among white gay and bisexual men, but stayed flat among Black and Hispanic/Latino gay and bisexual men, reported a media release last December. From 2010 to 2019, new HIV diagnoses remained stable among Black men who have sex with men (MSM)—from 9,000 to 8,900—rose among Latino MSM (from 6,800 to 7,900), and declined among white MSM (from 7,500 to 5,100).

In 2019, Black MSM (8.9% of all MSM) accounted for 25% of the new HIV diagnoses and Latino MSM (15.9% of all MSM) made up 21% of the new HIV diagnoses.

Black and Latino MSM face many of the same barriers to both PrEP and viral suppression

A general distrust of the healthcare system can be compounded by language and cultural differences that lead to miscommunication and perceived disrespect between providers and patients. Language differences severely limit the ability to find and secure needed services and access to public benefits to make care affordable. HIV stigma and homophobia greatly limit the providers that MSM will use.

Multiple studies have found that a provider's personal biases could potentially cause them to refuse to prescribe PrEP. One bias is the heterosexism of a straight doctor who has a negative moral view of homosexuality and thinks PrEP will promote it. A bias imposes the prescriber's moral judgments onto patient care, denying PrEP to an MSM with a history of condomless sex. Some providers have a negative bias against "other" cultures and think prescribing PrEP is undeserved. While researchers found no significant incidence of such bias, they strongly urged that PrEP training for medical students and practicing doctors include firm warnings against allowing such bias to influence care.

In discussions to inform this article, Jesus Felizzola, MD, MHSA, MA, Research Professor in the Department of Psychology at The George Washington University, brings his 25 years of experience as a physician and researcher that have focused on HIV in Latinx communities across the U.S. Dr. Felizzola explained the various barriers between Latinx people and health services, particularly PrEP utilization, retention in care, and medication adherence. According to the doctor, language, immigration, culture, and religion give rise to HIV stigma and homophobia, and fear that getting care could lead to discovery and deportation of undocumented loved ones. Some Latinx people avoid providers who fail to understand and accommodate their unique needs and expectations. Additionally, Latino MSM who fear stigma avoid care sites that their community views as "gay," "for LGBT," or "for HIV."

Black MSM share the distrust of the healthcare system that permeates the African American community as a result of the Tuskegee Syphilis Study (1932–1972) and other abuses inflicted on Black people under the guise of medical care. Black apprehension about healthcare, especially when it is associated with the government, has been a challenge during the COVID-19 pandemic. Treatments seen as new and unproven are often viewed with great skepticism and avoided. Mistrust of individual providers blocks the willingness of Black MSM to discuss and decide to use PrEP. Providers who lack training and cross-cultural skills cannot accurately assess a Black or Latino MSM's sexual history or always make the right decision about prescribing PrEP.

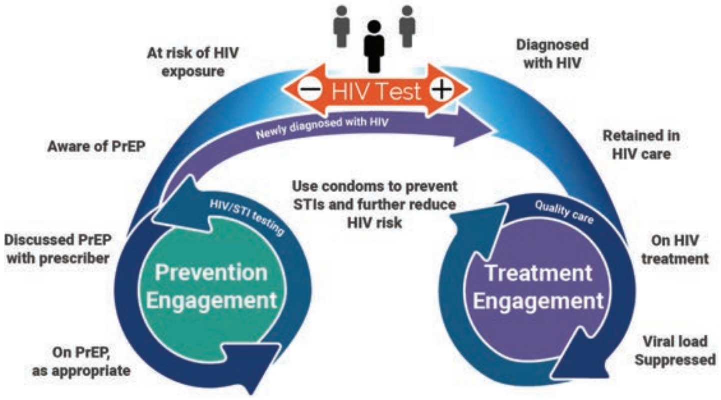
A small 2019 study revealed that many Black MSM have derogatory views of people who use PrEP and what that means about an individual's sexual promiscuity and fidelity in a relationship. Actual comments made to Black MSM using PrEP included, *"I feel like you being on PrEP means you like to sleep around"* and *"Are you a Truvada whore?"* These may seem petty and minor from a distance, but respondents made it clear that the consequences mattered to them.

Adherence to HIV medication leads

MESQUITA FMS-ISTOCKPHOTO

to viral suppression, which prevents transmission from a person living with HIV (PLWH) to their sexual partners. Retention in care includes doctor visits that can educate and persuade PLWH about HIV facts and new advances, information that can influence the person living with HIV and their partner(s), and become a source of awareness and accurate information in the community. That is why the HIV community sees that treatment is indeed prevention.

An HIV status-neutral service delivery model overcomes stigma by serving all patients—gay or straight, HIV-positive or -negative—under one roof.



Researchers have found that an HIV diagnosis can cause trauma in Black MSM, and that a patient-centered approach to help patients deal with the trauma is critical to entering and remaining in care. Such trauma is likely a factor among Latino MSM as well.

The term MSM (men who have sex with men) refers to a mode of transmission that includes gay, bisexual, as well as heterosexual men who occasionally cross over. Recent research has revealed significant differences between the behaviors of MSMO (men who have sex with men only) and MSMW (men who have sex with men and women). MSMW are less likely to get tested, know their status, be in care, or use PrEP. They are more likely to fear HIV stigma and homophobic stigma than MSMO. As such, they are more difficult to reach and engage. Different prevention strategies are needed to reach these groups.

Overcoming barriers for a more effective system of care

As we plan for a more successful future, we need to remember the five “As”—Availability, Awareness, Accessibility, Affordability, and Appropriateness—that must exist to maximize client utilization. Availability alone is of limited value if other conditions are not met. Awareness depends on culturally appropriate outreach to make individuals aware of services and encourage using them. Accessibility requires service proximity to clients and hours including evenings and weekends that fit client schedules. Self-tests and telehealth increase accessibility. Affordability is ensured when medical homes and other primary care providers have public benefits staff present to enroll clients. Testing site staff that refer those who test positive must stress that the ability to pay is not a barrier to care. Appropriateness requires culturally competent staff in every provider position to meet the needs and expectations of individuals from diverse cultures. Personalized assessment, flexibility in meeting needs, and respectful treatment are critical. Cultural competence is not just about language. It is also about accommodating differing values, mutual respect, and demonstrated understanding.

Status-neutral clinics (see figure above) overcome stigma by serving all patients under one roof (gay or straight, HIV-positive or HIV-negative, those with high blood pressure or diabetes) and the only place the patient’s needs are known is in the privacy of the doctor’s examination; HIV testing and PrEP prescriptions are made a part of regular visits to STD clinics and regular primary care doctors (as a routine part of preventative care); and self-tests are used along with telehealth doctor consultations.

Data to Care (D2C) improves outreach and connection to care. D2C includes using HIV surveillance data routinely collected by state and local health departments and other data sources to identify persons who are not in care (NIC) and then link or re-engage them in care, and identify persons who are in care but not virally suppressed and work with these clients and their providers to achieve viral suppression.

Care Navigators and Peer Support raise rates of retention in care by making the system accessible, and responding to issues the newly-diagnosed and newly-in-care may face, both medical and non-medical.

“Inclusion” of PLWH and staff from BIPOC (Black, indigenous, and other people of color) communities requires participation and full empowerment in the entire process. PLWH withdraw from participation when providers use them to check the boxes on grant applications but do not apply their input to crucial decisions. Black and Latino MSM and BIPOC who live with HIV are grossly underrepresented among provider staff and management. Those who are hired often report frustration with working conditions, disrespectful treatment, inadequate consideration for their input, and a lack of inclusion by other staff. Such shortcomings often result from a lack of effort to change the status quo.

A prototype of an integrated system of prevention and care synchronized to reduce new infections

Improving outcomes for Black and Latino MSM is just a small part of the challenge facing HIV prevention and care and a fraction of the challenge facing the U.S. healthcare system as a whole. In an increasingly diverse nation, genuine inclusion for all is an absolute necessity. Just as Black and Latino MSM need to be able to trust the HIV care system, to be understood and respected, to receive appropriate services, to see people who look and think the way they do shaping and delivering services they need, all PLWH and everyone using the healthcare system deserves the same.

Establishing the system that patients deserve will require change from the ground up, pairing the best of the existing system with new, more effective components. Healthcare personnel will need to acquire the skills and attitudes required to ensure the new strategies operate optimally. Creating a successful path forward will fare best if all participants are heard and respected, all ideas are heard without judgment, and participants move to a conclusion reached by genuine consensus that yields the best results, better than any other process by far.

So, this challenge is an opportunity to be better than ever before. It should be embraced, not feared.

MARK FISCHER (*he, him*) is a retired educator and business executive. He has lived with HIV for over 35 years. He is the past co-chair of the Metropolitan Washington, D.C. Ryan White Planning Council and now serves as a technical assistance consultant to the council.

Stepping onto new stages

Gerald Garth ushers in the next generation of leadership

BY **STEPHEN HICKS**

Gerald Garth's calendar is bursting with meeting invitations ranging from monthly check-ins to festive outings. He is a man-about-town wearing several hats, lending his advocacy along his travels. This afternoon, he's taking it easy—a Zoom call here and there, a coworker dropping off items, and a hard stop at 2 p.m. He's wrapping up his to-do list before attending a string of holiday parties and year-end celebrations.

Garth had a good 2021, personally and professionally. He describes prioritizing joy, setting boundaries, and tweaking his work-life balance. Sounds like sage advice, considering he's stepping into multiple new roles in 2022. For one, he will be Director of Diversity, Equity, and Inclusion with the Los Angeles LGBT Center. He was elected to two positions: vice president of community initiatives and programs with LA Pride and the head of media and communications for Global Black Pride.

"I start [at The Center] at the top of the year, building strategies," Garth said. "We are taking a robust view, looking at the hiring practices, programs, protocols, staffing structures, opportunities, next steps, and so forth."

The 800-employee-strong Los Angeles LGBT Center sprawls over nine locations. Close to 50,000 Angelenos receive services ranging from primary care, HIV specialty care, and legal assistance to gender-affirming services through the agency.

"The L.A. LGBT Center serves as a beacon around the world. A lot of organizations look to the Center or are supported through the Center, get resources through the Center. I recognized that this role and opportunity would be bigger than just the L.A. footprint," he said. "Then with my unapologetic approach to uplifting Blackness, I really see it as a wide-reaching opportunity to do one of a couple things. To one, address, dismantle, reimagine, deconstruct systems. Also uplift, empower, amplify Black folks and other underrepresented groups."

Garth's new job at the Center calls for greater visibility, and up until recently, he was perfectly fine working behind the scenes. This was his norm. Dating back to the theater days in his native Baton Rouge, Garth set out to help wherever he could. UpStage Theatre Company, seated in his hometown, served as a creative hub for a 20-something year-old Garth. There, under Dr. Ava Brewster-Turner's direction, he hoped to hone his storytelling craft as a budding playwright and set designer—somewhere in the background. He assisted with the wardrobe or swept the floors. One day, while striking the set (theater-speak for breaking down pieces of the stage), Dr. Brewster-Turner commented, "You look good on stage." He said thank you and continued the task at hand. She added, "Your voice is really good onstage also." He kept picking up cups. She then suggested he audition for an upcoming play, UpStage's rendition of August Wilson's *Radio*

ABOUT GARTH:
'He is somebody that people have a lot of respect for. He's really someone who people trust a lot and definitely trust to be reliable, to be consistent,' says Yolo Akili Robinson, executive director of BEAM (Black Emotional and Mental Health Collective)

JAMAAL MURRAY

Golf. Reluctantly, Garth auditioned but bombed badly and returned to his duties. Brewster-Turner offered him a second go. This time, she gave him notes and extra encouragement. He retreated to his car where he devoured the monologue, returned inside, and delivered it, scoring the lead.

"That was foreshadowing," he said. "Those times in gestation are in preparation for what's next. I do feel like all of those steps along the way [where it] felt like I was in hiding were actually just preparation. I'm prepared. I am actually excited. I feel like I have all of the tools. Even from my time in the media, my time as an actor, my time as an advocate. All these things have baked together to this newest chapter."

Garth trekked out west nine years ago while the bulk of his family still resides in Louisiana. He learned the city as he navigated his previous roles at the Black AIDS Institute (BAI), the City of Los Angeles, and most recently The AMAAD Institute (Arming Minorities Against Addiction and Disease).

He said he constantly encountered a lack of adequate resources in South L.A.—Watts, Compton, and Inglewood.

"For so long, disjointed systems have told our communities that they had to go someplace else to see support, to see resources, to see beauty, so much of my work with AMAAD and BAI has been to help communities to celebrate and strengthen our own spaces throughout Los Angeles," he said.

BAI's co-founder and former executive director, Phill Wilson, immediately launched into praise for his pupil Garth.

"Gerald is a leader for our time," Wilson said. "He understands that the issues we face, the challenges confronting us, and the nature of our existence is about intersectionality, so it is always an ampersand. It is always *and;* it is not Black *or* gay. It is Black and gay and cisgender and trans and non-binary. It's reflected in his body of work."

Wilson, now retired, says he's eager to see his once-pupil's star ascend.

"I am always proud when a young Black gay man—a young Black man—steps up to his leadership and is willing to embrace that and accept that responsibility, and I'm always proud when that happens. In Gerald's case," Wilson said, "it has been both amazing and heartwarming to watch."

Upon arrival, it didn't take long before Garth connected with the Center and not in the most ideal circumstances.

"My first interaction with the Center was not pleasant," he said. "Even though I wasn't a consumer of services, so many people who I was connected with, even in previous roles, had poor experiences with the Center. As a voice of the community, I was vocal about that, with the leadership team, with their service provision team. I laugh because I would not have imagined eight years ago, nine years ago, that I would even be considering going to them even for services and activities, let alone as a staff person."

Garth says the Center has implemented more approaches lodged from community members—namely, the Black LGBT people in L.A. A shift was taking hold, he said.

Sharon-Brown Franklin is the Director of Human Resources at the Center, and has known Garth for several years.

"One of the things that has impressed me is his ability to bring lived experiences and intersectionality together and bridging the gap while meeting people where they are. The Center is committed to creating a work environment in which employees who are Black and people of color can flourish," she said. "He has the ability to help us reach those goals."

Though staff have participated in internal Diversity, Equity, and Inclusion (DEI) trainings, Garth's arrival ushers in an opportunity for a rollout of new initiatives, Franklin said. Emerging from behind the scenes, Garth has several goals in mind. Shifting culture and raising morale rank high on his list, along with placing increased value in the lived experience of staff members. He hopes to sway things, but he knows patience is key considering the size of the Center's workforce.

"I've been reminding folks consistently that while [they] are excited about me assuming this role, I'm not a genie. It's not overnight. It's not my role alone," he added.

Yolo Akili Robinson, executive director of BEAM (Black Emotional and Mental Health Collective), is a peer who's shared panels and sat on councils with Garth.

"He is somebody that people have a lot of respect for. He's really someone who people trust a lot and definitely trust to be reliable, to be consistent. And I think that's really kind of representative [of] his work in L.A.," they said.

Garth remains motivated and steadfast while filling in different roles, whether at the Center, LA Pride, or Global Black Pride. He was also named a faculty mentor for Creating Responsible Intelligent Black Brothers (C.R.I.B.B.) at NAESM, a community-based organization in Atlanta devoted to Black gay men's health and wellness. The yearlong fellowship develops leadership skills for Black gay and bisexual men who are active in HIV/AIDS services.

"People living with or at highest risk of acquiring HIV, Black people, and LGBTQ+ people, are disproportionately impacted across several lines of social determinants of health. And so many of the needs and responses for these communities are where these experiences come together," Garth said. "For me, this further amplifies the need and unique role of those who represent and advocate at those intersections. I am very grateful to be trusted to bring my skills, passion, and voice to the work for those who are often underrepresented or misrepresented, if represented at all. I often say that 'none of us have to do everything if all of us do something'—the very definition of a village. It motivates me to know that what I bring to the work—to our village—is valued and valuable."

STEPHEN HICKS (*he, him*) is a writer and has been a public health advocate for more than 10 years, focusing on sexual health and harm reduction. He is the Narrative Justice Fellow at CNP (formerly The Counter Narrative Project).

Black women in biomedical interventions

Leveraging existing interventions to help protect Black women

BY **JUAN MICHAEL PORTER II**

(FROM LEFT): **LEISHA MCKINLEY-BEACH** AND **ONI BLACKSTOCK, MD, MPS**

LEISHA MCKINLEY SCOTT: TONA REEVES PHOTOGRAPHY
BLACKSTOCK: AKINFE FATOU

BLACK WOMEN are often overlooked by HIV researchers and prevention specialists. Fortunately, two crusaders are actively raising awareness about the virus throughout their community: Oni Blackstock, MD, MPS, HIV researcher, founder of Health Justice and Leisha McKinley-Beach, founder of the Black Women and Biomedical Interventions Institute.

Asked about the federal government's plan to reduce the number of novel seroconversions in the U.S. by 90% by 2030, Blackstock says there is no way to get there without involving Black women. She references the Centers for Disease Control and Prevention's (CDC) finding that even though Black women only make up 13% of all women in the United States, they accounted for 61% of new HIV diagnoses among women in 2015, and 55% in 2019. Compare that to white women who make up 62% of all women in the U.S. but accounted for only 22% of new HIV diagnoses among women in 2019. Buried in these statistics is the fact that 92% of Black women acquire HIV through heterosexual contact.

These figures are particularly disheartening considering the availability of pre-exposure prophylaxis (PrEP), which has been protecting people from HIV transmission since 2012.

In separate interviews, McKinley-Beach and Blackstock talked about raising awareness about PrEP among Black women, activists, and health organizations across the country.

McKinley-Beach, an HIV activist with over 30 years of experience, notes that PrEP is a wonderful biomedical intervention against HIV, but laments that it is marketed almost exclusively towards gay men, even though studies have found that Black women are receptive to it when they are given basic information about its use—this includes the realization that unlike condoms, using PrEP does not require discussion with a partner.

That's why McKinley-Beach says that all Black women need to know about PrEP "because it gives us more choices and greater freedom over sex." She adds that every woman who has sex needs to participate in this conversation—including those who are done with having children—because 36% of women who were newly diagnosed with HIV in 2018 were 45 and older.

JUAN MICHAEL PORTER II What has been your experience with PrEP and health advocates for Black women?

McKINLEY-BEACH Many of us have taken the position that we are the ones that we've been waiting for. Our overall HIV infrastructure has not ensured diversity in PrEP awareness and promotion, so we've decided that we're gonna have to save ourselves.

Can you talk about some of the groups you've connected with on PrEP awareness?

Yes! Last year was a rockstar year. We had our own health conference for Black women in November called "Where She Leads, We Will Follow Her," which was very intentional about looking at HIV care and treatment as well as focusing heavily on PrEP.

There's Jacky Bickham, a member of Louisiana's Department of Health, who has done a phenomenal job in getting promotional materials out and mobilizing with local coalitions. Crystal Mobley launched a PrEP marketing campaign in Fort Lauderdale with a picture of a beautiful Black woman on a bus saying something like, "I made a decision about PrEP."

And there's a group of women in D.C., both in the health department and at a contract provider that is similar to our Atlanta Black Women Leaders on PrEP group. We are all learning from each other.

It sounds like you're creating a real network. Has that been a major goal for you in developing the Black Women in Biomedical Interventions Institute?

Absolutely. I created the Institute because I know that I have to leave this knowledge that I've accumulated over the past three decades to the next generation of HIV activists and leaders. This network that I'm part of is here to ensure that there is support for people in various jurisdictions.

For my part, whenever I learn about something that's happening, I send an email to our director of the Office of National AIDS Policy, Harold Phillips, because it's important that our government partners acknowledge and learn about the best practices for serving Black women.

What is the biggest obstacle to PrEP access for Black women?

That people are talking about it, but they're not talking about it to Black women. I'd go even further and say that this is a problem with PrEP access for Black communities in general. I saw some prescription data that showed that less than 10% of PrEP prescriptions went to Black individuals, regardless of gender.

How does this get changed?

We constantly hear this excuse about Black women being hard to reach. But when it comes to making money off of us, people automatically know how to get in touch. So, why aren't HIV organizations doing it? Why aren't they partnering with beauty parlors, for instance, places they know Black women will be? We fix these issues by talking to Black women and getting rid of the excuses.

What are some of your goals?

To focus obstetricians and gynecologists on educating women and prescribing PrEP to them—period. I want to build a league of clinical ambassadors that is made up of OBGYN and nurse practitioners who are seeing women every day and ensuring that they are having these conversations about sexual health, including PrEP for women of all ages.

For Oni Blackstock, addressing PrEP inequity is a racial justice issue. She combats this through her group, Health Justice, which helps organizations center on equal access and antiracism.

JUAN MICHAEL PORTER II When you think about access to PrEP, what are you looking at?

BLACKSTOCK Follow the money. The CDC offers a lot of HIV prevention funding, but which jurisdictions are getting funded, and what are the underlying factors that prevent communities from experiencing change?

How do you address those disparities?

I've started to work with public health departments in the South and have found that many people within the health spaces and community-based organizations aren't aware of issues about PrEP access.

All of our Ryan White contracted providers have been required to take racial equity training. That means front desk staff and PrEP navigators as a start, though we want to get to a point where leadership is participating as well because they set the tone for behavior and values.

How do you get leadership to buy into participating?

By linking this type of training with funding and making funding contingent upon the results of racial equity—or even having folks explain what they're doing to address racial equity issues in their respective organizations.

My work with Health Justice has been focused on health departments, but equity issues and lack of awareness about PrEP exist in community organizations as well. I don't know if it will happen, but the hope is that this antiracism work will have a trickle down effect.

What key points do you focus on when addressing access to PrEP and Black women?

It comes back to equity. Think about the article that reported that of the $3.8 million for Ryan White-funded clinics that serve Black women, only 10% went to organizations that were actually run by Black women. The same system that puts Black women at risk for HIV turned around and excluded organizations that Black women run from funding. I make sure to highlight that.

But funding aside, I let people know that Black women are multi-dimensional and just like everyone else, we have different needs. So, addressing one issue isn't sufficient—if we want things to change, organizations have to figure out, *What are the priorities for Black women in this specific community?* And make sure the services they offer are addressing those needs in addition to their HIV treatment and prevention. Because you can't get to one if you don't address the other.

JUAN MICHAEL PORTER II *(he, him)* is a Black queer man living with HIV. He has written for TheBody.com, *PBS American Masters*, the *San Francisco Chronicle*, the *Christian Science Monitor*, *Playbill*, and the *New York Observer*. He is a National Critics Institute and Poynter Power of Diverse Voices Fellow.

IN THE ARTS

Playwright Dominic Colón on telling diverse stories: *We matter*

BY **NIC YEAGER**

CHANGE HAPPENS through policy and research, but it also occurs through our creative pursuits. Who are the artists dedicated to HIV/AIDS advocacy, and what are their challenges? Dominic Colón is a writer fighting to make space for a new, diverse canon of work about HIV/AIDS in theater, film, and television. In December 2021, Colón won the inaugural Write It Out! prize for playwrights living with HIV, presented by HIV-positive playwright Donja R. Love and the National Queer Theater.

Colón's prizewinning play, *The War I Know*, chronicles the impact of HIV/AIDS on the Latinx community in the Bronx starting in 1987. The story follows Eggie, a flamboyant 12-year-old, and his 10-year-old neighbor Maribel, who perinatally acquired HIV and lost both her parents to AIDS, and Maribel's older siblings who are struggling to step up as caretakers. It's a gripping, stunning work that locates AIDS as one axis of struggle. Through this lens, we see how stigma and poverty interact with race, sexuality, violence, housing, childcare, and policing. In a rageful monologue, one character declares: "You don't see them fancy ass white gay guys having to put up with this shit. ... So we need to show each other some love and take care of each other, because the rest of this world could give a shit about us."

NIC YEAGER What does the crossover of art and advocacy mean to you?

Well, that's how I came into writing. I've always been an actor and educator. But prior to seroconverting and becoming positive, I ran a company called *Teatro el Puente*—part of a larger organization called *El Puente* [the bridge] in Williamsburg, Brooklyn—that did HIV prevention through theater from 2000 to 2012. We would create our own pieces and go to high schools, afterschool programs, and community centers. When you catch young people's attention, that's when I realized the power that this medium has for change and social justice, and how you can be entertaining and impactful at the same time.

How did you start focusing on writing in addition to acting?

It was at a point in my life where I had just started to deal with my status. I tested positive in 2005. Although I sought out health care, I didn't feel comfortable really dealing with it in my personal life. I didn't even tell my mother for six years. It started to manifest in unhealthy ways. I needed to take care of myself, and that's when I went into therapy. Therapy ended up helping me find a spiritual practice, and eventually all that work manifested in weight loss and weight loss surgeries. For a big part of my life, I was a larger actor. I lost 200 pounds in 2014. Once I lost all that weight, I was at a weird place in terms of film and TV work. I had a conversation with my manager and she told me to use my writing talents and create something. And I did. I wrote a short film, *Skin,* about a guy dealing with extreme weight loss. He's scared to have sex with his boyfriend without a shirt on. I remember being on set the first day, and I was like, *Wow, you know, everyone is here because I had the bravery to create this script, to tell my story that is specific to me but that can affect other people. This*

WILBER POLANCO

is what I want the next part of my career to be. I created this pilot, *Papi,* that got on the Latinx TV Black List, and when lockdown happened [in 2020] I had the time to put pen to paper for *The War I Know*, and ultimately, the two plays that come after.

> **‘When you catch young people’s attention, that’s when I realized the power that this medium has for change and social justice, and how you can be entertaining and impactful at the same time.’**

The third play in *The War I Know* trilogy is called *Where’s Our Angels*?, a reference to *Angels in America*. One character points out that there are many plays about how AIDS affected white, generationally wealthy gay male characters, but not enough about how AIDS affected other communities. Where is the story of AIDS being told wrong in theater?

Here’s the thing. In terms of “wrong,” what I will say is this: I’m tired of seeing the same thing over and over and over again. I’m tired of hearing a lot of the same language like, “oh my god, this is the most important piece.” It’s like, God bless you. But, for me, it was just that this story should be represented because I hadn’t seen it before. This is a version of my story, and my family’s story, and the fact that before the age of 13, everyone that I lost was because of AIDS. You know what I’m saying? How it affected my community, specifically. It wasn’t just gay people—it was the poor, it was people who were addicted. I saw it everywhere except on stage. Even 30, 40 years later, we’re still—with the exception of Donja [R. Love], but in terms of whatever the larger version of the American theater is—it is a struggle to get our stories told.

I want us to have our *Angels*, our *The Normal Heart*. I feel like this [*The War I Know*] lives in that world of epic storytelling. I would love for this story to be seen on Broadway, and not just the Broadway community, but the community that this was written for.

Do you have advice for young creators working on changing narratives in theater, film, and television?

You are worthy. You are worthy. You are worthy. I think oftentimes—I’ll speak for myself—I felt like, because of shit that was put on me, I was not worthy of happiness, of love, of success. And I believed those lies. Until I decided not to, and changed my life, and affirmed every day that not only am I worthy, but that I matter, that my presence matters, that my voice matters, and that every day, when I press that Zoom link to go into that writers’ room [Colón is working on Netflix’s upcoming series, *Pink Marine*], I have a duty to show up as my full self. We have the potential to change lives through our art. I owe that to myself and to my community. It’s not just me, I am a representation of all those who couldn’t be here, who didn’t have that opportunity to tell their story. So go out there and do the work because it matters. PA

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NIC YEAGER (*they, she*) is a writer based in Brooklyn. They have written about social justice and the arts for the *Texas Observer*, *Texas Monthly*, and elsewhere. Find more of their work at nicyeager.com.

NASTAD's impact on health departments

Why this nonprofit has been fighting for equity for the last 30 years

BY **GRACIE BONDS STAPLES**

Beth Crutsinger-Perry, director of the Washington State Department of Health's Office of Infectious Disease, was doing HIV administrative work for Ryan White services in Texas when she first heard about the National Alliance of State and Territorial AIDS Directors (NASTAD). A colleague and friend of hers had moved to Washington, D.C. to work for the non-profit and stayed in touch. In 2004, Crutsinger-Perry followed him there, signing on to continue NASTAD's mission: providing technical assistance to state AIDS programs. When an opportunity opened up in Washington state, she jumped at the chance to oversee the state's AIDS Drug Assistance Program (ADAP), which provided HIV prescription drugs to low-income people with limited or no prescription drug coverage. Her work in the state may not have been as successful, she said, had it not been for NASTAD's near constant guidance.

Thirty years ago, a group of state public healthcare workers came together and founded NASTAD. Since its inception, the national non-profit has helped hundreds of state and local health departments develop and implement AIDS service programs across the country.

"I fully believe that NASTAD's efforts make health departments better at our work and also able to provide stronger programs and services to the communities we serve," Crutsinger-Perry said.

Washington state's department of health is just one of hundreds of state and local health departments across the country that NASTAD has helped develop and implement AIDS service programs.

"That means thousands of people either living with HIV or who have been impacted by the disease have been able to receive care that they would not have otherwise received," said Stephen Lee, MD, NASTAD's executive director.

"Often when we think of AIDS services we think of direct patient care," Lee said. "NASTAD does not do that. We work with health departments to help them better deliver care to patients."

As the first cases emerged in 1981, Lee was just starting his career taking care of people with AIDS and remembers them dying without access to treatment. Not only was the cause of AIDS unknown, there were also no tests or available treatments. By the time most patients presented with symptoms, they had just months to live.

"It was heartbreaking, exhausting. And it made me angry to see so many young men dying," said Lee. That started to change in 1987 when AZT, the first anti-HIV drug, became available, he said, but people were still dying of opportunistic infections related to the virus. AZT slowed the progression of HIV, but there was no cure in sight.

As they celebrate their 30th anniversary, Lee said that NASTAD is laser-focused on ending the epidemic as we know it.

"As there is no cure, ending the HIV epidemic does not mean HIV goes away," he said, "but that it is manageable in the same way you manage diabetes, with daily medication to keep the virus under control and undetectable. That also includes preventing transmission for those at high risk for acquiring HIV, through pre-exposure prophylaxis or PrEP."

NASTAD was founded in 1992 at a time when the HIV/AIDS epidemic had become the number one cause of death in the U.S. for men ages 25–44. Health departments across the country, already burdened by a lack of resources, were scrambling to keep up. NASTAD officials hoped to advance the health and dignity of people living with and impacted by HIV and AIDS, viral hepatitis, and intersecting epidemics by strengthening public health and leveraging community partnerships.

As the epidemic evolved, diagnosis, testing, prevention, and treatment became more common. At the same time, Lee said, NASTAD expanded its work to include ensuring access to care, securing funding and resources for prevention, and ending the HIV epidemic, a goal it has been pursuing since 2016.

In 2000, NASTAD expanded prevention and treatment to include people living with hepatitis, including hepatitis C, a viral infection transmitted primarily through injection drug use. While much of its work was done in person prior to COVID-19, NASTAD has since pivoted to primarily offering assistance via virtual and hybrid platforms, such as webinars, workshops, and blogs.

The CDC awarded NASTAD a five-year cooperative agreement in 2019 to enhance state and local health departments' ability to end the epidemic. While ending the epidemic is considered an ambitious goal, there are some who believe it will not happen if policies that create stigma and discrimination remain in place, particularly against those who are LGBTQ, immigrants, people of color, or women.

According to the latest CDC data, 36,801 people received an HIV diagnosis in the U.S. and dependent areas in 2019. Racial and ethnic minorities have been disproportionately affected by HIV/AIDS since the beginning

LEE: COURTESY OF NASTAD

> ‘Often when we think of AIDS services we think of direct patient care. NASTAD does not do that. We work with health departments to help them better deliver care to patients.’
>
> —STEPHEN LEE, MD

of the epidemic; they continue to represent the majority of new HIV diagnoses, people living with HIV, and deaths among people with HIV.

For instance, African Americans represented 13% of the U.S. population but accounted for 44% of new HIV diagnoses in 2019. Hispanics made up 18% of the U.S. population but accounted for 30% of new HIV diagnoses.

Also in 2019, among gay, bisexual, and other men who have sex with men, Black MSM comprised 26% (9,123) of new HIV diagnoses and 37.9% of diagnoses among all MSM, while Hispanic MSM made up 22% (7,820) of new HIV diagnoses and 32.5% of diagnoses among all MSM.

Lee said the challenge will be to end the epidemic across all those populations. Having spent the last 19 years in HIV program design, implementation, assessment, and evaluation, he remains undaunted. He said, however, “I’m less confident we will do that unless there is equitable access to all the tools in our toolbox to end the epidemic.”

Those tools, Lee said, include ensuring people get tested and know their status, are aware of prevention tools such as pre-exposure prophylaxis, or PrEP, and making sure they have access to treatment when they test positive. Equally important is ensuring social determinants such as housing and financial stability are addressed.

“In my heart, I believe we can do it,” Lee said. “We have to trust compassionate human beings to make sure all have access, and unfortunately we don’t see that as much as we’d like.”

Crutsinger-Perry, who was recently named chair of NASTAD’s board of directors, said her experience at the national, state, and community level provides her a unique lens from which to view NASTAD’s work. She maintains that “anti-racism work is vital to ending the HIV/AIDS and hepatitis epidemics, and NASTAD can be a critical partner to help health departments assess and evaluate our work through an anti-racism lens.” That includes exposing internal systems that could be promoting racism and developing programs to bring about change.

NASTAD has already been instrumental in this regard, Crutsinger-Perry said. For instance, when her office was doing work with the state legislature to remove a felony penalty for knowingly exposing someone to HIV without their knowledge, the non-profit provided her staff with a list of current HIV decriminalization statutes and their language and penalties. Previous language used was racist in outcome.

“This document was very helpful, both from helping draft bill language and in sharing with other legislators so they could see how other states have worked to decriminalize HIV,” she said. Washington state’s bill passed in 2020.

In addition, the state’s health department staff routinely consults with NASTAD to discuss and explore ways to examine the systems that affect access to and affordability of PrEP and antiretroviral therapy (ART). These consultations produce insights that help the department take positions on such issues as Medicaid policy or the science behind prevention campaigns such as U=U (undetectable equals untransmittable). NASTAD was one of the first organizations to sign on to the campaign and encourage health department members to add their endorsement and support.

Crutsinger-Perry explained that the PrEP and ART landscape is constantly changing and evolving. NASTAD summarizes issues, guidance, and opportunities in a way that is digestible and actionable for local, regional, and national efforts. Any time there are changes to guidelines from the CDC, the National Institutes of Health, or the Food and Drug Administration, she said, NASTAD brings health departments up to speed, explaining those changes so that staff can understand and know how to implement them.

For 30 years, Lee said, NASTAD has been committed to prioritizing the health of people from marginalized communities, including people who are LGBTQ, Black people, and other racial and ethnic groups. Looking ahead, he said, “We must continue to address health disparities and inequities in order to end the HIV/AIDS, viral hepatitis, and intersecting epidemics, and ensure optimal health outcomes for all.”

GRACIE BONDS STAPLES (*she, her*) is an award-winning feature writer and columnist with more than 40 years of experience writing for daily newspapers. Before retiring in 2021, she spent 20 years at *The Atlanta Journal-Constitution*, producing high-impact narratives and the twice-weekly “This Life with Gracie” column.

Artificial intelligence, healthcare, and racial bias

How flaws in a clinical algorithm design are causing more harm than good

BY **CANDACE Y.A. MONTAGUE**

MORE AND MORE, artificial intelligence (AI) is being used to make decisions—evaluating job applications, approving home loans, and even predicting who will be more likely to commit a crime. However, AI is designed by humans. That means these algorithms can often be built on homogenous data sets, questionable rules, and implicit biases, while omitting environmental factors—all of which can have a negative impact on a person's access to healthcare.

AI in healthcare is sometimes used as a risk prediction tool designed to make responses to health issues more individualized and equitable. Algorithms use past data to determine who would benefit the most from certain programs and treatment options, and how much insurance companies will cover. The data used for making these decisions comes from information on factors such as health care costs, treatment adherence, and utilization of services.

In healthcare, the algorithm used to make critical decisions regarding treatment uses health costs as the intermediary. Patients who receive more care appear to be sicker than others and require more healthcare spending. But can spending alone really determine who is worthy of more care?

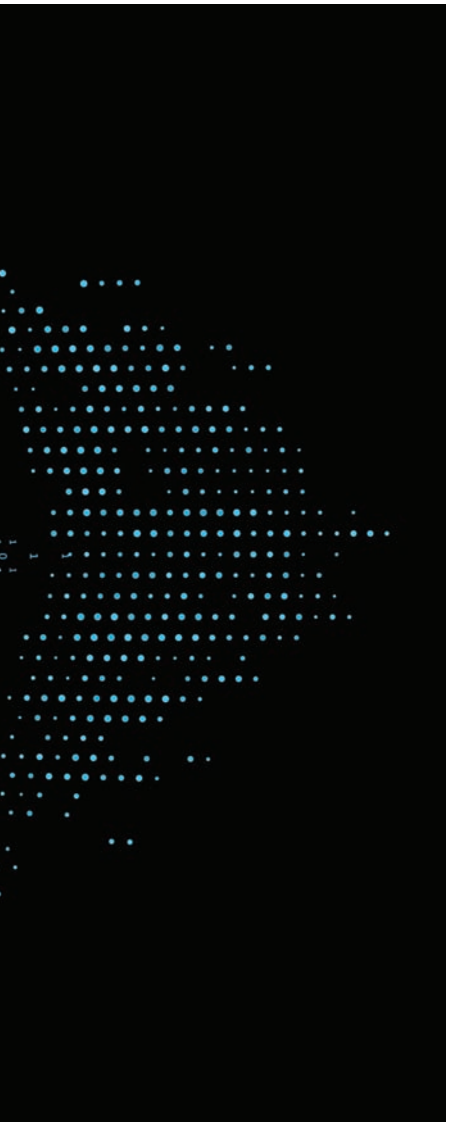
Can we trust data?

A study published in *Science* in 2019 reported that racial bias had been detected in health algorithms. The study found that a widely used algorithm was less likely to refer Black people than white people who were equally sick for extra care. This algorithm is used by hospitals and insurers to help evaluate and manage care for 200 million people in the United States each year. These data concluded that Black people are healthier than their white counterparts because less money is spent on their care.

Since then, Optum, the company that made the algorithm, has denied racial bias, stating that there were other parts of the algorithm that were not applied.

"The algorithm is not racially biased," a spokesperson responded. The study in question mischaracterized a cost prediction

SEAMARTINI-ISTOCKPHOTO



algorithm used in a clinical analytics tool based on one health system's incorrect use of it, which was inconsistent with any recommended use of the tool. The algorithm is designed to predict future costs that individual patients may incur based on past health care experiences and does not result in racial bias when used for that purpose—a fact with which the study authors agreed.

Making healthcare decisions based on race is proving to be an obsolete practice, as race is a social construct, not a biological one. But taking race out of the equation can also be detrimental since adding factors such as race, gender, socioeconomic background, and disability can reveal disparities and help target efforts to improve care overall. It's a delicate balance not easily found.

The algorithms used in healthcare discriminate against the people who need care the most by giving more credit to non-Black patients. For example, in nephrology–kidney care–a tool called STONE is used to predict whether a patient has kidney stones. This calculator uses **s**ex (gender), **t**iming, **o**rigin (i.e., race), **n**ausea, and **e**rythrocytes (red blood cells) as factors to determine a person's score. A low score indicates low probability of having kidney stones, while a high score shows the opposite. But this tool inexplicably adds three points to patients who are "non-black". The same kind of scoring rubric is used for the Get With The Guidelines-Heart Failure Risk Score.

What algorithms miss are the social determinants of health that can impact outcomes, such as access to local resources, medical providers denying care, high prescription costs, and low health literacy.

This kind of feedback could sway physicians away from giving Black patients a thorough evaluation for kidney stones and lead to a misdiagnosis. Race is now optional on these forms, and medical staff are encouraged to consider more than just a checklist when determining the next steps in care. Why does race have to be included at all?

AI and people living with HIV

People living with HIV/AIDS are also subjected to biases in AI. It's not what the algorithm is saying about their needs, but more about what it doesn't consider. Faye Cobb Payton, PhD, Chief Programs Officer at Kapor Center in Oakland, California, says that it's often the small data that get left out of the picture. "What the big data will not do is show an understanding of the nuances that come with people living with HIV itself. Small data, like the human condition and lived experiences, are overlooked."

What algorithms miss are the social determinants of health that can impact outcomes, such as access to local resources, medical providers denying care, high prescription costs, and low health literacy. Payton explains that a person's community and access level must be considered when using algorithms to decide who needs care.

"Where one actually lives, works, and plays can be a mismatch in terms of what an algorithm could potentially tell you about a person, particularly communities of color. I worked on a project in a rural environment where the antiretrovirals were available to persons living with HIV but they weren't accessible because the people didn't have affordable transportation. So when you think of those kinds of things, the algorithms must be paired with some understanding of communities and lived experiences. Without that context, we miss the mark.

"What AIDS has shown us, and probably COVID has heightened, is that no one is stereotypical. Everything is behavioral-based. What the data will not do is show us the nuances that come with people living with HIV itself."

Calling them out

How do we ensure that the algorithms are more equitable going forward? For one, development teams should be composed of a heterogeneous group of experts from diverse backgrounds and professional experiences. Also, call out the biases on a regular basis. If professionals and researchers who have experience in evaluating algorithms cite the biases they see frequently, it sends a message to private companies to be careful about the systems they trust. Finally, the algorithms being used right now need to be audited and reformulated to eliminate factors such as costs and race unless explicitly connected to other determinants of health.

If everyone started out on the same proverbial playing field and access was equal and uninterrupted, this AI thing could be an even bigger hit. Unfortunately, that's not how our world works. And it's not how healthcare works either. Data creates a picture of the work that needs to be done. But one thing it cannot do is erase the human experience.

Powerful moments in the HIV/AIDS movement

A reflection on the beauty and strength of diversity

PHOTOS AND TEXT BY **LARRY BRYANT**

> *"A photographer can be a storyteller. Images of experiences captured on film, when put together like words, can weave tales of feeling and emotion as bold as literature."*
>
> —**Philip Brookman**, CHIEF CURATOR AT THE CORCORAN GALLERY OF ART, WASHINGTON, D.C.

WHEN CHOOSING IMAGES for this piece, I included many that to me reflect the diversity of the HIV/AIDS movement I wish I saw more of in the earlier days of the epidemic. However, in 2022 we can identify many more voices and experiences, all of which represent people living with and affected by HIV/AIDS. This 40-year epidemic has grown to be a significant driving force in providing specific, community-based interventions and solutions for more positive health outcomes, especially for many marginalized and vulnerable individuals and communities. I hope that these powerful moments, captured digitally and collected over a couple of decades working with some of the most amazing people in the HIV community, will leave you with bold feelings and emotions as profound and as unique as the individuals captured in each.

A young participant on the outskirts of a World AIDS Day rally outside the John Wilson Building in Washington, D.C.

Transgender-led organizations such as The New York Transgender Advocacy Group for years have been fighting in the streets and in the offices of elected officials for more inclusive, gender-based policies that benefit transgender and gender non-conforming individuals through building community leadership, educating practitioners, and influencing policymakers.

During my 36 years of living with HIV I have lost many friends and peers, many of whom I would consider role models and mentors. There aren't many anywhere as fierce an advocate as the late Regina “Gina” Quatrocchi, former CEO of Bailey House, a pioneering figure in the AIDS housing movement. Gina also had a smile that lit up the Apollo Theater.

The leadership of the Afiya Center. The Afiya Center was established in response to the increasing disparities between the incidence of HIV worldwide and the extraordinary prevalence of HIV among Black womxn and girls in Texas.

The Housing Works Bookstore Café regularly hosts a wide array of events to raise funds for healthcare, housing, and other lifesaving needs for homeless New Yorkers living with HIV.

Music and lyrics have been as present in my HIV activism journey as much as civil disobedience. Whether it's listening to homegrown blues at the 930 Blues Cafe while sipping Long Island iced teas, bouncing to mesmerizing Afro-Brazilian beats from the women of Batalá Washington, or thrilling to heavenly harmonies from the members of the New York Gay Men’s Chorus as they perform while names of people who died of HIV/AIDS appear on a screen at a World AIDS Day gathering in Harlem on December 1, 2015 in New York City.

The Theater of the Oppressed, founded in 2011, provides interactive theater experiences created and performed by community members who themselves have faced oppression. TONYC produces more than 60 performances a year.

“**All social movements** are founded by, guided by, motivated, and seen through by the passion of individuals.” —Margaret Mead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