The POZ Army

March 23, 2009 By Peter Staley

I must admit, I've become deeply cynical about people with AIDS. I hate that I feel this way. The community I've always felt a part of - Americans living with HIV - has, in my mind, become impotent. Stigma seems to rule us, and we now find it easier to compartmentalize or hide this significant health challenge we all face.

Maybe it's not cynicism I'm feeling, as much as a deep sense of loss. I mourn the days when we were bound by anger and willing to fight together for our dignity and our place in the world. We used to suffer far more external stigma than we do today, but it only made us angrier and stronger. We'd yell out to all who would listen and to those who tried not the listen, "WE ARE PEOPLE LIVING WITH AIDS."

The stigma we live with today seems far more internal than external, as if we no longer feel we deserve to be heard or respected. We wrap ourselves in stigma, convinced that being uncloseted will lead to lesser rather than fuller lives.

I mourn the days when we would stand up and be counted. We would organize and act-up. We had power. Some of the very first AIDS organizations were local People with AIDS Coalitions. People with AIDS San Francisco was the first, when Bobbi Campbell and Dan Turner started meeting in Dan's house in the Castro hills in 1982. Then came People with AIDS New York (later called the People with AIDS Coalition), with Michael Callan, Richard Berkowitz, Phil Lanzaratta, Artie Felson and others leading the way.

Then, in June, 1983, people with AIDS from New York, San Francisco, Los Angeles, Minneapolis and Houston came together in Denver to strategize. They wrote a manifesto - a blueprint for a people with AIDS self-empowerment movement - which would come to be known as The Denver Principles. (For a great read of this history, and the text of this manifesto, click here).

From there, the National Association of People with AIDS (NAPWA) was born; many of us founded the first AIDS service organizations in each city and state; we were instrumental in ACT UP. And we changed the world.

Anyone living with HIV today owes their life to this self-empowerment movement. Conversely, most of the issues we all still deal with, like treatment access, a rising rate of new HIV infections, and overwhelming stigma, are all made worse by the waning of this movement.

I mourn the waning of our power.

But recently, I've found reason for hope. There's a project in the works that has the potential to revive our self-empowerment movement. As before, this project is being driven by people living with HIV - people like Sean Strub, Regan Hofmann, Tim Horn, and Frank Oldham. AIDSmeds.com, POZ Magazine, and NAPWA are all involved, along with nearly 400 AIDS service organizations (and counting) around the country.

It's called The Denver Principles Project - a three-part campaign to recommit our community to the principles of self-empowerment, raise awareness of the Denver Principles amongst service providers and the communities they serve and to build a large national membership for NAPWA to give them the voice and authority they need to be most effective.

Imagine if we could turn NAPWA into the MoveOn.org of people with AIDS. Imagine if NAPWA could sit down with a senator or president and say "we represent 100,000 Americans living with HIV - all NAPWA members - and we demand to be heard." Imagine if tens of thousands of us participated in anonymous surveys and an ongoing database that could finally provide a true picture of the issues we face. Imagine if 100,000 of us could be called to action when important legislation is up for a vote or when someone attacks our dignity with stigmatizing falsehoods (I mourn the loss of highly effective ACT UP phone zaps).

All of this could happen if each of us was willing to join together, stand up and be counted again. This isn't about telling the world you're HIV positive - the NAPWA membership list will never be disclosed or sold. If you're HIV positive and can't afford the $35 membership, NAPWA will find sponsorship funds to cover your fee (just check the "I would like to be sponsored" option during the sign-up process). If you or your family and friends can afford it, please join and donate so NAPWA can sponsor as many members as possible.

I joined today. The goal is to have 100,000 of us join by December 1st, World AIDS Day. You can join here.

I want to shed my cynicism and believe in our power to create change again. Trust me, there is nothing like the feeling of true self-empowerment, and our collective action is the only way to achieve it.

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