The HIV Community

Vickie Lynn, MSW, MPH, is a doctoral student at the University of Florida and an advocate living with HIV. In an opinion piece titled "The HIV Community," she argues for the need to continue working together. Here is an edited excerpt.

February 18, 2016 By Vickie Lynn

That anyone in the United States is still dying from AIDS-related complications is a prime example of why the HIV community needs to continue working together for change. We need to continue to advocate so that everyone living with HIV can access physical and mental health care.

This is one of the reasons my research includes looking at the system-level factors affecting the adoption and implementation of integrated care. Holistically treating people with chronic health conditions is an innovative solution to our current system of care. We need to continue educating others about the issues facing our community and the need for increased access to both physical and mental health care.

When I contracted HIV 30 years ago, there were no medications to help fight the virus; there were no treatments to slow the progression of the disease or to deal with the multitude of issues brought on by the lack of an immune system. There was little hope that anyone diagnosed with HIV would survive more than a few years.

Many of us found ourselves rejected by our families, homeless without access to care and treatment, and lacking any hope. Even when medications were discovered, we faced health care bureaucracy that limited our ability to access care and treatment, and we lost many friends along the way.

People diagnosed with HIV today can expect to have a normal life span, as long as they are in care and on treatment. There have been countless medical discoveries allowing us the opportunity to maintain our immune system and control the amount of virus in our body, thus reducing the risk of transmitting HIV to others. This has allowed many of us to return to school, to follow our hopes and dreams, to find love for ourselves and others, and to make a life worth living.

The HIV community in the United States has grown by almost 50,000 new members every year for the past decade. The new members come from all occupations and backgrounds, all genders, all races and all religions. Although we wish there were no more new members, we still welcome them. We are a community of people living with HIV who are here to support one another.

When I talk to people outside the HIV community, they seem confused and often ask, “Why do you call it a community?” I reply that I have always called those of us living with HIV a “community” from as far back as I can remember. We are a community. Doesn’t everyone see us as a community?

Those of us living with HIV are a group of people who have a similar illness; we may come from different backgrounds and different worlds, but we work together helping to fight for the rights of people living with HIV everywhere. We are a community—the HIV community.

We have a feeling of fellowship with one another; many of us share common attitudes, interests and goals. We all want access to affordable care and treatment. We want to be treated with dignity, respect and equality. We want the freedom to love and live as we choose. We want to eliminate stigma and discrimination. And most of all, we want a cure for HIV.

Although there have been numerous changes in the HIV community over the years, I believe we are and always have been a community, and my hope is we will always stay one.

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