What Makes an Activist?

Claim your place at our community table.

February 14, 2022 By Mark S. King

Atlanta isn't called "Hotlanta" for nothing. It's scorching there. I think the handcuffs I was wearing one spring day in 1994 absorbed the heat and burned my wrists. But I had other things on my mind.

The protest that day was chaotic, as all good protests are. We had a great turnout from the local ACT UP chapter, and plenty more people showed up from the coalition of people living with HIV that I headed. I was the group's new executive director, but my board wasn't convinced I was enough of an activist to suit them. Maybe, I thought, as I stood handcuffed to the county health department entrance, this will help change their minds.

"Stop the madness!" we screamed, while other activists carried around a life-size cardboard coffin on their shoulders.

Mark S. King at a 1994 protest in AtlantaCourtesy of Mark S. King

We had a serious problem with an unjust health department policy that directly affected people living with HIV. Our protests lasted weeks before meaningful dialogue about a policy change began.

So there I was, handcuffed and yelling my brains out, fully engaged in the street theater of AIDS activism. Our cries grew louder as police arrived and television news cameras drew closer to my shrieking, sweating face. “Can you wait until the ABC station gets here before you arrest me?” I discreetly asked the officer who approached. He obliged.

It was thrilling and scary and triumphant, and I have never felt more like a fraud in my entire life.

I wasn’t an activist. Not in the overt way that was expected of me. I had spent the previous years working for a Los Angeles organization that provided emotional support to people dying of AIDS. We were care providers in the truest, most intimate way.

My new job in Atlanta, I believed, was to lead the agency out of financial hardship and promote our programs to the community. The board, however, populated largely by gay men living with AIDS, was more interested in fury than financing.

As a coalition of people living with HIV the organization practiced its mission to a fault, too often using activism and identity as insurmountable purity tests. HIV status was treated as an ace to play in any conflict.

I believe wholeheartedly in the importance of coalitions of people living with HIV and the power of our collective voices. I had just never seen our identity weaponized against people in our own community.

During my first week on the job, I was invited to a nighttime activism action in which gravestones would be placed on the front yard of the director of the city’s largest HIV service organization. My staff abhorred her, believing she didn’t prioritize people living with HIV.

I declined to participate in the public humiliation of a fellow administrator I had never met. Instead, I invited the executive directors of every HIV agency in town to a monthly breakfast for us to socialize and build trust. My coworkers were mortified.

Our agency would not accept government money, like Ryan White funding, because the board believed it might compromise our coalition’s integrity. Pharmaceutical donations were out of the question. Meanwhile, our finances were weeks away from insolvency when I arrived. I demanded that the board apply for pharma and government grants and then used them to put us back on fiscal track.

I recognize my part in my disastrous stint at that agency. I was young and inexperienced as an administrator, naive about asking the right questions beforehand and had more ambition than

qualifications for a job that didn't suit me. And I'm sure my attitude suffered as it became clear I wasn't the executive director they wanted.

I lasted barely more than a year. A board meeting was surreptitiously arranged the night of the most successful fundraising event in our history. I was fired. The fundraising, the hobnobbing with community leaders, the grants from government and Big Pharma and my misgivings about marching in the streets were antithetical to their definition of true activism.

It was a humiliating punch in my gut. As a so-called activist, I was a documented failure. For years afterward, I would refer to myself as an "advocate," believing it was the only title I deserved. The coalition thrived for another decade, fortunately, and kept my disdained funding policies in place. I'm glad it served the community so long and so well.

And yet, here I am, nearly 30 years later, defending my activism credentials and reliving the personal embarrassment of having been fired from my job.

Why? Because our worth as activists has nothing to do with our arrest record or how loud we scream at protests. Because the iconic images of our great AIDS activism history represent only a fraction of who we were then and who we are now. Because attempts to emulate the heroics of the early years of AIDS sometimes lead to a misguided fundamentalism that pits those with resources, privilege or personal desperation against their own allies. And because, God help us, our movement isn't immune to fanaticism.

Any effective social justice effort is built on addition, not subtraction. We can use all the help we can get. Yes, there are people whose judgment I question. But it sure as hell isn't measured by their HIV status or how many die-ins they've attended.

Purity tests over identity remain with us, unfortunately. Months ago, I was debating an issue about living with HIV with another long-term survivor when I mentioned that despite having tested positive in 1985, I've never received an AIDS diagnosis. My T cells have never fallen below the 200-count threshold that serves as a clinical marker for the syndrome.

The long-term survivor was aghast. My disclosure effectively ended the conversation. I couldn't possibly understand, he assumed. I might be washed in the blood, but I hadn't nearly drowned in it.

Our community is peopled by almost-activists who felt intimidated or were made to feel they didn't measure up, so they quietly backed out of the room. Even within our ranks, accomplished people still wince at the activist label because they're comparing themselves unkindly to burnished images of yesteryear or they have been unfairly sidelined for one reason or another. That includes, by the way, the younger activists we so desperately need but who often report that they feel daunted by our activism history.

Some of our most effective community members share a self-consciousness about whether they deserve to be viewed as activists. Their stories are instructive.

A couple of years ago, Queen Hatcher-Johnson had a hard time sitting quietly during a visit by Robert Redfield, MD, then the director of the Centers for Disease Control and Prevention (CDC), to her HIV service organization. As the Black transgender woman listened, Redfield's language bothered her.

"He kept saying, 'high-risk population,' which I found really stigmatizing," Queen tells me. So she spoke up and called him out on it. "Who are you to say who is 'high-risk'?" she asked the CDC director. "I'm a Black trans woman. I take a risk when I leave the house every day."

Queen had to be encouraged to share that story with me and even to participate in this article because she didn't feel like the title of activist applied to her. "I still have that problem," she confides. "If I'm not out there in the street, I'm not an activist."

Queen Hatcher-JohnsonCourtesy of Queen Hatcher-Johnson

There are very practical concerns for Queen, who describes her age as “50-plus,” for not having participated in the high-profile AIDS activism that she remembers well. “I don’t do protests,” Queen says flatly. “It’s a safety issue for me because of my gender identity.”

Queen’s track record is stellar nonetheless. She is the first Black trans person in a management position at her organization, Positive Impact Health Centers, in Atlanta. She even created her job title: gender inclusive program manager.

“I was having a conversation with a senior person here one day,” Queen recalls, “and he asked me why I thought we didn’t have more people of trans experience coming through our doors. I told him we needed to incorporate hormone therapy into our services, because you cannot say you are supportive of my community and then not include that. Hormone therapy helps confirm our gender identity.”

After numerous meetings, the agency now provides hormone therapy among its array of clinical services and has dozens more trans feminine and masculine clients as a result.

“I created the responsibilities for my job,” Queen tells me. “That was a win for me. When I started with the agency, I just wanted to be employed. I had no idea I would be where I am now. But I wanted to be of service to the community I come from.”

Queen has well-earned pride in her promotion to a management position, but she still has goals, as much for herself as for those she represents. “I will not stop,” she says, “until I have a director position at my agency.”

Queen challenged the head of the CDC and changed the public face of her organization and the services it offers without ever once shouting at a protest. Only after we discussed how crucial visibility is to our respective communities—mine as a gay man living openly with HIV and hers as a Black trans woman—did we agree that transparency is the ultimate expression of activism.

The conversation hit Queen like a revelation. “Quiet activism is still activism,” she says, finally, as much to herself as to me.

Queen Hatcher-Johnson, my friends, is an activist.

Matthew Rose, at 35 years old, is too young to remember the activism that defined the first decades of the AIDS epidemic. That hasn’t kept him from being at the forefront of HIV policy and prevention debates that affect Black gay men like him. He’s currently a director at Global Health Strategies.

“We need more options for prevention,” Matthew tells me. He explained this to the Food and Drug Administration at hearings for the approval of Truvada as pre-exposure prophylaxis (PrEP). “Black gay men have fewer sex partners and use condoms more often and yet are more likely to get HIV

because there is a higher incidence of HIV in our community.”

Matthew RoseCourtesy of Matthew Rose

At a CDC conference, he got explicit about the sexuality of gay men because no one was talking openly about it. “I had to really challenge their perceptions that every gay man is doing the same thing on Grindr and that this app is part of the problem, not part of the solution, or the unreality of viewing us as strict tops or bottoms.”

Pushing for clinical trials that better reflect diverse communities is central to Matthew’s focus. “We are not a monolith,” Matthew observes. “That means we must have the right proportion of Black men and women and representation for trans women. We have to get more creative to make this happen.” Matthew’s fingerprints can also be found on the federal “Ending the HIV Epidemic”

initiative, because he worked with the administration on outlining its standard of care.

Matthew has challenged authority within several governmental agencies, raised the issues of racial diversity and helped map a national HIV response. His commitment is total. He has accomplished this without having been arrested at a protest and without, it is worth mentioning, living with HIV.

Matthew Rose, folks, is an activist.

Street activism will live on as long as there is injustice and the courage to respond to it. We see reverberations of our early history in the ferocious work of PrEP4All, in the international effort to share the Undetectable Equals Untransmittable (U=U) message, in the voter drives by the Positive Women's Network–USA, in the successful efforts by the Desiree Alliance and others to have sex workers acknowledged in the National HIV/AIDS Strategy and in the ongoing work of ACT UP chapters around the globe.

Which brings us to you. Just as we must know our worth as people living with HIV, I encourage you to claim your place at our community table. You'll find that most of our seasoned community figures will welcome you. Call yourself anything you want. Step out of the long shadow of our activism history and find your own light.

There is a time and a place for chalk outlines and crowds of righteous rage. This is now your time and your place. Use it as you see fit. Your activism forebears are cheering you on.

Activism isn't just about what we did then. Activism is now about what you do next.

Mark S. King won the 2020 GLAAD Media Award for his ongoing blog My Fabulous Disease, which chronicles his life as a gay man living with HIV and the people who inspire him.

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