It leaves a mark: Current realities of HIV-related stigma

May 31, 2018 By Andrew Spieldenner, PhD

HIV-related stigma is pervasive in American society. It is personally felt, but manifests throughout institutions, communities, and even interpersonal interactions. Sociologist Erving Goffman conceptualized stigma as a process where one's character is discredited due to a perceived or actual condition. This can result in a variety of reactions from people who experience the condition – from avoiding potentially stigmatizing situations to experiencing discrimination or harm. In the case of HIV, many remain concerned with secondary disclosure – where someone feels the need to inform other people of our HIV status.

In the past decade, I have heard grumblings that HIV-related stigma is no longer an issue, or that it is solved - at least in the American context. It is no surprise that these people are all publicly HIV-negative, or that these lawyers, public health officials, heads of HIV organizations and clinics do not want to believe how they are complicit in propagating and supporting HIV-related stigma in their daily businesses and actions. It is a surprise that most of them imagine themselves "allies" to people living with HIV. In fact, I heard two spewing this at the HIV Is Not A Crime Training Academy two years ago. As we come up on HIV Is Not A Crime Training Academy this week, I hope that I will not have to listen to this rhetoric. I hope that people will be able to hear how HIV-related stigma operates, impacts us differently, and allow us to build resilience within our communities without interference.

This is always the hope.

As a gay man of color living with HIV, I am aware of the many ways that stigma paints me in this society: a slut, someone who should know better, irresponsible, unworthy of sex and love, trashy, a drug addict, a burden on society, a failure, deserving of abuse and disgust, less than. (And, yes, people have actually said all of this directly to or about me.) Other people living with HIV understand this. We have all been scared, unsure and vulnerable to stigma – whether actual, perceived or expected. Sometimes we internalize these messages and honestly believe we are unworthy or less than in certain circumstances.

It's hard to believe we are enough. It's made more difficult when leaders in public health or self-proclaimed "allies" discount our experiences of stigma, relegate stigma to the past, or even worse – try to take over our spaces for their own needs and purposes.

As a researcher, I am cognizant that HIV-treatment has changed everything. When I was diagnosed in 1998, I was told I could have 5-7 years, maybe as much as a decade. Now people who are diagnosed are told they can have a normal life span if they stay on HIV treatment. I see the importance of science demonstrating that when we are virally suppressed, we cannot transmit the virus. I have experienced the boldness of men on PrEP, suddenly not caring that I have HIV. I appreciate how these advances have shifted my quality of life in many areas.

These advances in HIV science did not help me get a job, or feel safe in a relationship. They do not help me with my rent, or the trauma and stressors in my life. They did not educate my family about my disease, or improve the social meaning of HIV in society or my community. They do not prevent the many ways that I am still disciplined – especially on the job - for being "too gay" or "too ethnic" or talking about sex and drugs openly. They do not stop the massive wave of violence aimed at trans folks; they do not protect against intimate partner violence; they do not help manage government processes like immigration or probation.

HIV-related stigma has changed since the 1980s and early 1990s, but it has not gone away. We know more about it. We know that job training, rights training, affordable and accessible housing, community building, personal resilience and mental health are integral components to battling stigma. We know that people of color - particularly trans people of color, sex workers, immigrants and people who have been incarcerated face different kinds of stigma, and have different resources to battle it than our White counterparts. We know that better policies and laws could be in place to protect us and encourage us to thrive.

I coordinate the HIV Stigma Index in the United States on behalf of Global Network of People with HIV/AIDS-North America (GNP+/NA). The Stigma Index involves a network of people living with HIV collaborating with a research partner to collect and analyze data on stigma amongst people living with HIV in order to advance advocacy platforms that directly address the kinds of stigma found in the community. So far, over 750 people living with HIV have participated in the Stigma Index in Michigan, Louisiana and New Jersey.

One of my roles is to filter requests for the Stigma Index tool and resources for those people who do not qualify. A lot of researchers have asked for this tool for their research. We also get a lot of requests from organizations to enhance clinic evaluation tools.

A memorable encounter: an e-introduction to a woman who has been in HIV since the 1980s. Since then, she has relocated to the South and works in HIV services. She wants the Stigma Index to do evaluation at her clinic. There are other evaluation tools available and the Stigma Index is meant to be used in community-based participatory research to change stigma in local communities, not just collect data for one clinic. When I informed her, she responded with an angry lengthy email whose highlights include: "You don't understand what we need in the South," "Who are you to question my intent – I've been in the field longer than you've been alive," and "…been doing this work so long, I speak for people living with HIV."

This was not the first time that someone HIV-negative has said this to me (nor, even, the last).

Some of our self-proclaimed “allies” have gotten very comfortable speaking for us, taking a seat at the table meant for us, sometimes even to our exclusion. Because they believe they can do better than we can. Do they consider us “less than”?

HIV and the stigma associated with it has left its mark. We do not need “allies” to privilege their voice over ours. We need to have a space at the table to talk about how stigma impacts us, the nuances between our experiences and our resources to manage this trauma. We need to hold each other accountable and ensure our own diversity is fully represented. We need spaces of our own to come together and learn from each other. We need to listen to how stigma impacts us differently, and respect that reality. We need to work together to build solutions, accepting that these solutions will look different depending on where we live, with whom we have sex, how we make our living, and what communities we call home.
