From Crisis to Community: Why HIV Work Continues to Demand Our Attention

I struggled after my AIDS diagnosis, writes C.J. Tobe for AIDS United, but community saved my life, literally.

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By C.J. Tobe

There are moments in life that divide everything into “before” and “after.”

For me, that moment came in my early twenties, sitting in the kitchen as I learned I had AIDS.

The diagnosis changed everything.

What followed was fear, isolation, and uncertainty. At times, it felt like everything I thought I understood about my future had disappeared. I did not handle it well. The weight of the diagnosis, the stigma, and the uncertainty felt overwhelming.

HIV carried stigma.

AIDS felt final. I struggled to imagine what came next, or whether there even was a “next” worth imagining. But I was not left to carry it alone.

My therapist saw how much I was struggling and stepped in immediately. They made me sign a no-harm contract and worked closely with my mother to help pull me back from a place I am not sure I could have found my way out of on my own. I still think about that often; my mother refusing to let me disappear into despair, showing up even when neither of us fully knew what came next.

Together, they helped me slowly find my footing again. They reminded me of something I had lost sight of in that moment: that my life still had value.

What I did not fully understand then, but carry with me every day now, is that this kind of care does not happen by accident. It exists because communities build systems of support. Because advocates fight for resources. Because someone, somewhere, decided another person’s life was

worth showing up for.

In my case, it was dollars raised through community-driven events like Dining Out For Life that helped me get to and from medical appointments during a time when stability felt impossible. Those resources mattered. They helped make care reachable when I needed it most.

The Fragility of Progress

We are living through a moment of contradiction in the HIV response.

On one hand, the progress is extraordinary. HIV is no longer the death sentence it once was. Treatment works. Prevention tools like PrEP have transformed what is possible.

But progress can create the illusion that the crisis is over.

It isn't.

Across the country, access to care remains fragile. Stigma still shapes outcomes. LGBTQ+ people, Black and Brown communities, transgender individuals, and people living in poverty continue to face barriers to prevention, treatment, housing, transportation, and healthcare. At the same time, organizations are being asked to do more with fewer resources while policy shifts threaten hard-won gains.

I see this every day. I see people choosing between transportation and treatment. I see people delay care because of fear; fear of cost, fear of judgment, fear of being seen.

The truth is simple: progress in HIV is not permanent. It must be protected, funded, and adapted to the realities communities face today.

What Still Works and What the Future Requires

If HIV has taught us anything over the last four decades, it is this: the most effective solutions come from community.

Not assumptions about what people need. Not top-down systems alone. But organizations willing to meet people where they are, physically, emotionally, culturally, and without judgment.

Across the country, we see this every day: HIV care integrated into broader health settings to reduce stigma, transportation and outreach efforts that remove barriers, mental health and housing support embedded alongside medical care, and harm reduction programs grounded in dignity and trust.

We also see it through community-driven efforts like Dining Out For Life, powered by the Amplify Network, which raises both resources and visibility for local organizations doing this work every

day.

These are not just programs. They are lifelines.

Because healthcare is not only about treatment. It is about connection, stability, and dignity, ensuring people do not have to navigate crisis alone.

I often think back to the version of myself who did not know what came next. The young man who had lost his hearing, much of his stability, and pieces of the support system he thought he could rely on. That version of me is partly why I do this work.

But I also carry others with me.

I often think about the transgender Black woman and others I spent nights alongside in a local park when I was unhoused. Many of them are no longer here. Their stories mattered. Their lives mattered. And they remind me that HIV has never impacted communities equally. Vulnerability has always been shaped by race, poverty, housing instability, stigma, and systems that fail people long before they reach care.

Those realities still exist. Which means our work is not finished.

If we are serious about ending the HIV epidemic, we cannot become complacent. We must continue investing in prevention and treatment, protect access to care regardless of income or geography, and confront stigma, not only in communities, but within systems of care themselves.

Most importantly, we must continue investing in the organizations and leaders closest to the work. The HIV response of 2026 cannot look exactly like the HIV response of 1996. Community organizations need space to adapt, learn from one another, and build stronger systems together.

HIV has always demanded more than medicine. It asks something of all of us: What do we owe one another? Who do we fight for? What kind of systems are we willing to build?

A Reason to Stay Hopeful

More than 45 years into this movement, one thing remains true: community is still our greatest strength.

I know this because community saved my life. Literally.

People showed up for me. Organizations invested in me. Strangers fought for systems I would one day rely on. And because of that, I am still here.

That is why I remain hopeful. Because I have seen what happens when people come together; not only in moments of crisis, but in long-term commitment.

We do not just respond to HIV. We build the care, relationships, and communities that help people go beyond surviving; we remind them that their lives have value, their dignity matters, and their stories are not finished.

And that work is far from over.

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