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Denver Principles Empowerment Index

The proposed Empowerment Index will create a quantifiable measure of not-for-profit AIDS service providers' adherence to and fulfillment of self-empowerment ideals in their delivery of services, governance, development of program and policy, advocacy and provision of HIV treatment information.

The Empowerment Index is designed to achieve several important goals:

- Improve health outcomes for people with HIV.
- Incrementally evolve not-for-profit HIV social service delivery from a traditional benefactor/victim model to one that is more partnership-based, focused on empowering the clients served.
- Increase client participation in civic and political processes.

A growing body of research demonstrates that people with chronic or life-threatening illnesses who are well-informed and empowered in their healthcare decision-making have better health outcomes.^{1,2} “*Activists live longer*” was a mantra in the early days of the epidemic; those who took action to influence the course of the epidemic are better able to influence the course of the disease in their own bodies.

Adherence to treatment regimens improves when the person with HIV understands the treatment and is actively engaged in treatment decision-making.³ People with HIV who know their sero-status—the first step towards empowerment—are more responsible in their sexual behaviors than those who do not know their HIV status.⁴

The AIDS epidemic pioneered many profound changes in healthcare, politics and society. One of the most innovative is in how the communities first affected by AIDS—mostly,

¹ Williams, Tyna. 2002. "Patient Empowerment and Ethical Decision Making ." *Dimensions of Critical Care Nursing* 21, no. 3: 100.

² Todd, W.E., and E.H. Ladon. 1998. "Disease Management: Maximising Treatment Adherence and Self-Management." *Disease Management & Health Outcomes* 3, no. 1: 1-10.

³ Beusterien, K. M., E. A. Davis, R. Flood, K. Howard, and J. Jordan. 2008. "HIV patient insight on adhering to medication: a qualitative analysis." *AIDS Care* 20, no. 2: 251-259.

⁴ Frieden TR, Das-Douglas M, Kellerman SE, Henning KJ. Applying public health principles to the HIV epidemic. *New England Journal Medicine* 2005;353(22):2397-402.

but not entirely, gay men who either had the disease themselves or thought they might get it—created their own healthcare, social service and political response to the epidemic.⁵

People who had the disease founded and served on the boards of directors and comprised much of the staff and volunteers of the first AIDS organizations in the U.S. Those organizations grew dramatically in the 1980s and 1990s, pioneering a peer-to-peer self-empowerment service delivery model. Absent these organizations' efforts, many tens of thousands more would surely have died.

Over time, as the epidemic institutionalized, the peer-to-peer self-empowerment model receded, supplanted by the more traditional benefactor/victim model.⁶ The Empowerment Index will highlight best practices to provide examples and guidance to service providers, provide an empowering accountability tool for the communities they serve and introduce a new competitive factor for consideration by funders.

An empowerment-focused service delivery system also increases participation in civic and political processes. Housing Works, which has championed the self-empowerment movement, is now one of the largest AIDS service providers in the country. Their client demographic is typically not one with a high level of voter registration and turnout: almost all of their ~2,000 clients are or were homeless; most also face substance use, mental health or other concurrent chronic health issues.

Yet they report extraordinary voter registration and voter turnout amongst their clientele, largely due to how the empowerment philosophy is reflected in the organization's governance, development of program and delivery of services.⁷

This agency's philosophy is that for a person with HIV to be empowered in their healthcare, they must also be empowered within the political system in order to gain access to that healthcare. An informal analysis shows that of their clients eligible to vote, more than 90% are registered. Of those registered, approximately 75% turned out to vote in the November 2008 election.

The Empowerment Index

The Empowerment Index is designed to establish standards, share best practices and celebrate and encourage incremental movement towards the self-empowered service delivery paradigm.

Participation will be voluntary and self-reported on-line by AIDS service organizations whose performance is being measured. The data will be collected in part through regular questionnaires emailed to thousands of AIDS service providers. The data collection

⁵ Roy, C. M., and R. Cain. 2001. "The involvement of people living with HIV/AIDS in community-based organizations: contributions and constraints." *AIDS Care* 13, no. 4: 421-432.

⁶ Crossley, Michele. 1998. "'Sick role' or 'empowerment'? The ambiguities of life with an HIV positive diagnosis." *Sociology of Health & Illness* 20, no. 4: 507.

⁷ Charles King, CEO, Housing Works, email to Sean Strub, DATE

process will be transparent and subject to public scrutiny, in order to generate interest and support for the project and to minimize reporting errors or misrepresentations.

The Empowerment Index will initially focus on five areas.

1. The **governance** section will look at the agency's corporate structure, by-laws, diversity on its board of directors and staff, responsiveness to the community, funding diversity and overall transparency.
2. The **program and policy development** section will review how the agency develops program, specifically focusing on how the clients the agency serves are incorporated into those processes.
3. The **political empowerment** section measures efforts to engage clients in the political process through education on timely issues, participation in advocacy efforts, voter registration and turnout.
4. The **advocacy** section examines the scope and focus of the agency's advocacy work. It will examine whether such work is global, national, state or local, and the extent to which the agency's advocacy addresses public policy and social justice issues.
5. The **treatment information** section will note whether the agency is a conduit for single-sourced treatment information, formulates its own standards of care or provides information on multiple treatment strategies. It will look at the extent to which the flow of treatment information goes both ways; for example, whether the agency solicits and utilizes input from its clients' in their agency's development of treatment protocols and policies.

In addition to the agency questionnaire, there will also be a community-reported ratings component that can address other issues that, while esoteric, are of profound importance to successful service delivery and to maintaining a continuum of client care. These may include the agency's adherence to or coordination of appointment times, the attitude and style of interaction between agency staff and clients or even the comfort of waiting rooms.

The Empowerment Index is a tool for agencies to measure their success in realizing empowerment-driven systems of governance, management and delivery of services. It is a tool for the community to hold agencies accountable and improve health outcomes. For funders, it is a tool to enable them to more closely align their funding with their empowerment priorities.

People with HIV, executives and staff of AIDS service providers and experts in non-profit governance, social service delivery, advocacy and empowerment of disenfranchised communities will all be involved in development of the Empowerment Index.

A Brief History of the Self-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.⁸

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.^{9 1011}

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.¹² 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

⁸ 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.

⁹ 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

¹⁰ The Paris Declaration made by the heads of government or representatives of 42 countries at the December 1, 1994, Paris AIDS Summit.

¹¹ Mexico Manifesto presented by PLWHA at the XVII International Conference on AIDS, Mexico City, August, 2008

¹² 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.

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.¹³ 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.

¹³ POZ survey cited in December 1, 2005, (World AIDS Day) speech by Sean Strub at the National AIDS Memorial Grove, San Francisco.

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.¹⁴ Many recognize the drift away from self-empowerment and are eager for tools to move back towards the self-empowerment service delivery paradigm.

¹⁴ The Denver Principles Project promoted by POZ Magazine and the National Association of People with AIDS