45 Years Later: The Unfinished Fight for Equity in the HIV/AIDS Response

Longtime advocates contemplate the impact of funding cuts on a new generation of long-term survivors.

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Forty-five years after the first reported cases of what would become the HIV/AIDS epidemic, the United States stands at a crossroads. What was once a mysterious and deadly illness has become, for many, a manageable chronic condition. Yet, this milestone should be a moment not just of recognition, but of reckoning.

As leaders working at the intersection of HIV care, policy, and community advocacy, and as we reflect on HIV Long-Term Survivors Awareness Day, we see both how far we have come and how fragile that progress remains.

Science has transformed HIV.

From the early days of the epidemic, HIV has followed the fault lines of inequality—race, income, housing, and access to care. Advances in treatment and prevention have reshaped how living with HIV and not transmitting it to a sexual partner are what is medically possible. Antiretroviral therapy allows people to live long, healthy lives. Undetectable equals untransmittable (U=U) has revolutionized prevention. Tools like PrEP, PEP, and long-acting injectables can stop new infections before they occur.

But we have not systemically erased the complex structural barriers and biases that determine who receives lifesaving care and who does not.

Access—not innovation—remains the defining challenge. And access is exactly what is now at risk.

Today, policy decisions threaten to weaken the systems that have expanded access, through federally-funded safety net programs which have proven a high return on investment for taxpayer dollars. These decisions risk repeating the very failures that defined the early years of the epidemic.

Medicaid is the backbone of HIV care in the United States, covering roughly 40 percent of adults living with HIV. It funds medical treatment, as well as the integrated services that make care

effective: behavioral health care, linkage to housing and social services, and case management. A “whole person health approach” that puts people living with HIV at the center of systems and not the other way around.

For many of the people Amida Care serves—low-income Black and Latino New Yorkers—and those most impacted by HIV who are the focus of NMAC’s national and state-based efforts, Medicaid is more than just insurance. It is a lifeline - the difference between stability and crisis, between viral suppression and serious illness, between life and death.

H.R. 1 strips more than $1trillion from Medicaid—the largest rollback in the program’s history—and layers on new eligibility rules that will push millions off their coverage. On paper, these policies look like administrative tweaks: stricter work requirements, lower eligibility thresholds, more frequent paperwork checks. In reality, they translate into dangerous gaps in care. They mean missed appointments, missed doses, and treatment interruptions that no one chooses but are forced by red tape.

In HIV care, interruption is not a minor setback. It is a direct threat to both individual and public health. Treatment disruptions can lead to viral rebound, drug resistance, and increased risk of transmission.

We have seen this before. And we know that the communities we serve will be most affected.

Our Black and Latino communities—already disproportionately affected by HIV due to longstanding inequities—are also more likely to rely on Medicaid. Cuts to this program do not land evenly; they fall hardest on those who have borne the greatest burden for decades.

At the same time, the infrastructure that has driven progress is under strain. Safety-net providers, community organizations, and HIV-specialized plans will be forced to do more with less, even as demand grows.

Meanwhile, a new generation of long-term survivors is emerging.

Thanks to effective treatment, people diagnosed today can expect to live into older age. Those who survived the earliest years of the epidemic are now in their 50s, 60s, and beyond—often managing multiple chronic conditions alongside HIV, while carrying the lasting effects of stigma and loss.

Long-term survivorship for people aging with HIV depends on more than clinical treatment alone—it hinges on steady coverage and a web of support that keeps people healthy, housed, and connected. Medicaid is the backbone that makes that possible. It provides the stable insurance many long-term survivors rely on, and it funds the services that meet the full reality of aging with HIV: mental health care, housing supports, nutrition programs, and the social services that keep people anchored in their communities. In short, Medicaid is the infrastructure that turns coordinated, continuous care from an aspiration into something people can count on.

We cannot claim to be ending the HIV epidemic while weakening the systems that make prevention and treatment accessible. We cannot celebrate scientific breakthroughs while allowing policy decisions to widen the disparities those breakthroughs were meant to overcome.

The lessons of the past are clear.

Early in the epidemic, a federal report from the Centers for Disease Control and Prevention identified a troubling pattern: HIV was already disproportionately affecting Black and Latino communities. The warning was unmistakable. This was not only a biomedical crisis—it was a structural one.

The failure was not a lack of knowledge. It was a lack of sustained, equitable action. Today, we face that same test. Will we strengthen what works, or will we allow preventable inequities to persist?

Ending HIV is not just a scientific goal. It is a moral and economic one. It demands confronting the systems that shape who gets care, who stays in care, and who is left behind. Medicaid is central to that effort. Weakening it does not reduce costs; it shifts them—onto communities, providers, and ultimately, human lives.

Forty-five years later, we know what works. We know what is at stake. The question is whether our elected officials are willing to act.

This time, failure is a choice by policymakers and political leaders. The fight is not over. Let’s choose better. Let’s choose equitable dignity, health, and well-being for all Americans.

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