Denver Principles Empowerment Index & A Brief History of the Empowerment Movement

July 7, 2011 By Sean Strub

I have been working on a project to create an online accountability, transparency and empowerment tool to measure empowerment principles in the delivery of health and social services to people with HIV.

We talk so much about “empowerment”, but defining it has been somewhat more difficult. There are amazing programs and examples of empowerment principles in practice, but defining and measuring empowerment is difficult. This is reminiscent of US Supreme Court Justice Potter Stewart in 1964, when the court was wrestling with defining pornography. Justice Stewart said “I know it when I see it”. Many of us recognize empowerment when we see it.

The Denver Principles Empowerment Index is an idea to enable us to measure empowerment and, as a result, improve health outcomes, create a more equitable and effective service delivery system and increase participation in civic processes.

Here’s a link to a proposal I wrote describing the Denver Principles Empowerment Index. I am eager to hear comments; this project is in its early stages and I know it will be greatly improved once the community and, especially, those experienced in service delivery, have a chance to consider the idea and provide comment. Below are a few thoughts about the history of the empowerment movement.

Thanks, Sean

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A Brief History of the PLWHIV Empowerment Movement

The self-empowerment movement for people with HIV was formally founded with a manifesto written by a group of people with AIDS in 1983.Known as the Denver Principles, it outlines rights and responsibilities for people with AIDS and provides recommendations to healthcare professionals, family and friends.[1]

It was later referenced in the World Health Organization's 1986 Ottawa Charter for Health Promotion, the 1994 UNAIDS Paris Declaration, signed by 42 countries, which outlined the Greater Involvement of People with AIDS (GIPA) principle and the 2008 Mexico Manifesto.[2][3][4]

The Denver Principles document is historic in its assertion that those who have HIV/AIDS have a fundamental and inalienable right to participate in the decision-making that would so significantly impact their lives and survival.

While that concept was radical in regards to healthcare, it was not original.It was inspired by the feminist health movement as well as elements of traditional community-based healing systems.[5] But in 1983, the medical establishment, pharmaceutical-industry and public health policymakers were hardly the champion of these inclusive ideals; more typically they were their enemy.

These existing institutions poorly served, if not entirely ignored, the healthcare needs of sexual minorities.The advent of a deadly new illness that was rapidly killing gay men was viewed as punishment for immorality as often as it was viewed as a health crisis that urgently demanded attention.

There was also an absence of political will or leadership to address the burgeoning crisis; it was soon obvious that the government, medical establishment and pharmaceutical industry would not respond with the urgency, care or commitment necessary.

So the LGBT community--inspired by the ideals expressed in the Denver Principles--created its own response. It was an achievement unparalleled in history, with an outpouring of volunteerism, activism, caring and love that defined a generation and has had an impact far beyond the HIV/AIDS pandemic.

Thousands of organizations created by people with HIV, their partners and nearest loved ones pioneered new models for engaging and empowering communities and individuals impacted by AIDS.

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

That meeting in Denver was not only the first time a group of people with AIDS from around the country got together to define themselves and strategize politically, but it was also the first time in the history of humanity that a group of people who shared a disease organized and asserted their collective rights.

Over time, the initial AIDS activists who championed the self-empowerment movement died or became overwhelmed and exhausted from their years of social and political action. As the epidemic spread and settled into communities already ravaged by poverty and discrimination, the leadership of the self-empowerment movement became displaced and the epidemic institutionalized.

This created an abdication of the self-empowerment agenda, compartmentalizing the epidemic rather than taking into account the relevant sub-factors that continued to fuel it. The pioneering self-empowerment model of service delivery took a backseat to a more traditional--some label it patriarchal or “victim-based”--service delivery model.

A gap emerged between those who provided services and those who received them: staff and boards of directors that once spoke in terms of “us” began thinking and acting in terms of “them”.

AIDS service organizations founded by, or mostly by, people with AIDS often now have only token HIV positive representation, or even no such representation, on their boards of directors.[6] Programs created and developed by communities that sought to empower themselves have been replaced by centrally-created efforts filtered through political and religious agendas.

The level of transparency in governance that was a hallmark of early efforts is now the exception rather than the rule. Advocacy that was integral to virtually every early AIDS service provider’s program is now limited to a dwindling few and often solely focused on funding streams.

Despite the decline in the self-empowerment overall, there remain a number of notable examples of organizations, programs and policies that continue to embrace and develop program and service delivery around the empowerment philosophy.

Moreover, the Denver Principles document is considered iconic by many in the AIDS movement. An effort early in 2009 to ask HIV/AIDS service and advocacy organizations to “recommit” to the concept of self-empowerment and the ideals expressed in the Denver Principles now has more than 400 institutional endorsers.[7] Many recognize the drift away from self-empowerment and are eager for tools to move back towards the self-empowerment service delivery paradigm.

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[1] The Denver Principles were created by the PWA Caucus at the 5th annual National Lesbian and Gay Health Conference and the 2nd National AIDS Forum, held in Denver, Colorado, June 1983.

[2] The Ottawa Charter for Health Promotion was adopted at an international conference sponsored by World Health Organization, Health and Welfare Canada and the Canadian Public Health Association, November 17, 1986, Ottawa, Ontario, Canada

[3] The Paris Declaration made by the heads of government or representatives of 42 countries at the December 1, 1994, Paris AIDS Summit.

[4] Mexico Manifesto presented by PLWHA at the XVII International Conference on AIDS, Mexico City, August, 2008.

[5] Detailed evidence of the correlation between the women’s movement and the AIDS response is shown in Sheryl Ruzek and Julie Becker, *The Women’s Health Movement in the United States: From Grass-Roots Activism to Professional Agendas* (JAMWA Vol.54, No.1), p. 6.

[6] POZ survey cited in December 1, 2005, (World AIDS Day) speech by Sean Strub at the National AIDS Memorial Grove, San Francisco.

[7] The Denver Principles Project promoted by POZ Magazine and the National Association of People with AIDS.

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