



# Advocacy in Action: Vision of an HIV/AIDS Activist

by Shawn M. Lang, CT AIDS Resource Coalition

**Having a vision of the way things should be, the way they need to be, will help guide and fuel our advocacy work in an active, passionate and compassionate way... We can *never* underestimate the power of one person's personal story and journey, nor can we ever underestimate the power of our advocacy work.**

In April, CT AIDS Resource Coalition (CARC) held the 10th annual AIDS Awareness Rally and Lobby Day on the north steps of the state capitol. Over three hundred people were in attendance, most of whom had HIV/AIDS. Speakers fired up the crowd who later, en masse, entered the capitol to meet with their legislators and share personal stories of how proposed cuts to HIV/AIDS services would affect their lives.

Regardless of the issue, when we look back to the roots of most movements for social change – including advocating for good policies, services and adequate funding – more often than not, it was those who were most impacted who began those fights.

Thirty years ago, I was sitting in the office of our gay student group reading the first news reports of this disease that was killing young gay men all across the country. We didn't know what this disease was. We didn't know what caused it. We only knew that it was scary, that it was killing people like us and that it was polarizing communities. At the time, we didn't know anyone who was infected. None of our friends had gotten sick. None of our friends had died.

From the days when I was reading those early reports, to this very moment, this has been a deeply personal fight for me.

In those early days, it was people with HIV/AIDS, gay men and lesbians and a handful of allies who were on the frontline fighting for funding services, prevention, care and good public health policy. And, for the most part, that is still true today.

I have been an AIDS activist for over 20 years and while CARC's vision guides my work, it's not the only thing that propels me forward in the realm of advocacy and activism.

I am invited to programs around the state to talk about advocacy – why it's important and why it's critical to be involved. My message is that legislators are regular people who may not live in "our world" (meaning, the HIV/AIDS, disability, mental health world, etc.) and what our constituencies face in their day-to-day lives may be completely outside of individual legislators' experiences. Our "job" is to invite legislators into our world to share those realities and make them a part of our world so that future decisions are made with real people in mind. And that simply will not happen unless we make it so.

Having a vision of the way things should be, the way they need to be, will help guide and fuel our advocacy work in an active, passionate and compassionate way. In good times, this vision allows us to dream of innovative programs and new policy changes that will have a positive impact on our constituencies.

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Senator Jonathan Harris was asked by a reporter if events like AIDS Awareness Day were effective. He said yes, and that the advocates were also very effective. But, he said, what has the most impact is

when people who are most affected by a particular issue meet with him. He said it can be easy to read words on a page, or see numbers in a budget; but when you get to hear people's stories and struggles, it informs his (and other legislators') perspectives.

The majority of us who work in the nonprofit world run programs that are the foundational frontline in care and prevention for extremely vulnerable people. Many of us, and especially those we serve, may never have been asked to be involved in advocacy and in fact, may find the entire process intimidating. But if we don't stand up and ensure that our voice is heard and our vision seen, who will?

We have to continue to create an atmosphere in which legislators are urged to do more than just care about us. We need them to be champions with us and to fight hard for the appropriate funding, solid policies and the services that are so desperately needed.

In the world of HIV/AIDS, thirty years later, our struggle continues; as does yours. As it has always been, it is up to us to lead the fight, be present, involve consumers and stay the course.

*Shawn M. Lang is Director of Public Policy at CT AIDS Resource Coalition, a statewide umbrella organization supporting HIV/AIDS service providers in Connecticut. CARC envisions a future where all people living with HIV/AIDS can live in dignity, and the AIDS epidemic has ended. For more information, visit [www.ctaidscoalition.org](http://www.ctaidscoalition.org).*