

Highlights from the 2019 AIDS Philanthropy Summit – Part 2



“There’s no pill to rebuild will” – Larry Scott-Walker, ThriveSS

As 2019 marks the penultimate year of the FCAA strategic plan, we have started to reflect on the progress to date on our current plan. Established in 2015, it was the first in our history to include a specific focus on the underlying drivers of the epidemic. We realize our next plan will need to go even further. We crafted the second day of the [2019 AIDS Philanthropy Summit](#) agenda to support that effort. To that end, we focused the conversation on what it means to be an HIV funder as we balance the need to prioritize HIV with the need to integrate it into broader efforts to address healthcare and human rights.

This topic elicited invaluable dialogue. There’s no easy way to summarize the six engaging sessions that took place. What follows are just a few highlights of the day’s themes; not surprisingly, all conversations pointed to the importance of community.

To read about Day 1 – which focused on the role of media and messaging in the HIV response - please see our [previous post](#).

Follow the Community’s Lead



Panelists (L to R): Maryse Mitchell-Brody, Third Wave Fund; Peninah Mwangi, Bar Hostess Empowerment and Support Programme (BHESP); Tamika Spellman, HIPS; Dr. Stellah Bosire, UHAI EASHRI; Vera Rodriguez, Red Umbrella Fund; Julia Lukomnik, Open Society Foundations

“It’s important to have people with lived realities leading this work...People living with HIV are NOT the disease. It is the system that is not well.”

Dr. Stellah Bosire, UHAI-EASHRI

The day started with a conversation focused on how HIV funders can draw lessons from communities on the frontlines of the HIV epidemic, namely criminalized communities - especially sex workers - LGBTQI+ people and people of color. HIPS’ Tamika Spellman explained that we have to focus on what really works; that the endless counting – the

number of condoms or syringes handed out - is missing the point. What is most needed for her community is housing and the way to impact that is through the flexibility of cash – not gift cards. She encouraged funders to consider whether or not their resources are having the desired impact. If not, shift course, even if it might be uncomfortable.

Peninah Mwangi, of the Bar Hostess Empowerment & Support Programme (BHESP), shared an experience from Kenya. BHESP only received 20% of the funding (compared to larger organizations) to support a local PrEP campaign. But, by sitting down with sex workers and asking them how to create demand, and how to reach young girls where they are, it generated *five times as much interest*.

Designed by three participatory grantmakers – the Third Wave Fund, Red Umbrella Fund and UHAI EASHRI – the session ignited the morning by sharing “***The Hack List: Hustler Lessons From Community Grantmaking By and For Sex Workers***” inspired by the creativity, resilience and hustle of sex worker communities [note: we will share the full list when it’s available! An overview is provided here].

Hacks from the Frontlines

Just a few of the related hacks (or creative work-arounds) and related issues that were highlighted during the conversation:

- Communities should be at the table (or head of) and making decisions
- Relationships should be based on trust, not targets
- Pay community for their time and expertise
- Create more accessible application/reporting processes (meet people where they’re at)
- Consider that HIV-specific funding, particularly in Africa, may leave out many of the issues and realities that impact the lives of key populations
- Understand and talk about the intersections of different types of (de)criminalization together, but also in conjunction with wider issues (same sex relations, gender equality, abortion, etc.).

Find Opportunities for Leverage



Panelists (L to R): Greg Millett, amfAR; Jonathan Mermin, Centers for Disease Control and Prevention; Lindsey Dawson, Kaiser Family Foundation; Michael Kharfen, DC Department of Health

“Policy is associated with health, and more specifically, with HIV. We need to fund advocacy to push policy forward and end the epidemic.” Greg Millett, amfAR

Every year, FCAA’s resource tracking report reminds us that HIV-related philanthropy is just a small part of total global resources for HIV and AIDS. However, our mission and vision also remind us of the sector’s unique ability to remain nimble, to support things governments cannot or will not fund – particularly advocacy and key populations –

and to look for opportunities for leverage. The two morning breakouts were intended to highlight the community's opportunity to further this mission. They focused on the U.S. domestic agenda for ending the epidemic and the role of philanthropy in countries experiencing donor transition.

Announced in February of 2019, the Ending the HIV Epidemic (EHE) initiative is the Administration's goal to end the HIV epidemic in the United States within 10 years. As roughly half of new HIV diagnoses occurred in only 48 counties, Washington, D.C., and San Juan, Puerto Rico, the EHE will focus geographically and prioritize populations at greatest risk. Some of those jurisdictions, such as Washington, D.C., have already made significant progress towards their own goals by instituting evidence-based interventions such as PrEP and needle exchanges.

Notable lessons from the "D.C. Model" include building partnerships and using your influence to bring more people to the table. Additionally, Michael Kharfen, from the DC Department of Health emphasized that partnership with community is key to any multi-sector initiative – it creates effective and innovative programs. Underscoring the importance of evidence, Greg Millett shared amfAR's new EHE database that "zeroes in on the geographic hotspots of HIV that are targeted in the plan by offering contextual data of service availability, policy and infectious disease information for each state and locality."

The conversation ended with the critical question: what is the role of philanthropy in the EHE? Dr. Jonathan Mermin shared that funders can help scale up interventions; provide information campaigns; compile and share best practices; and fund advocacy. Dr. Mermin had previously highlighted the role of Syringe Services Programs (SSPs) to prevent HIV infections. However, even in areas where SSPs are legal, the federal government can't fund them. A clear and tactical response from philanthropy is to resource the actual equipment to support SSPs.

The critical need to support advocacy is not a new rally cry from FCAA meetings; however, what the amfAR EHE database demonstrates*, is that there is a direct connect between policy and health and HIV outcomes, notably:

- A. Syringe Services Programs (SSPs) as an example of how policy *does* and *doesn't* work
- B. People with HIV are much more likely to be virally suppressed if they live in a state with Medicaid expansion (ACA)
- C. HIV criminalization laws do not make a difference to HIV transmission in a state - these laws are not preventing transmission
- D. LGBTQI+ discrimination - mortality rates from HIV are *lower* in places where there is less discrimination

**Quoted from Greg Millett's presentation*

In a simultaneous breakout session, Pavlo Smyrnov of the Alliance for Public Health provided details on Ukraine’s experience as a transitioning country and how that’s affected support for harm reduction. He noted that key challenges in transition have included difficulty in reaching key populations and the general lack of trust among those communities that keeps them from utilizing government services. This challenge was underscored by David Barr of the Joep Lange Institute who noted that a clear role for philanthropy is supporting country level advocacy. This will be essential to ensuring ongoing support for treatment and care while also protecting the human rights of people living with HIV. Philanthropy should also support advocacy focused on holding governments accountable for their commitments. The session also highlighted the basic need for funder-to-funder communication and sharing; to know how transition is impacting your grantees on the ground and to connect them to other advocates and funders to help coordinate efforts during transition periods.



Panelists (L to R): Gillian Holmes, Frontline AIDS; Pavlo Smyrnov, Alliance for Public Health; Matthew McGregor, Global Fund to Fight AIDS, Tuberculosis and Malaria; David Barr, Joep Lange Institute

Empower Communities

“Ending the epidemic means something very different for people living with HIV. Does that mean we are housed? That we all have therapists and food? We have to be careful about what our end goal is.” Andrew Spieldenner, US People Living with HIV Caucus



Panelists (L to R): Sean Strub, Sero Project; Larry Scott-Walker, Thrive SS; Stanley Lee, Levi Strauss Foundation; Naina Khanna, PWN-USA; Andrew Spieldenner, US People Living with HIV Caucus; Marissa Miller, NYTAG

Networks of people living with HIV (PLHIV) drove discourse and disrupted the status quo throughout the early years of the epidemic. They called for harm reduction and comprehensive care. Sean Strub, of the Sero Project, started the panel by sharing how the Denver Principles, first developed in 1983, outlined a series of rights for PLHIV and their family and friends. The principles allowed people to organize and establish networks and support groups. However, as the epidemic has become more black and brown, funding for PLHIV networks has significantly decreased.

So, where are the opportunities for philanthropy to support this work? As noted by Marissa Miller, board member of NYTAG, the epidemic is about the structures and systems that allow the virus to destroy specific communities. In response, the panel conversation highlighted that funders should prioritize building the leadership of people of color; infrastructure and fiscal

management of community-led organizations; and trust, including trusting that community organizers know how to spend resources. Funders should also work to understand and support intersectionality, particularly around sexual health and circumstances that lead to health and income disparities. The need for support for policy and social change work, as well as for protecting the safety of impacted communities, remains critical.

As HIV is the second largest cause of death of adolescents globally, and the first in Africa, the afternoon international breakout session focused on new ways to empower communities of young people. In Africa, for instance, one of the largest barriers to HIV testing among teens is just crossing the line into the clinic. Self-care – think pregnancy tests, Band-Aids, insulin pumps, etc. – is a new way to give consumers direct control over HIV testing. This could provide an important solution to some of largest challenges in the fight against HIV, including stigma, healthcare worker shortages, and scarcity of health clinics and/or services.



Panelists (L to R): Donna McCarraher, FHI360; Karen Johnson, Frontline AIDS; Anabel Gomez, AVAC; Nina Hasen, Population Services International; Taryn Barker, Children's Investment Fund Foundation

This panel also highlighted the importance of ensuring that those who are most impacted have a seat at the table and that their voices are amplified along the entire continuum – from planning through reporting. As just one example, READY –supported by Frontline AIDS – is a portfolio of programs designed to build resilient and empowered adolescents and young people. All READY programs place adolescents and young people at the center of design, delivery, monitoring and evaluation. According to Frontline AIDS' Karen Johnson, giving adolescents a voice in self-care can help address critical human rights issues. The READY WORK program is training 100 young women to advocate on HIV and sexual health, including self-care options. Each of these young women will then go on to train 10 more young women themselves, helping to ensure self-care becomes more entrenched among this population.

What it means to be an HIV Funder



Panelists (L to R): Amelia Korangy, ViiV Healthcare; Lisa Bohmer, Conrad N. Hilton Foundation; Stanley Wong, Levi Strauss Foundation; Sergey Votyagov, Robert Carr Fund; Crystal Crawford, California Wellness Foundation

“The HIV/AIDS movement has great things to contribute [to political change]. And the reality is, if HIV movement leaders are not there, then the most marginalized groups might be left out of universal healthcare.” Sergey Votyagov, Robert Carr Fund

Speakers throughout Day 2 outlined community-focused strategies for funding HIV. To close the Summit, our final plenary moderator, Amelia Korangy of ViiV Healthcare, brought us back to the central question, asking the panelists: what one word would you use to describe being an HIV Funder today?

HOLISTIC. *“California Wellness doesn’t identify as an HIV funder, rather as a funder concerned about HIV. Our HIV and STI work is done under the umbrella of reproductive health... we try to look at issues holistically to bring reproductive and HIV justice together to promote health and wellness for women of color.”* - Crystal Crawford, California Wellness Foundation

HOPEFUL. *“I am hopeful. But as a movement, our partners are working from a place of deficit. We are so close to being AIDS free but are not sufficiently funding.”* – Stan Wong, Levi Strauss Foundation

SOUL SEARCHING. *“We’re struggling to support the communities in a way that will help them survive and thrive. How do we design grant programs that ensure long-term thinking and planning? It’s easy to generate technical solutions. But structural barriers are long standing, insurmountable challenges that civil society is on the front lines fighting against. Funders are in a tricky situation.”* - Sergey Votyagov, Robert Carr Fund

EVOLVING. *“We have to bring the biomedical and psychosocial together. Funding is decreasing. We’ve got to be able to work better. We must deliver a holistic package of support. We’re funding people, not targets.”* – Lisa Bohmer, Conrad N. Hilton Foundation

IN SUMMARY

As you can tell, this was an extremely rich day of discussion. Although we did our best to capture the highlights, there is just so much more to unpack! To that end, FCAA will be sharing further insights as well as videos in the coming weeks. We have also provided a list of additional resources below.

We also want to share our extreme gratitude for the wisdom, energy and time shared by all our speakers and attendees. It is only through the power of our community and thought leaders like you that we have been able to achieve such astonishing progress over the past three decades.

The environment and the epidemic continue to change shape and pose new challenges, but convenings like this serve to bolster our faith in the power of this collective. Thank you, again, and we look forward to seeing you at the Summit in 2020!

SUMMIT RESOURCES: DAY 2 SESSIONS

- DOWNLOAD AVAILABLE [DAY 2 PRESENTATIONS](#)

HACKS FROM THE FRONTLINE: SEX WORKER-SOURCED STRATEGIES FOR CREATIVE AND RESPONSIVE HIV FUNDING.

1. [About UHAI-EASHRI](#)
2. [About Red Umbrella Fund](#)
3. [About the Sex Worker Giving Circle at Third Wave Fund](#)
4. [About the Sex Work Donor Collaborative](#)
5. [HIV Philanthropy for Sex Workers \(2017\)](#)
6. [Defining Sex Worker Rights Funding \(Sex Worker Donor Collaborative\)](#)
7. [Funding for Sex Worker Rights: Opportunities to Fund More and Better \(Red Umbrella Fund\)](#)

ENDING THE HIV EPIDEMIC: A PLAN FOR AMERICA LEVERAGING LESSONS FROM D.C.

1. [90/90/90/50 Plan: Ending the Epidemic in the District of Columbia by 2020](#)
2. Ending the HIV Epidemic: A Plan for the United States. [JAMA. 2019;321\(9\):844-845. doi:10.1001/jama.2019.1343](#)
3. [What is 'Ending the HIV Epidemic: A Plan for America'?](#)
4. [amfAR's Ending the HIV Epidemic database](#)

CATALYZING HIV AND FAMILY PLANNING INTEGRATION THROUGH SELF-CARE

1. [The WHO self-care guidelines](#)
2. [PrEP for Youth](#)
3. [Self-injection of contraception study in Malawi](#)