The Denver Principles Empowerment Index

April 21, 2010 By Sean Strub

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POZ founder Sean Strub delivered the keynote speech at the opening of the 5th anniversary commemoration in Washington, DC, of the Campaign to End AIDS (C2EA). The speech details his plan to measure HIV/AIDS groups against the ideals of self-empowerment in the Denver Principles. Below is the full text of his speech, which was delivered on April 19, 2010.

For those of you who don't know me, I've been HIV positive all of my adult life. Like so many others, I acquired the virus when I was a young person, back in 1979 or 1980. At one time I weighed about thirty pounds less than I weigh now, I was covered with Kaposi's sarcoma lesions and was very sick. I'm somebody who was fortunate enough to have access to and respond well to combination therapy when it became available in 1996. I'm probably healthier today than at anytime in my adult life.

Today I work with the Center for HIV Law and Policy on a campaign to combat HIV criminalization, and I'm also involved with the North American chapter of the Global Network of People Living with HIV and AIDS.

I've been asked to talk about the Denver Principles and their relevance today. The first question is, Why do we revisit the Denver Principles? It's very simple, they're the foundation of the People with HIV Self-Empowerment Movement. They show us how earlier activism influences our struggle today and what we can learn from that experience.

The Denver Principles are also the foundation of building a grass roots movement, one led by people with HIV, into a powerful voice. They also give us an opportunity to participate in the broader global movement towards the Greater Involvement of People Living with HIV and AIDS–greater and meaningful involvement, sometimes called GIPA.

Self-empowerment is what enables us to demand resources from government for treatment, care and prevention. Self-empowerment is what gives us the authority to speak to complex ethical considerations with research and treatment; like pre-exposure prophylaxis, the proposal to give HIV meds to those who are HIV negative but believed to be at high risk of acquiring HIV; or the "test and treat" proposals that we've been hearing so much about lately, that propose to test everybody and put virtually all of those who test positive on treatment, whether they need it or not.

With "test and treat" we're asking or recommending to people with high CD4 counts, again, for whom there is no demonstrated benefit, to go on lifetime treatment, to participate in an experiment, for a presumed "community benefit" to prevent the spread of HIV rather than individual benefit. We don't know whether above 500 CD4-cells it makes sense to start treatment or not. But "test and treat" advocates want to put those people on treatment, despite the absence of conclusive evidence that it will benefit them and with a very significant chance that it could harm them substantially.

Self-empowerment enables us to fight stigma, discrimination and criminalization, and most important of all self-empowerment helps us to live longer and healthier lives. I am alive because of self-empowerment. I am alive because of the Denver Principles.

The History of the Denver Principles

The Denver Principles were created in Denver, Colorado in 1983. It was the Fifth Annual Gay and Lesbian Health Conference, and it was the first national gathering of people with AIDS to organize and strategize politically and empower themselves; there had been some local activism in New York and San Francisco and elsewhere, but there had never been an occasion where people with AIDS came from around the country and got together and said, "We've got to organize as people with AIDS."

Twelve or thirteen people gathered at the conference in Denver, they couldn't afford to pay their way there; their tickets were bought by some other people with AIDS who had resources and some people who supported them. They didn't come representing organizations; they were just people who were struggling to survive, struggling to make sense of an epidemic that had so profoundly stigmatized them. They were very ill and the political and cultural environment was terrifying, including talk of quarantine. It was a very frightening time.

They met in a hotel room and wrote a powerful manifesto we know today as the Denver Principles, I refer to it as the manifesto that launched a movement. This manifesto was inspired by the Women's Health Movement, and it was inspired by traditional healing systems in communities all over the world, drawing on the collective wisdom of a community, not just experts imposing their wisdom on a community.

There is plenty to be learned both ways. We need experts and I don't diminish the importance of experts, but we need to listen to ourselves, and we need to listen to each other's experiences, because there is so much for us to learn and to share with others from that. In writing this document, they argued and debated about what was important, what they needed to say. And so they wrote a manifesto that outlined the rights and responsibilities of people with AIDS and guidelines for health care providers and others.

This was profoundly historic. It was the first time, the very first time in the history of humanity, when people who shared a disease organized and asserted the right to their voice, to a place at the table, when decisions were being made affecting their lives.

Before that, people who were ill were on the outside, they had no voice, and they certainly had not organized politically to assert the right to that voice. The Denver Principles manifesto is the Bill of Rights, The Declaration of Independence, The Constitution, The Magna Carta all rolled into one, not just for people with AIDS, not just for people with HIV, but for people who are dependent on a health care system, for people who struggle with life threatening illnesses.

In the scope of history, I am confident that a hundred years from now that the birth of the people with AIDS empowerment movement, starting from that hotel room in Denver with this document, and running right this room today—because we are the representation, we are the heirs to that, those of us sitting here today—will be seen as a profoundly, profoundly important event.

After that manifesto was written, it led to the founding of hundreds of community-based organizations. Most of our early AIDS organizations were started by people who had AIDS, people who thought they might have AIDS and their very closest friends and loved ones. That's where they came from.

The ideas in the Denver Principles spread outside the U.S. In 1986 in Ottawa, Canada, at a World Health Organization conference, they issued something called The Ottawa Charter for Health Promotion. It specifically references this Denver Principles' model of empowering people to improve their health. In 1994 The Paris Declaration that UNAIDS organized, and I think forty-seven countries signed it, including the United States, specifically referenced The Denver Principles. Inspired by the Denver Principles, the Paris Declaration defined GIPA, the Greater Involvement of People with AIDS.

The Denver Principles document begins with a very important sentence. The sentence is, "We condemn attempts to label us as victims, which implies defeat. We are only occasionally patients, which implies passivity, helplessness, and dependence upon the care of others. We are people with AIDS."

Near the end of the conference the group who wrote this manifesto stormed the stage without invitation. They took the microphone, they all stood there behind a banner that read 'Fighting for our Lives,' and they read their manifesto to the conference attendees. The room went totally silent, and then, according to press reports at the time, the crowd came to their feet, many were weeping and began to applaud. For 15 minutes the guys who wrote the Denver Principles got a standing ovation. The people in that room knew that history was being made at that moment, and today, 27 years later, we are the continuation of that history.

Let me just break for a moment, is there a board member or a member of the staff from the National Association of People with AIDS here? [silence] Is there a board member of a member of the staff from the American Foundation for AIDS Research here? [silence] Is there a board member of a staff member from AIDS Action Council here, the lobby group in Washington?

[silence]

Is my point clear?

[Audience responds loudly, "yes"]

The Denver Principles first established the right to define ourselves. We rejected other people's labels of victim or patient. We demanded that we be treated as whole persons, with a respect for sexual diversity. We asserted our right to participate, and specifically this is in the Denver Principles document—to serve on the boards of directors of provider organizations. The Denver Principles' recognized the ethical responsibility to inform partners of one's health status, of things that could potentially endanger another partner. And that's important because there is a difference between an ethical responsibility which also depends greatly on a person's ability to disclose safely. The Denver Principles asserted our right to as full and satisfying a sexual and emotional lives as anyone, and it demanded that we get a full explanation of treatment and risks, and the right to choose or refuse any treatment modality.

So the question is what is the relevance of this document written in 1983 when the epidemic, in some ways, was very different to today?

The Relevance of the Denver Principles Today

Last year I made myself unpopular at a briefing the Kaiser Foundation held on a big survey they conducted. They had all sorts of media present, and one of their findings, they claimed, was that there was evidence that stigma may be lessening. They based that finding on their survey results that asked, 'How do you feel about somebody with HIV working in a restaurant and preparing your food, or caring for your children," or whatever. And they were comparing those responses from today to 10 or 12 years ago and the numbers were better, people are not as afraid of working with someone with HIV or having them prepare food as they once were. They said this is evidence that the stigma is lessening.

I stood up and I said, 'What your results are evidence of is that there is less fear of contagion.

Stigma is about much more than fear of contagion. Stigma is about pre-judgment! [applause] Stigma is about marginalization! [applause] Then, just to make sure I would never get invited back [Laughter], I said, 'The next time you want to know about the experience of stigma for people with HIV you could start by asking them.' [Loud Applause]

So why else is the Denver Principles document relevant today? Well the most extreme manifestation of stigma is when government sanctions stigma. We know the Jim Crow laws, we know apartheid, we know that when the government enforces discrimination that this is the most extreme manifestation of stigma. When we see how the law treats people with HIV differently from people with other viruses, when the law treats our sexual behaviors differently from others, we see stigmatization. The HIV criminalization statues are the most extreme manifestation of AIDS-related stigma. If anybody talks to you about doing something about stigma and they are not talking about repealing HIV criminalization statures, then you tell them their conversation is hollow. We won't effectively fight stigma by buying billboards or ads on the sides of a buses and then continue to persecute and prosecute people with HIV under the law.

So why else is the Denver Principles document relevant today? There was a time when most of the AIDS organizations in the country had boards of directors that were entirely or mostly people with HIV, or people who thought they might have HIV. Indeed many of the largest organizations were founded by people who were virtually all HIV positive. A few years ago, on World AIDS Day, I spoke in San Francisco at the National AIDS Memorial Grove. I talked specifically about this issue of representation on the boards of directors of provider organizations.

In their wisdom, the people with AIDS who wrote the Denver Principles specifically included a provision that noted the importance of and our right to serve on the boards of directors of provider organizations. So before I gave that talk in San Francisco, I checked with some agencies and asked how many positive people are on their boards. Some just said, "Oh, we wouldn't disclose that information.' Some of them said, "Well, there's one, or there's two." A number of them, including some very large groups, said they had no one at all with HIV on their board of directors. At other major agencies the representation that once had been the agency's founding energy and board and what drove the agency's growth had been reduced to only a small number, five or ten percent of their board. Very often that was a person who already had other obligations that potentially posed a conflict, like they worked for another AIDS agency across town. We need people who are HIV-positive to work in the epidemic, perhaps most importantly in the delivery of services, so that is something I support strongly. But we also need the independent voices who can come to a board meeting and just speak the truth about what the real priorities are, independent of worrying whether their AIDS-related employer might agree or not.

Participation on the boards of directors of provider organizations has declined to where it's very nominal or token. Too often, where there are HIV-positive people, there is not the commitment on these boards of directors to provide them the training and tools necessary to maximize their effectiveness as board members. They'll sometimes find somebody who will be a compliant HIV-positive person so they can check that box off, 'Oh, we've got somebody positive on our board', without making the commitment to ensuring that person's meaningful participation.

The Denver Principles' further relevance today is found in comparing the empowerment model that started these agencies initially, where the philosophy and work was peer to peer, it was people with HIV, their friends, their loved ones, people who thought they might be HIV helping others with HIV. It was an empowered service delivery model.

Over time the system of service delivery has strayed farther and farther away from that initial model to the more traditional 'benefactor/victim' model, where you get what we give you and you should feel lucky to have that. Another reason the Denver Principles is relevant today involves some of the new prevention and treatment strategies that present such serious ethical concerns, like pre-exposure prophylaxis and the test and treat strategies that I mentioned. All of these things are why it is so important that we revisit the Denver Principles and use them as a foundation and guide for our work today.

So part of my mission has been to educate people about this document and to share copies of it, and to urge you to take it back to your homes, to your agencies, to your friends, to your support groups, and share the empowerment message of this document, because when we organize and assert our voice we have an incredible authority, an inalienable right to participate and to be heard. We cannot be ignored because we are the people who have the disease, we are the people who will thrive or suffer, survive or die depending on how the epidemic is managed. There will be others who can try and co-opt us, but when we are working together we will not be ignored.

A Denver Principles Empowerment Index

One of the projects that I'm working on and welcome other people's ideas and input on is to translate the Denver Principles document into an accountable measure where we can look at service providers. We are starting with non-profit organizations providing AIDS services (there are lots of other places we could and eventually will go, including doctors, government agencies, different places). How do we measure how consistent their organization and their service delivery is with these ideals of self-empowerment, with these Denver Principal ideals? We're trying to come up with quantifiable measures in different categories, not just to beat them up and just rant and rave, but to provide measures of and encouragement towards incremental progress. There are lots of people in these agencies who want to integrate empowerment into their service delivery but don't know how. I met with one director of a big AIDS service agency in the South. He's been around a long time and knew all about the Denver Principles. He said, "Sean, look, you know me," he said, 'I love the idea of the Denver Principles, but I'm running an agency and I'll tell you we do a crappy job of using the Denver Principles into our work here,' he says, 'what we need is help, we need best practices, we need to learn what has worked elsewhere and how we can use that here at our agency." So that's something else this empowerment index can do is it can identify best practices and things that work and share them with others.

So with the Denver Principles Empowerment Index, we're looking at four categories in which we'll develop these measures. One is in the agency's governance and transparency, one of the examples I cite often is Housing Works, as evidence of an agency that can grow large and can integrate empowerment principles. I'm not saying Housing Works is perfect, I don't think they would say that they're perfect. But I'll tell you something important that relates to their success.

Their by-laws require that one-third of Housing Works' board is elected by its clients and the staff and volunteers have representation on the board of directors as well. That alone is fundamentally different from almost every other major AIDS service provider in the entire country.

In addition to the governance structure, we'll look at transparency—are the minutes of the board meetings put on the web site, are clients and the public welcome to come to board meetings?

We'll also look at how they develop their programs and policies; how are clients, how is the community they served involved in those processes? Is it just experts and staff hidden away in a room coming out with a document, without involving clients and community, and saying, 'This is our policy?'

Then we'll consider how they deliver services. I'll again use Housing Works as an example. Everyone knows that Housing Works has managed to retain a political identity and activist identity even as it grew large. Part of the reason has to do with the philosophy behind the organization. They believe that one cannot be empowered around one's health care in this country, in this day and age, unless one is also empowered within the political system to access that health care.

And "empowered within the political system" has range from just being informed to participating in demonstrations to showing up here at this conference, to writing a letter to the editor, to testifying at a hearing—but it's about participating. And so Housing Works builds that into how they work with their clients and measures staff performance based on their ability to create that engagement with their clients.

The empowerment index will also enable the community to create its own measures, to rate agencies, programs, providers. There are often factors that greatly influence our ability to access care that aren't adequately considered by service providers. We know that if you go to an agency and you've got three different appointments, they sometimes make them on three different days, and you've got to arrange childcare on three different days and transportation on three different days, and take three different days off of work. If the agency could coordinate those appointments for the same day, it would be vastly more efficient and enable more of us to get the care we need.

We know that when we go to an agency for service and the waiting room for clients is like a waiting room at a prison where you're on steel benches and the staff is behind bulletproof glass and metal doors, that isn't exactly welcoming. It exacerbates a divide between clients and staff. I can tell you that didn't exist in AIDS 25 years ago. It's a new development in AIDS.

So there are lots of measures that we can come up with and the idea is to put this Denver Principles Index on-line so not only will there be the objective measures of looking at their board and this and that and responses from the agencies, which we will then have to lobby them to get them to participate in it, but also ratings from the community, any of us can go on and talk about our experience there or identify other measures that we think are important.

Another category for the empowerment index is treatment education. How an agency first of all develops its policies around treatment, who they recommend or don't recommend for treatment is

important. I don’t believe in one size fits all treatment strategies—agencies that have one treatment protocol for everybody, or simply manage clients based on numbers on a lab report. Well why do we need to show up if they’re doing it from a recipe; we could just send them our blood! Many of us survived because in the early days of the epidemic we could only learn from each other because we were the experts.

Well, we are still the experts, yet how are agencies using our experience today, do they listen to us or do they just tell us? From the beginning of the epidemic we’ve been the guinea pigs for new drugs. We’re the ones who first discovered many side effects, like facial wasting and said, ‘Hey something’s going on here, the Crixbelly, buffalo hump, broken fractures, broken hips, heart attacks, heart problems, kidney failure. And almost every one of those side effects were first responded to by the drug companies and government officials with “Oh, that is anecdotal” as a way of dismissing or diminishing our experience. [Audience members say, ‘Yes.’]

Well ‘anecdotal’ saved my life. We continue to be the canaries in the pharmaceutical coal mine. We know what these things are doing to us before they know. So those of us who are providing treatment to us, they need to listen to us, they need to collect data from us and learn from our experience and send that information upstream to regulators, to researchers, to pharma.

And so with that I’m going to close and take questions, but I just have to tell you I am so proud to be here with you, those of us in this room today, as we are the heirs to that group that met in that hotel room in Denver. And as beleaguered and as frustrating and as difficult as it is, as lonely as it sometimes feels, history is going to look back on us carrying the torch of hope and empowerment through to another generation, to another time. That is an awesome responsibility, but I am proud to share it with you.

Thank you.

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