

SELF-EMPOWERMENT: FROM COLLECTIVE UNDERSTANDING TO ACTION

by Richard Elovich

In HIV/AIDS circles, the notion of the self-empowered individual has a rich and discursive history. In the 1980s, AIDS activists in the United States transformed the popular understanding of someone with AIDS as a victim or patient into a *person*, someone fully in control of her or his self-identity. By taking charge of their lives, AIDS activists were not only demanding adequate treatment but, equally important, they wanted people with HIV to be able to shape their own representation. Through public testimony they gave visibility to a collective struggle to break silences, challenge stigmatization, and demand government action.

This process helped people transform their experience of HIV from shame about the mode of transmission to pride in belonging to an activist movement, and gaining, perhaps for the first time, access to social and material support related to HIV that was often lacking in their families, neighborhoods, and in medical and social services. Consciousness and empowerment gave them the tools to resist, challenge, and negotiate the terms of how they lived their lives. Many AIDS activists can recall a transformative moment in a training, at a demonstration, or attending a conference, when they felt seen by others in a positive light for the first time.

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The American AIDS activist networks, such as the AIDS Coalition to Unleash Power (ACT UP), drew heavily from the women's health, gay liberation, and civil rights movements. The women's health movement—under the slogan, “the personal is political”—encouraged women to experience, learn, and share their own authoritative knowledge of their bodies as distinct from the authority of knowledge possessed by professionals, lawmakers, churches, and cultures, largely dominated by males.

The gay liberation movement encouraged lesbian, gay, bisexual, and transgendered individuals to take on precisely what was used to stigmatize them and turn that into an identity of resistance and pride. One of their slogans was: *We're here, we're queer, get used to it.* If the women's health movement allowed AIDS activists to conceive of empowered people with AIDS who could be assertive with medical professionals and educate each other about treatment options and

safer sex, gay liberation allowed AIDS activists to leaven demonstrations with spectacle and theater, often driving home deadly serious points with humor. This also provided media with images they were eager to broadcast.

Both of these movements drew in turn on their predecessor, the nonviolent direct action of the American civil rights and antiwar movements in the Vietnam War era. Central to these were actions that taught people how to collectively train and prepare for direct nonviolent action—such as mass marches or street demonstrations, sit-ins or die-ins, seizure or disruption of offices or office routines where power resided—and to take their case to a larger public by capturing the attention of the media through theatrical demonstrations and mass arrests.

Outside of America, in South Africa and Brazil, for example, the response to AIDS was shaped by local liberation struggles as well as the globalization of AIDS activism. South Africans taking on AIDS activism were still in the process of successfully overthrowing the white regime of apartheid. Songs and demonstration tactics drew explicitly on the history of liberation struggles. In both South Africa and Brazil, the idea of a shared stake in social transformation has proved as important as individual empowerment. There is a pronounced collective and political dimension to self-empowerment not just within the marginalized or stigmatized group but across all of society. In other societies, such as the United States, empowerment is not seen as necessarily connected to political or collective change.

The empowerment movement has a self-help dimension as well. The current organization of drug users can trace its roots in part to the 1930s in the United States when, during the Great Depression, alcoholism was at an all time high. Two alcoholics who were deemed hopeless by medicine came together to help each other, and in hand-to-hand organizing launched Alcoholics Anonymous (AA), a social movement that today numbers in the millions. AA and Narcotics Anonymous have been locally reproduced in diverse communities across the world.

Many activists recall how certain events allowed the unthinkable to become reality. It might be dangerous for an individual or small group to march through the street or into a seat of corporate power shouting, risking arrest. But when individuals or small groups join throngs of hundreds and thousands, spectacle is possible, as are mass arrests.

Many activists recall leaving the bedside of an ill or dying friend to march arm-in-arm through the streets, shouting chants. They released the bottled up feelings of desperation, grief, and anger to the group. Often amidst the spectacle and shouting, tears streamed down faces. People hugged and comforted one another. Demonstrations have strategic objectives with fact sheets listing demands, but they also bring people out of isolation and shame, empowering the participants to continue the struggle. The small affinity groups in which individuals collectively train, brainstorm ideas for spectacles, and create costumes and signs, over time also serve multiple purposes—creating care groups for members who are ill, opportunities for people to self-actualize by taking on new responsibilities or by “being gay” in front of others for the first time, and forming life long friendships.

Collective self-empowerment is an ongoing process across the world. When Thai activist Paisan Tha-Ud stood up last year at the International Harm Reduction Conference and identified himself as an HIV-positive drug user, he defined the terms of an identity of resistance. When people with HIV in St. Petersburg stage a World AIDS Day demonstration, this tells the world that a community is mobilized.

Through this identification, we can claim our rights.

In his essay, “Invisible Women: Class, Gender and HIV,” (in *Infections and Inequalities*, University of California Press, 1999) Paul Farmer warns us that we often exaggerate personal agency because of Western society’s fixation on the individual as a unit of explanation. The individual in American society is expected to be an independent, autonomous unit, concerned primarily with pursuing individual desires. Most folks, however, depending on their economic and social location and gender, see themselves embedded in families, work environments, and social networks, with their norms and constraints, which provide them with the opportunity for survival and meaning.

The danger of self-empowerment rhetoric, notes Farmer, is that it can easily slide into blame of the individual. “There is nothing wrong with underlining personal agency,” writes Farmer, “but there is something unfair about using personal agency as a basis for assigning blame while simultaneously denying those who are blamed the opportunity to exert agency in their lives.” Attempting to change individual low-self-esteem and powerlessness—unless it is combined with collective action—deflects attention away from the real engines of the AIDS pandemic: the structures of inequality that condition vulnerability and risk and limit people’s options and access to resources.

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