Renewing the Denver Principles

Sean Strub, POZ's founder and advisory editor, advocates for a renewed commitment to the empowerment of people with HIV/AIDS during remarks at the 2008 United States Conference on AIDS.

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In 1983, 25 years ago this past summer, a small group of people with AIDS met at a gay-health conference in Denver, Colorado, and wrote a document now known as the Denver Principles.

Written at a time of great social fear and political hysteria, the Denver Principles spells out the rights and responsibilities of people with AIDS.

Back then, the average survival between diagnosis and death was mere months; many died within weeks or days. Despite that terrible prognosis, this handful of people with AIDS asserted an identity for those who had the disease. I quote:

"We condemn attempts to label us as 'victims,' a term that implies defeat, and we are only occasionally 'patients' a term that implies passivity, helplessness and dependence upon the care of others. We are people with AIDS."

They demanded the right to be involved at every level of decision-making, from shaping government programs to involvement in prevention campaigns to meaningful roles on staff and in the governance of organizations providing services to us and in response to the epidemic.

It was a powerful and radical concept. In the history of humankind, never before had sufferers of a disease united to assert their rights in this way.

Near the end of the health conference, they stormed the podium to read their manifesto under a banner that read, *"Fighting For Our Lives."* They got a ten-minute standing ovation. The conference cochair said, "There wasn't a dry eye in the house." Those present knew history was being made at that moment.

Indeed it was, as their revolutionary document profoundly influenced the development—in a remarkably short period of time—of a massive AIDS service delivery system, which sought to fill the void left by traditional medical and social service organizations that were too scared or prejudiced to serve people with HIV/AIDS.

Many of the organizations and efforts represented at this conference and in this room can trace

their origins to the empowerment philosophy embodied in the Denver Principles.

The Denver Principles expressed a fundamental truth: to be successful, the fight against the epidemic *must* include—as equal partners in the battle—the people who have the disease.

That truth has been recognized globally, including in the World Health Organization's 1986 Ottawa Charter for Health Promotion; establishment of the GIPA Principle, endorsed by 42 nations at the 1994 Paris AIDS Summit; in the 2003 World Health Organization's "3x5" treatment initiative; and, most recently, in the Mexico Manifesto, presented last month at the International AIDS Conference in Mexico City.

From the earliest days of the epidemic, we have had to fight horrific stigma against those who hate or fear us. But when they would not allow us to hold their children, work at their side, touch their dishes, use their towels or live under the same roof, it was our empowered voice that educated them.

When the nation's political leadership failed to address the emerging crisis—and was content to watch us die—it was our *empowered* voice that gave us the political muscle to force change.

But today, all too often our focus on empowerment is a slogan rather than a system. One only needs to look at the invisibility of AIDS in this year's presidential contest to see how our political muscle has atrophied, which has paved the way for greater stigmatization and disempowerment.

Another mark of this disempowerment is how people with HIV have disappeared from the boards of directors of AIDS organizations. Several years ago, I gave a World AIDS Day speech bemoaning the fact that some of the largest and best-known AIDS organizations in the country had diminished or only nominal HIV-positive representation on their boards of directors.

And even of those few HIV-positive people on the boards, it should be noted that they are individuals chosen by HIV-*negative* board majorities. Sometimes the people with HIV chosen to serve on boards are also employees of other AIDS-related agencies. Both are factors which sometimes can cloud or compromise priorities.

Many of these groups were founded by people with AIDS—founded to confront a status quo that was killing us. It still is, but some of the organizations we created to combat that status quo have abdicated their responsibility.

What's more, they have cast those of us with HIV out of their boardrooms. That has been costly indeed. Concurrent with the decline of HIV-positive representation on these boards has been a decline in our number amongst the senior staff, as well as a decline in advocacy—a "toning down," with some of the toughest issues relegated to backburner status.

In too many instances, prevention programs with integrity and results became secondary to those that could get funded. Complicated and controversial issues, like fighting criminalization, have been downplayed or ignored. The loss of positive representation on the boards of directors

constitutes a de facto abandonment of the Denver Principles's mandate to fight the epidemic in partnership with people who have the disease.

Representation on boards is, of course, only one measure of an organization's commitment to empowerment. I acknowledge that it is an imperfect measure. But it is indicative of something that has gone terribly wrong—and which we must fix.

Measuring a provider organization's commitment to empowerment is not an easy task, but I think it is time that we set out to do so in a systematic fashion.

I have a modest proposal, which is that we establish objective, quantifiable empowerment standards by which we can measure adherence to the Denver Principles.

This isn't about saying this group is good and that one is bad; it is about providing a yardstick against which agencies and administrators and boards of directors and the community could measure performance.

It is about articulating what "empowerment" truly means in the challenging real world of nonprofit governance, resource constraints and delivery of services to communities already burdened by poverty, racism, sexism, homophobia, homelessness, addiction and mental health issues.

One model of empowerment is Housing Works, based in New York. Housing Works is legally constituted as a membership organization; every client, every volunteer and every staff member has voting rights, including for board positions. That is empowerment and very different from agencies whose boards are self-perpetuating.

Housing Works's bylaws require that a third of their board be people with HIV and that people of color comprise more than 50 percent of their board. That is empowerment and a far cry from agencies with little diversity or that put one or two people with HIV on their board and then don't provide those persons the training, skills and tools necessary to become effective board members.

Housing Works has more than 400 employees; about a third of them are former clients: people with HIV who were once homeless. That is empowerment and very different from many agencies whose proportion of HIV-positive employees has declined over the years.

Housing Works measures the performance of their caseworkers, in part, on how successful the caseworker is in getting a client registered to vote and involved in advocating for their rights. That is empowerment because participating in the political system is a necessary component to truly taking control of one's life and health; the failure to encourage and promote such participation is, in my view, profoundly disempowering and shortsighted.

Housing Works is a huge agency with a budget this year of over $40 million. My point is not about Housing Works, but that this is not theoretical; genuine empowerment can be achieved in a large agency.

Housing Works is activist-oriented, often speaking first and most passionately about the rights of people with AIDS, demonstrating leadership, and fighting stigma and criminalization. That is not a coincidence; it is a result of its governance structure and putting into practice a commitment to the Denver Principles.

One aspect of the epidemic that I think has especially suffered from the diminished influence of HIV-positive voices is in regards to HIV prevention.

We have a prevention paradigm built on the illusion of "zero risk," which contributes to stigmatization of people with HIV as vectors of disease and encourages HIV-negative people to have a false knowledge of the actual risks inherent in sexual contact.

We must work to expand the sexual safety zone for people with HIV—which I believe is critical to HIV prevention—through risk-reduction strategies like serosorting, seropositioning, pre- and post-exposure prophylaxis and incorporating viral load and treatment status into risk assessment.

There are circumstances, for some serodiscordant couples, when the risk of sexual transmission of HIV is so negligible or nonexistent as to render obligatory condom use—to further reduce the risk of transmission—as unnecessary. The January 30, 2008 statement by the Swiss Federal HIV/AIDS Committee (EKAF) recognized these facts.

The assertions made in the Swiss statement are rightfully subject to continued and important scientific debate. They ought to also be subject to a widespread discussion within the community. But that has not happened.

The provocative Swiss statement was first met by silence or outright rejection from most AIDS policy leaders in the United States, who were more intent on reinforcing the "use a condom every time" message than taking advantage of an extraordinary opportunity to engage the community in a more nuanced discussion about risk reduction, and the impact of antiretroviral treatment on infectiousness.

Perpetuating an illusion of safety for those who are HIV negative is more important to many than recognizing the right to sexual intimacy for people with HIV and how that can be safely achieved.

Put simply, the sexuality of people with HIV is considered more as a threat to society than it is as a fundamental and necessary part of our lives and identity. Our right to intimacy has been devalued, despite the Denver Principles proclamation of "as full and satisfying sexual and emotional lives as anyone else."

Restoring complete intimacy to the sexual lives of people with HIV is of vital importance to the dignity, quality of life and health of people with HIV. Moreover, social integration, without the crippling burdens of stigma or stereotyping, is crucial to reducing the spread of the virus and enabling people with HIV to fulfill one of the responsibilities outlined in the Denver Principles, which is to disclose their HIV status to their sex partners.

Efforts to restore safe intimacy to the sexual lives of people with HIV are to be celebrated. Opposing such efforts is an insult to people living with HIV, is discriminatory, perpetuates stigma, and reveals the hypocrisy of some who claim to be concerned with the well-being of people with HIV.

We ought not to be timid or shamed when pursuing our rights, whether that is demanding representation on boards of directors or pursuing our right to sexual intimacy. We may be stigmatized by the culture, marginalized by political leaders and criminalized by the law, but we must not be silent.

In the darkest days of the epidemic—when we were *all* frightened, when we were *all* suffering, when we were *all* angry—we knew what to do, and we did it. The Denver Principles are the Magna Carta of AIDS activism—our Declaration of Independence, Constitution and Bill of Rights rolled into one.

Returning to that original vision, heeding its clarion call and empowering positive people is our hope for the future. Thank you.

Sean Strub is a longtime AIDS activist and the founder of POZ magazine. He has lived with HIV for more than 25 years.

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