Medium

The Next Chapter in HIV/AIDS Treatment and Prevention: The Equity Era

Arthur Fitting, BSN, RN

March 01, 2023

Where are we now in the trajectory of the AIDS epidemic? In a recent conversation with veteran infectious disease expert Dr. Jay Dobkin, the two of us delved into this very question. Dr. Dobkin and I reflect on our earliest days on the frontlines of the epidemic, and the critical impact early AIDS activists had in raising awareness and bringing together public support and funding that laid the foundation for HIV/AIDS health and policy initiatives.

Today, thanks in large part to the efforts of these brave men and women—and those who follow in their footsteps—perception of HIV/AIDS is has been transformed in significant ways. But stigma is stubborn and is always a threat for vulnerable populations.

*As many of us reflect on HIV is Not a Crime Awareness Day this week, it's important to remember that across the world, and in parts of the U.S., HIV is still stigmatized, and even criminalized. Like other intersections of an individual's identity, from race, to gender, to HIV status, encountering stigmas can have a distinct impact on health outcomes. While care, treatment, and research remain a priority, it is essential that we not forget what the earliest days of the epidemic taught us: "**Silence = Death**." The conversation must continue.*

Arthur Fitting: So many of the people we work with were born after the AIDS crisis and have no historical context of the early days of the epidemic. What would you like people to understand most about that time?

Jay Dobkin: I got in on the ground floor, starting at Harlem Hospital in 1979. We were already seeing AIDS cases, although we wouldn't know what it was for another year or two. As the epidemic got rolling, peaking in the 1980s, things were bleak. Huge numbers of people were sick and dying, with no end in sight.

I went into infectious diseases to cure people. But we couldn't. I thought, *This isn't what I signed up for.* But it made me a better doctor. I learned to do things because I had to: pain relief, counseling families, intervening in psychosocial turmoil, including patients whose family won't let them back in the house after discharge from the hospital. I don't look on that time fondly, but it was a time when providers and the community made a big difference.

The other thing that made a tremendous difference were the AIDS activists. In those early years, the silence from the government was deafening. Public health agencies were asleep at the switch. I remember in the mid-1980s trying to get harm-reduction information to our drug-using patients in Harlem, and the New York City Health Department wouldn't provide any. The AIDS activists stiffened everybody's spine—ACT UP, Body Positive, Treatment Action Group made a huge difference.

They provided a bed of support to clinicians like me who felt we were on our own, out at the Alamo. The activists also got into the machinery of treatment policy. They accelerated approval of drugs, expanded access. All these things that are now standards with the FDA—they were created by AIDS activists' putting pressure on the appropriate parts of government.

Thanks to that legacy, all of a sudden in 1995, HIV went from incurable, hopeless disease to something that could be effectively treated. You can divide AIDS into two parts: the Crisis Era of the first fifteen years and the Treatment Era.

Arthur Fitting: Talk about the Treatment Era. Not all patients have benefitted equally.

Jay Dobkin: At places like VNS Health, and our SelectHealth specialized insurance plan, we recognized that even though there was effective treatment, the game wasn't over. There were a lot of people who weren't engaging in care, staying in care, adhering to their meds, that the benefit was really not being realized. We could not declare victory and go home. We had to—and still have to—keep up the struggle until the last patient out there gets the benefit of this truly spectacular advance in medical treatment.

Arthur Fitting: With Western medicine, people think all you have to do is take a pill. But there's so much more to it than that.

Jay Dobkin: Treatment is not always purely medical. It's psychosocial—a housing issue, mental health issue, family issue. One of things I'm most proud of about SelectHealth is that thanks to recognition by the CDC and New York State Health Department, and a grant from the AIDS Institute, we've been able to engage our most troubled members, people who've fallen out of care. The answer is not, "Oh, just take a pill," because if it was that easy, they would do it.

VNS Health engages both the health plan and the provider in these concrete issues, whether it's counseling people, helping them with housing, getting them into psychiatric care, pairing them with peer counselors who've been through this and they can lean on. We talk about health equity—that's health equity, to make sure that people even at the margins of society get the same benefit from these spectacular medical advances.

When I went to medical school they didn't teach us any of this. That was really a deficiency. If you're serious about effective medical care—not to mention public health—then it's a responsibility of everyone in the system to engage in all those issues, not just the nuts-and-bolts medicine.

Arthur Fitting: What suggestions would you offer a person newly diagnosed with HIV?

Jay Dobkin: First, this is a very treatable condition. You can be restored to full health and a normal life span—as long as you get the right treatment and stick with it. You've got to engage in care and stay engaged.

One thing that frustrates older AIDS activists and older AIDS providers like myself is casual attitude that seems to have taken hold in terms of safe sex and safe injection practices and so forth. It's true, we have very effective treatment for HIV, but still you'd be well advised to avoid it and not spread it. The same goes for STDs.

Things have gotten much easier. Long-acting PrEP is now a reality. PrEP itself is a relatively recent development. HIV treatments—which in 1995 seemed revolutionary but involved a bucketful of pills and a lot of side-effects—have now become extraordinarily simple and well-tolerated. A single small pill once a day, or even an injection once every month or two, and you can essentially lead a normal life. That's all wonderful. But it's not a free pass to get infected or transmit infection. That's got to be part of the mindset.

Arthur Fitting: There's still so much stigma attached to HIV and AIDS. We were reminded of stigma again recently with mpox. You've taken care of the HIV/AIDS community for more than four decades and have helped clinical staff and patients deal with stigma. What are some of the lessons that you've learned?

Jay Dobkin: There are no easy answers. There were a lot of people who ran away from the early AIDS epidemic—providers, families, you name it. It's a credit to the people who didn't run away that eventually the tables turned.

Starting about 15 years ago, we began getting applicants coming for residency and fellowship programs who said, “I want to work in AIDS—that's why I'm doing this.” I was astounded. Early on, we had trouble even getting people's meals brought into their rooms or getting their rooms cleaned.

Eventually, a lot of ignorance-based stigma and fear resolved. Once again, all credit to the AIDS activists who, often in very dramatic fashion, told everybody available— including *yours truly*—that we were all full of it and needed to wake up and get with the program.

It's a matter of walking the walk and not just talking the talk. I would credit all the people over the years who were there because they wanted to be there, who made it very clear to patients that they were safe, accepted, and supported. You may not be able to deal with every bigot out there, but giving people a safe harbor makes a lot of difference. That was one of the great advancements that I saw over the years.