



HIV Has Changed. The Stigma Hasn't.

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June 12, 2025 By [Tom Duane](#)

Stigma.

Stigma has been on my mind for several days. It's very much on my mind, because these may be the most perilous times for people living with HIV since the beginning of the pandemic.

I live in New York City, where I often have some interaction with a person or people who work for an HIV/AIDS or Recovery focused organization. As is often the case, the interaction takes place in a formal setting where I am one of several people gathered around a "name-plated" conference table.

HIV/AIDS (back in the day, we just called it AIDS) and people affected by the virus have been stigmatized since the very beginning. Fear and the fact that we didn't know very much about HIV magnified the disgrace that came with a positive diagnosis. However misguided and inhumane, the stigma was ever present.

One example of the profound stigma and discrimination, based on incorrect knowledge of widely known and accepted science, is that in 1991, the legendary basketball player Magic Johnson, who bravely shared his HIV status in November of that year, was thrown out of, barred from, and forbidden to play basketball on any team, any league, anywhere. This edict was decided by those who were in charge of the National Basketball Association (NBA): the team owners.

Johnson was invited to be in the starting lineup for "The Dream Team" in the 1992 Olympics, despite some teammates expressing worry that the virus could be transmitted, should Johnson have an open wound during a game. Regardless, Johnson joined other NBA powerhouse players on the team. While suffering with a knee injury, Magic still scored an average of 8 points per game in the Olympics, and the U.S. dominated their opponents in every game, securing the gold medal for the USA. (I just realized how butch I sound!)

Another example of extreme stigma from that time was that international travelers living with HIV were forbidden entry into our country. This ban remained in effect for 20 years. And, to this day, some countries still deny people entry based on their positive HIV status.

I am a person who is open about their HIV status. When I was deciding to run for New York City

Council in 1991, I knew that it would be a challenge if voters knew, since the stigma was so oppressive and so widespread at the time. AIDS was thought to be a death sentence, so logically it followed that disclosing my status would be the death of my political career as well.

I decided that I wasn't going to hide, so I disclosed that I was living with HIV to the voting public. And I was elected.

In 1999, when I ran for and was elected to the NY State Senate, the stigma there was, well, a lot. I was shocked, although maybe I should not have been, by the ignorance, fear and judgement on display among many in and around the NYS Legislature. It wasn't just that one Senator did not want to shake my hand, it was that I arrived to witness ignorance by so many regarding how HIV is contracted. That lack of knowledge informed some very poorly conceived legislation and policy regarding HIV and AIDS.

Tragically, still today, with all the advances in medications and treatment, and the fact that HIV is no longer a death sentence, the stigma is as powerful as ever.

Back to the "name-plated" meetings that I described earlier. Here other attendees likely come from HIV/AIDS service organizations, a Substance Abuse Disorder umbrella organization, or other non-profits. I know that these special people would not intentionally, under any circumstance, perpetuate negative attitudes or actions regarding HIV/AIDS or people living with HIV/AIDS. And, I believe that all, well certainly most, of these people are good people, doing good work, and want to and are helping people in many different and important ways.

Yet, in many of these meetings, I am often struck by the misconception of some of these people that the stigma around HIV/AIDS is vastly diminished or practically non-existent. I tell them to ask their clients!

I would venture to say that if service providers asked their clients at these organizations, they'd find that the vast majority haven't told anyone about their HIV status, except maybe a small circle of friends.

I'm well aware that I'm an exception, having decided to publicly disclose my HIV status back in 1991. But the vast majority of people living with HIV will tell you that they haven't disclosed, not to employers, co-workers, landlords, neighbors, or family. Because stigma is alive and well, and sadly, thriving.

Thomas K. Duane is a former New York State Senator and a pioneering advocate for LGBTQ+ rights and public health. Elected in 1998, he became the first openly gay and openly HIV-positive member of the New York State Senate. Duane represented the 29th District, encompassing Manhattan neighborhoods like the Upper West Side, Chelsea, and Greenwich Village, until his retirement in 2012. He played a pivotal role in passing landmark legislation, including the Sexual Orientation Non-Discrimination Act (SONDA), Timothy's Law mandating mental health parity, and the Hate Crimes Protection Act. Duane was also instrumental in the 2011 legalization of same-sex

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