Constructive Anger can be Positive: Lessons from the AIDS Movement

David Harvey

Pre-reading:

- 1. What does HIV/AIDS stand for?
- 2. Share what you know about HIV/AIDS.

David Harvey founded the AIDS Alliance for Children, Youth, and Families and served as the executive director for 13 years. In 2007, he left his position there and became the President of Pro-Literacy, an international literacy organization. Cynthia Peters interviewed him in December 2008.

Why did you start the AIDS Alliance for Children, Youth and Families?

Prior to our formation, women and children struggling with HIV/AIDS didn't have much of a voice. This disease was affecting their lives, but they had no way of being heard.

Why couldn't you depend on the government and health care system to provide the care that children, youth and families needed?

There is so much stigma and shame associated with HIV and AIDS because of the way people get it, which is often through unprotected sex and drug use. Because of that stigma, the federal government did not respond at all. In the early days of the disease, the government did nothing to educate people. It did not move quickly to find treatments or cures.

Has that changed?

Yes. Government inaction prompted a massive grassroots effort. That effort was started and led by the gay community. A key feature of this movement was that it empowered consumers to speak for themselves, to advocate for themselves, and to help shape the health care systems that served them. It changed the doctor/patient relationship. It changed the power equation by having educated and empowered patients who were actively informed about the disease that was affecting them. They could work in partnership with doctors, who



traditionally had called all the shots.

How did people in the HIV/AIDS movement convince the government to pay attention? What actions did they take?

There were a number of grassroots organizations, and they were active in all sorts of ways. For example, one group called ACT UP (AIDS Coalition to Unleash Power) had a massive demonstration at the Food and Drug Administration (FDA). ACT UP members felt that the FDA was moving too slowly to test and release drugs that people needed to stay alive. That demonstration, without a doubt, helped get drugs tested and released more quickly.

How did all that organizing affect the Alliance for Children, Youth, and Families?

We benefited from what the first wave of activists accomplished. They paved the way. Their work made it easier for us.

What sorts of actions did your members participate in?

Grassroots activists in our network called their legislators. They wrote letters and emails. They came to Washington, DC, and met with their congresspeople about how HIV/AIDS was affecting them. They educated their congresspeople. It was ordinary people working together that got the Ryan White Care Act passed.

What is the Ryan White Care Act?

This Act is the largest federally funded program for people living with HIV/AIDS. The Ryan White Care Act funds programs to improve availability of care for low-income, uninsured, and underinsured victims of AIDS and their families.

Does the advocacy work you did around AIDS hold lessons for other health issues that people might be dealing with?

AIDS is not the only health issue with a history of political organizing. The disability rights movement, led by disabled folks and parents of disabled children, has had a huge impact. The breast cancer movement, led by women affected by the disease, has also had a huge impact. These grassroots movements have fundamentally reshaped public policy. They have changed the way doctors deal



Activists use this phrase, to bring attention to the AIDS crisis.

- 1. In what sense do you think silence could equal death?
- 2. Name other health conditions that you know of that are made worse by silence. How?
- Think of some words that are the opposite of silence. Make your own phrase (modeled on "Silence=Death") that includes an antonym to silence, the equals sign, and then another word.

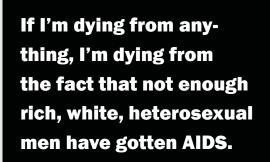
with patients. They have resulted in incredible progress.

You left the HIV/AIDS field, and now you work in literacy. What lessons have you brought with you to the field of literacy?

Constructive anger can be positive. Dynamic tension can bring change. It's a good thing to have healthy debate about what constitutes good public policy. We need more of that in the field of adult literacy. Since coming to the adult literacy field, I have been talking a lot about advocacy and activism. The response has been positive. It's an indication that folks are hungry for this. But things don't change overnight. It takes a while to build a community that's in a position to speak and be heard. I have to be a little patient.

But a lesson from the HIV field is: it's good to be a little impatient too.

David Harvey is the President of ProLiteracy. Cynthia Peters is the editor of The Change Agent.



From a speech by Vito Russo at a protest at the Dept. of Health and Human Services, 1988.

- 1. Why do you think AIDS activists demonstrated at the Dept. of Health and Human Services?
- 2. Vito Russo had AIDS when he gave this speech. But he says he is not dying from AIDS. What do you think he means by that?
- 3. Do you think it would have made a difference if more "rich, white, heterosexual men" had AIDS? Explain.