

Highlights from the 2019 AIDS Philanthropy Summit – Part 1



“We must reject the myth of scarcity and embrace a sense of abundance. Social justice is not a zero-sum game. We can expand our efforts to include others without abandoning people we’ve been serving all along.”

John Barnes, Executive Director, FCAA

FCAA Executive Director John Barnes opened the [2019 AIDS Philanthropy Summit](#) by connecting its two themes – *Keeping AIDS in the Headlines: Maintaining Focus, Expanding Priorities*. Hosted for the first time at the National Press Club, the venue offered an important opportunity to remind attendees of the influence of media, and the potential to harness it to further our work to end AIDS. The second day of the Summit, Barnes indicated in his remarks, would focus on the challenge of balancing the need to prioritize HIV with the need to integrate it into broader efforts to address healthcare and human rights. The agenda that followed this address featured 40 speakers from 10 countries. In this first recap, we will review just a few of the highlights, key themes, and proposed actions that emerged from Day 1 discussions. Keep an eye out for Day 2 highlights - *coming soon!*

Panel 1: Why Media Matters

Panelists (L to R): Robbyn Kistler, Kaiser Family Foundation; Kenyon Farrow, TheBody.com; DaShawn Usher, GLAAD



“Viewers may not have sex education, but they have YouTube.” Robbyn Kistler, Kaiser Family Foundation

Prior to the Summit, FCAA dug into its [resource tracking data](#) and found that less than 1% of HIV-related philanthropy in 2017 supported communications and media-related efforts. As such, we invited the Kaiser Family Foundation (KFF) to design our opening plenary “Why Media Matters.” It clear that “media” involves a long list

of tools, strategies, approaches, and vehicles. Through it, people are connecting, seeking information, and educating others.

One tool is social media, which has created a more equitable and accessible channel to reach *all* stakeholders - from those making global policy and funding decisions to individuals most impacted by the epidemic. Through it, we can reach people where they are – whether that is Twitter, Facebook, YouTube, etc. - and we can reach them in a highly targeted way.

Traditional media still plays an important role. Longer form journalism provides a channel to educate and contextualize the epidemic. *TheBody.com*'s Kenyon Farrow made the point that, where there are problems with the system, we want to make sure the people living with HIV see that – and themselves – reflected in the coverage. We want to ensure that not only are people aware of the problem, but that it resonates with them. TheBody.com is also working to foster the next generation of HIV-focused journalists.

GLAAD's DeShawn Usher advises that we broaden media coverage and representation to appeal to a wider audience, including within the entertainment industry. Interestingly, in the 38 years since HIV was discovered, only 22 songs and 123 films have referenced the epidemic. Just 54 television programs have featured it as a significant plot element or had a main character affected by it. That is why programs like *Pose* on FX are such important vehicles for showing the lived reality of those affected by HIV.

Panel 2: Media, Messaging & Strategy for HIV Justice

Panelists (L to R): Kate Harrison, Avert; Janet Butler McPhee, Canadian HIV/AIDS Legal Network; Zachary Ford, AIDS United; Bruce Richman, Prevention Access Campaign; Naina Khanna, PWN-USA and HIV Justice Network



“Stigma is a public health emergency.” -
Bruce Richman, Prevention Access Campaign/U=U

After establishing “Why Media Matters,” the next plenary used HIV criminalization, the U=U campaign, and harm reduction as case studies to examine how strategic interventions can start conversations, change narratives, correct misconceptions and anchor

critical advocacy and prevention initiatives.

Issues around criminalization are frequently the only time that HIV makes into the headlines. As a result, coverage is often informed from police press releases and other potentially erroneous sources. Most HIV-specific criminal laws are also overly broad, too vague, and do not reflect up-to-date understanding of HIV science. They also vary from state to state and country to country – leading to misinterpretation. But dominant narratives around HIV criminalization are changing, largely due to sustained activism and media interventions.

At times, the landscape makes it challenging for the media to affect the desired change. In fact, the media environment can impede progress. One example, raised by AIDS United, was the recent outcry in the media over planned syringe access sites in Cape Cod. The pushback by detractors was so aggressive the staff at the sites felt unsafe and the plans were scrapped. In such cases, funding capacity building

How can Funders support Strategic Media Interventions

- Janet Butler McPhee, Canadian HIV/AIDS Legal Network

- Understand that moving people from awareness to action is not a linear process (think behavior change communications)
- Play the long game with your grantees; strategic advocacy and policy change take time
- Understand that narrative change indicators can be harder to track, but just as meaningful
- Understand that media interventions can go a long way to changing hearts and minds

efforts to help support advocacy and communications is a role that private philanthropy can provide and offers an opportunity to circumvent these challenges.

The U=U campaign is an example of community working with researchers, public health officials and other stakeholders to build a consensus statement and to prioritize outreach to ensure that clear and life-changing data could reach the people it was intended to benefit. Much of that work has happened on social media; the hashtag #UequalsU has built a global network of community partners sharing the campaign to help dismantle HIV stigma and transform social, sexual, and reproductive lives.

Key Takeaways for Funders - Naina Khanna, PWN-USA and HIV Justice Network

- Consider community-based media as a strategy to democratize and decentralize power; shift policy (e.g. #UequalsU, #AskaboutAbortion)
- Fund proactive + reactive strategies
- Invest in long-term strategies
- Remember that HIV decriminalization also serves as “trojan horse”
- Consider the horizon: End the HIV Epidemic; 2020 Elections

Panel 3: The Art of Storytelling in the HIV Response

Panelists (L to R): Regan Hofmann, UNAIDS; Steven Thrasher, Northwestern University; Georgia Arnold, MTV Staying Alive Foundation; Chris Ridley, Gilead Sciences; Morris Singletary, poZitive2poSitive



“My God is too good to believe that bad story.” Morris Singletary, positive2poZitive

Many of the conversations throughout the first day circled back to the concept of storytelling, starting when Kenyon Farrow shared that personal stories are often among the top performing stories on Thebody.com.

MTV Shuga is an example of entertainment media utilizing storytelling to drive change.

Centered around an award-winning TV drama, it’s a multi-platform campaign that’s been proven to effect positive behavior change in sexual health and HIV. MTV Shuga engages young people in all stages of its development - from formative research, to scriptwriting, to working on set – in a way that allows that the show to tell their stories, in their world. This strategy has led to measurable change. Viewers of the program – which has aired in 10 countries over the past decade – are two times more likely to get tested for HIV. The rate of sexually transmitted infections among young woman in countries that broadcast the show was reduced as was the number of concurrent sexual partners among young men.

Social media has created a new “microphone” for community to share their stories. Morris Singletary, for example, turned to Facebook to create a livestream called #hivandme to speak directly to LGBTQ Black men who were in the church. In this way, he wanted to share his story as a God-loving, Black queer man living with HIV.

What is the role of storytelling in reclaiming narratives that have been created out of bias or misinformation? The story of Michael Johnson – a young Black college student arrested in 2013 in Missouri on charges he had knowingly infected or exposed multiple men to HIV – came up several times during the day. After being sentenced to 30 years in prison, his sentence was overturned in July 2019 due to the work of HIV and criminal justice activists, as well as sustained media coverage. Dr. Steven Thrasher, of Northwestern University, joined to talk about his five years of coverage of the Johnson case for BuzzFeed, and importantly, how it has informed his research on how Blackness and HIV/AIDS are criminalized in the media. In this case, most of the media coverage – including stories that focused on correcting scientific inaccuracies and began to tell Michael’s story – happened after his conviction. Dr. Thrasher reminded funders of the importance of investing in long lead proactive journalism in the model of ProPublica.

Takeaways from Day 1

Some of the key points we took away from Day 1 of the Summit include:

- Social media is a critical tool to help take messages directly to stakeholders.
- Traditional media continues to play an important role, educating and contextualizing the epidemic for a broad audience.
- Funders must find ways to amplify the voices of those telling their own story, who can truly inspire people to make change.
- It is important to invest in mapping influence to identify the best story tellers and the right places for the story to be told.

As you can tell, summing up such a rich conversation isn’t easy. And this is just a recap of Day 1! We will be wrapping up Day 2 shortly, so please stay tuned. And, because we couldn’t possibly share everything in a few blog posts, a list of resources has been provided below. We also encourage you to take a look at a social media summary we put together, which is available [here](#).

DAY 1 PRESENTATIONS & RESOURCES

DAY 1 PRESENTATIONS

- [Day 1 Presentations](#)

DAY 1 RESOURCES

WHY MEDIA MATTERS

1. [Ask KFF: Tina Hoff Answers 3 Questions on Challenges, Efforts to End HIV With Greater Than AIDS](#)
2. [KFF Health Tracking Poll – March 2019: Public Opinion on the Domestic HIV Epidemic](#)
3. [AIDS at 21: Media Coverage of the HIV Epidemic 1981-2002](#)
4. [Leveraging The Power Of The Media To Combat HIV/AIDS](#)
5. [“No, Dr. Sebi Did Not Have the Cure for HIV -- Despite Nipsey Hussle's Planned Documentary”](#)
6. [I Moved to Atlanta Four Months Ago, and Getting Into HIV Care Was Hell](#)
7. [I Moved Back to Atlanta from Boston, and I've Been Out of HIV Meds for a Month](#)

FINDING THE WORDS: MEDIA, MESSAGING AND STRATEGY FOR HIV JUSTICE

1. [Poverty to Power Blog: How Does Journalism Drive Change](#)
2. [Media coverage of harm reduction, 2000–2016: A content analysis of tone, topics, and interventions in Canadian print news](#)
3. [AIDS United. The Right Hit. Developing Effective Media Strategies at Syringe Services Programs](#)
4. [Making Media Work for HIV Justice: An introduction to media engagement for advocates opposing HIV criminalisation](#)
5. [New York Times. Editorial: Living With H.I.V. Isn't a Crime. Why Is the United States Treating It Like One?](#)
6. [POZ March 2019 Edition: U=U](#)

THE ART OF STORYTELLING IN THE HIV RESPONSE

1. [This HIV Activist Uses Social Media to Uplift Black LGBTQ+ Men in the Church](#)
2. [MTV SHUGA: Changing Social Norms and Behaviors.](#)
3. ["Tiger Mandingo," Who Got 30 Years For Not Telling Sex Partners He Had HIV, Is Free 25 Years Early](#)