

Living Outside the Circle: The Politics of HIV/AIDS Education and the Disenfranchisement of HIV-Negative Gay Men

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Abstract: The purpose of this qualitative study was to use the lens of political planning theory to explore the relationship between how HIV-negative gay men think HIV/AIDS prevention efforts "should" be handled and how they actually *are* handled.

Background, Problem, and Methods

Within the last 15 years the Human Immunodeficiency Virus (HIV) has emerged from complete obscurity to become the leading cause of death for Americans 25 to 44 years of age (Altman, 1995). According to current estimates there are more than 900,000 people, or about 1 out of every 280 Americans, infected with the virus (Karon et al., 1996). These infections are not uniformly distributed among the United States' adult population however. Of those men who self-identify as being gay, an estimated 70% of older men living in large urban centers and 10 - 40% of younger men are presumed to have HIV disease (Hoover et al., 1991).

Of the almost 360,000 cases of Acquired Immune Deficiency Syndrome (AIDS) reported through June 1998 among men having sex with men (CDC, 1998), all but about 6,000 were reported during or after January 1989. Given the normal length of delay between infection with HIV and an AIDS diagnosis, it can be inferred that most gay men with AIDS were probably infected after 1985, the first year that antibody testing made it possible to determine if a healthy looking person was or was not infected with HIV. Under best-case conditions then, if antibody testing had been encouraged from the time it first became available, and if this testing had been functionally linked to a 100% effective program of prevention education specifically targeting uninfected gay men, it is possible that up to 354,000 cases of AIDS could have been prevented.

The above assertion is naively simplistic of course. Ignoring for a moment the implausibility of designing a 100% effective prevention program, a core reality of education planning in the gay community is that HIV education programs targeting gay men have almost never specifically targeted *uninfected* gay men. Instead, prevention programs are designed without reference to participants' HIV status. This is not by accident. Planning for HIV prevention education occurs in a turbulent world of often-conflicting political, social, medical, and economic interests and it is the relative priority assigned to each of these interests--not just to those of uninfected people--which drive program planning decisions. Since the beginning of the epidemic, that process has routinely given the needs of HIV-negative gay men a low priority.

In the earliest years of the epidemic, the highest priority was given to those interests that stressed community solidarity and protection for the HIV-infected. With good reason, activists working in gay organizations saw AIDS not just as a personal tragedy but as a political threat to hard-won civil rights and the long push toward inclusion of homosexuals as fully franchised citizens of the

United States (Shilts, 1988). The response of those activists was to circle the wagons; provide shelter for the infected at the protected heart of the community and present at least the appearance of a unified front both to the outside world and to other gay men (Patton, 1990; Rofes, 1996; Rotello, 1997). Accordingly, gay men, regardless of their HIV serostatus, were massed together as education targets by prevention planners into one generic bloc and presented with information that focused on the similarities they shared while ignoring the very real serostatus differences that divided them. Furthermore, this information was presented in a context that stressed the pragmatic need to protect the disenfranchised by placing the interests, sensibilities, and concerns of the infected over those of the uninfected (Rotello, 1997). Unfortunately, this well-intentioned approach has served only to replace one disenfranchised group with another. Uninfected gay men, denied the right to publicly discuss their own need for inclusion and support, have been actively encouraged to view themselves only in relation to how their actions affect HIV-positive gay men (Rofes, 1996). Ironically, this also means that the unique prevention needs of the people most capable of benefiting from HIV/AIDS prevention education are also seen only in relation to the needs of people for whom the primary benefit of prevention is no longer relevant. Furthermore, this situation has proven to be remarkably stable. Despite large-scale changes in the general public's acceptance of HIV-positive people over the last 18 years, adult education planners and facilitators working in the gay community still routinely subordinate the priorities of HIV-negative gay men to other interests.

Does this state of affairs meet with approval by HIV-negative gay men? Does it *matter* if it meets with their approval or not? High and rising rates of HIV-infection among gay men have led to assertions that prevention education efforts for the gay community have either failed or were never effectively delivered in the first place (Odets, 1995a; Rofes, 1996; Van Gorder, 1995). Yet those efforts have remained essentially unchanged over the last 18 years. Why? What is causing the situation's inherent stability? Unfortunately, very little empirical research has been done in understanding the relationship between the prevention needs and concerns of HIV-negative gay men and the political realities of community-based HIV education. The purpose of this qualitative study was to address these issues by using the lens of political planning theory (Cervero & Wilson, 1996) to explore the interrelated nature of program planner and program participant interests in HIV/AIDS education for gay men. In short, to examine the relationship between how HIV-negative gay men think prevention efforts "should" be handled and how they actually *are* handled.

The site of the study was a large, urban AIDS service organization, here called "Helping Hearts, Inc." Individuals who planned, facilitated, or attended Helping Hearts education and support programs designed to address HIV/AIDS transmission and prevention in the lives of gay men formed the unit of analysis for the study. All programs attended by participants in this study were designed for "generic" (undifferentiated by serostatus) gay men. At the time of the study, Helping Hearts had never designed nor presented an educational program specifically targeting HIV-negative gay men. Data collection primarily consisted of audio-taped interviews with a total of 24 agency institutional leaders, planners, program facilitators, and HIV-negative gay men who had attended one or more of the programs included in the study. Additional data sources consisted of official agency documents, program marketing tools, copies of educational curricula, and personal documents brought in by study respondents. Data were analyzed according to the constant comparative method. A qualitative approach to data collection and

analysis was selected because a naturalistic mode of inquiry which encourages dialogue and self-reflection was considered to be best suited for revealing the participants' own understanding of their decisions and experiences.

Findings

There were six major findings from the study. Two of these emerged from interviews with HIV-negative gay men who attended HIV education programs at Helping Hearts. These included first, that many uninfected gay men have a desire for prevention education that is designed to acknowledge, address, and give value to their identity as HIV-negative individuals. And second, that program participants feel HIV/AIDS educators should assist in bringing about a cultural change that would help HIV-negative gay men survive and thrive as valued members of an HIV-centric society. The other four findings emerged from interviews with program planners, facilitators, and agency leaders at Helping Hearts. These included first, that HIV/AIDS education continues to play a role in maintaining the appearance of a cohesive gay society by reinforcing the myth of generic (undifferentiated by serostatus) gay men requiring generic (undifferentiated by need) prevention education. Second, that the felt need to promote solidarity in the gay community is not the sole--or even the most personally compelling--reason that education planners continue to support undifferentiated prevention education for gay men. Third, that a strong institutional interest in avoiding public controversy controls educational planning decisions. And fourth, that this institutional desire to avoid controversy is combined with a personal philosophy of non-interference to make education leaders reluctant to act as agents of social change for gay men, even when that change would directly benefit (uninfected) gay men. Each of these findings is briefly discussed below.

Program Participants. First, while program participants expressed a diversity of educational expectations, a common thread was their desire for education based on an (as yet unrealized) acknowledgment of their separateness from HIV-positive gay men. As one program participant said, "if there are two [serostatus] categories, HIV-negative is not one of them." Currently, self-understanding for uninfected gay men is not conceptualized around what they are; it is conceptualized around what they are *not*. Or, as another program participant said, "we only know what it is like to be HIV-positive and I am not that." This situation leaves many HIV-negative men feeling unprepared to address the complexity of HIV in their own lives and dissatisfied with advice that they simply "find other issues to actualize their identity around," as one program planner suggested.

An analysis of the data also revealed that program participants feel HIV/AIDS educators should (but don't) go beyond helping individual gay men to promoting a cultural change that would help all HIV-negative gay men thrive as valued members of an HIV-centric society. As one HIV-negative gay man said, "I don't know if there is a program that confers protection [against infection] but I do know that there could be programs that confer *value* on being uninfected." The depth of this need was starkly apparent. When asked "Do you think that the gay community provides support for HIV negative gay men?," *every single person* interviewed for this study but one answered with a resounding "No!" The lone dissident based his belief on "... our adult films now. The male stars are obviously wearing a condom, you can see it." The feelings of the rest of the respondents are concisely encapsulated in one HIV-positive man's acknowledgment: "We

don't support the value of being negative the way that we do being positive." Not surprisingly then, analysis of the data also revealed that internalizing this perception provides some gay men with an incentive to become HIV positive. As one program participant put it, "I am sure it's like this golden door opening. Maybe I am romanticizing it but it seems totally wonderful, you enter this wonderful world of open arms and loving people when you become positive but when you are negative there is nothing."

Program Planners. As mentioned above, the marginalization of HIV-negative gay men is not a new phenomenon. Adult education planners began early in the epidemic to suppress the separate needs of HIV-negative gay men in order to focus their efforts on promoting at least the appearance of solidarity among all gay men. Study findings support the assertion that with the passing of time, the worsening of the epidemic, and the general move towards political conservatism in American society, this perceived need to present a united front has remained unchanged. An analysis of the data suggests that within this frame, HIV educators have little incentive to publicly acknowledge the separate educational needs and issues of HIV-negative gay men and much incentive to continue to treat them generically. In fact, until the larger battle for equality is won, the greatest good for the greatest number may require that educators continue to push the separate identity and educational needs of uninfected gay men into the shadows. Because, as two Helping Hearts program planners pointed out, "you may be doing yourself a ... disservice to try to segment the population" (current director of Gay Outreach) by "dividing them into two camps" (former director of Gay Outreach). The solution then, as another planner put it, is to "make anything that looks like a disagreement a background issue. Make people keep their mouths shut."

The findings also suggest that education planners would still report a compelling interest in promoting undifferentiated education for gay men even in the absence of a felt need to promote solidarity in the gay community. That is, that despite being fully aware that infected and uninfected gay men may have different motivations for engaging in safer sex, and that HIV-negative men certainly face far more serious consequences for failing to do so, education planners still insist that it is unwise to provide programs specifically designed to address the unique prevention needs of HIV-negative gay men. This decision was not based on the perception that such classes would be unpopular with HIV negative clients. On the contrary, as one education leader asserted, "if I advertised a [class] just for HIV-negative gay men, I could fill it right away." Rather, this opinion appears to be rooted in two deeply held, albeit untested, beliefs. First, that the various benefits of education which include HIV-positive and negative gay men in the same discussion will always outweigh the singular benefits of targeted education solely for HIV-negative gay men. And second, that prevention education should target behavior, not (serostatus) identity. In support of the first belief, education planners referred to post-program evaluations that consistently and uniformly reported respondents as preferring mixed (by serostatus) classes. On the other hand, since the programs those evaluations referred to were intentionally designed to address mixed audiences, this was not a totally surprising outcome. Without classes providing education targeted by serostatus to use for comparison purposes, the belief remains ultimately untested. The same lack of evidence applies to the second belief. Because prevention programs sponsored by Helping Hearts invariably avoided customizing messages by serostatus identity, there was no way to test the planners' assertion that prevention education should address behavior in a vacuum, rather than in the context of serostatus identity.

Their lack of supporting evidence did not, however, prevent program planners from staunchly defending either belief as a justification for continuing to provide undifferentiated education.

Third, findings revealed a compelling institutional interest in avoiding controversy when designing prevention education for gay men. This interest seems to be the result of economic, political, and social pressures on the agency. Economically, from the agency director's perspective, what really matters in making programmatic decisions is, "how the donors look at it." Because, "without funding, *no* messages get out." For political reasons related to the agency's history with gay men, the agency's education department director concurs. "I am not convinced," he says, "that taking a stand, on any particular issue, is the healthiest thing for us to do." The agency's job, he maintains "is to go into the gay male community, try not to offend people if we can at all help it...and get the hell out." This attitude is hard won. When a previous administration was perceived as turning its back on the gay community in favor of broadening the agency's service area to other affected populations, Helping Hearts was widely viewed as betraying its founding mission of providing assistance and support to infected gay men. Subsequent financial and volunteer support from the gay community dropped precipitously and was not replaced by equal funding and volunteer support from the straight community. Not surprisingly then, the current agency administration sees reversing this perception of gay neglect as a top priority. Socially, analysis of the data reveal that the agency's interest in avoiding controversy is intertwined with the first two program planner findings, controls what sort of education may be offered, and largely underlies the belief noted above that prevention education should address behavior in an identity vacuum. Singling HIV-negative gay men out for separate attention would simply be too controversial in a community that places serving the needs of people with HIV, not without it, at the heart of its collective identity.

Finally, study findings also revealed that the above institutional interest in avoiding controversy is combined with a personal philosophy of non-interference to make education leaders reluctant to go beyond providing assistance for individual gay men to acting as agents of social change for gay men as a group. Rotello (1997) argues that HIV education not only can, but *must* convince gay men that they need to change gay sexual culture in fundamental ways if they, as a society, are to survive and thrive in a world that has shown itself incapable of curing or preventing communicable disease. Unfortunately, his argument runs headlong against the obstacle of many gay men's lived experience. Most of the respondents interviewed in this study exhibited an almost visceral loathing for what they perceived as authoritarian education. This is a response that in many cases seems to spring from childhood memories of rejection and disenfranchisement while growing up gay in a society that despises and denigrates homosexuality. Among HIV education planners and facilitators (all of whom were themselves gay men) this contempt for punitive authority exhibited itself as an extreme aversion to being perceived as using their position of power to impose their own beliefs on other people (i.e., program participants). Among education planners and facilitators, the resultant golden-rule-based doctrine ("because I would not want others to tell me what to do, I can not, in good faith, tell others what to do") appears stronger than any desire to exert leadership authority. This was true even in cases in which an education planner or facilitator felt the public health was at stake. Hence, when this personal doctrine is combined with an institutional reluctance to do anything that the local gay community might find polarizing or offensive, a compelling interest in avoiding an appearance of dictatorial authority is formed.

Conclusions and Discussion

The findings suggest three general conclusions. First, that the educational expectations of HIV-negative gay men and the educational philosophies of program planners frequently act at cross-purposes to one another. Second, that HIV/AIDS education is an effective, albeit unintended, mechanism for keeping HIV-negative men outside the circle of gay community support and attention. And third, that despite the fact that neither education providers nor education clients appear satisfied with the situation, the current recursive dynamic between gay men and HIV/AIDS education efforts for gay men nonetheless serves to justify and reinforce this mechanism. This suggests an inherent stability of the status quo that will only be overcome through deliberate and thoughtful action on the part of institutional leaders and program planner/facilitators. The need to do so however can be found in an unintended irony. By helping to shape cultural decisions that exclude HIV-negative men from full membership in the gay community, program planners successfully reproduce the dynamic that gay men in general face in relation to the larger heterosexual society. As asserted above, this leaves HIV negative gay men feeling doubly excluded - an overwhelmingly hurtful experience for men who initially sought out the gay community precisely because they had spent a life time being the "other."

The findings also suggest some general implications for the practice of adult education. First, if education planners are to perform their role in a responsible fashion, they must begin by becoming aware of the relative priorities that have traditionally been assigned to the diverse interests that are affected by program planning. For example, if HIV/AIDS educators are to increase educational and societal attention to HIV-negative gay men, they first need to be aware of the reasons that that attention has been limited in the past. Second, adult educators who choose to alter a stable--even if ultimately unhealthy--educational dynamic should be aware that they may face tremendous personal, professional, or societal obstacles to doing so. If these obstacles are too large, the status quo may hold regardless of how evident the need for change may be.

This study was important because lives are at stake. To the extent that adult educators believe education can affect behavior, each day brings new opportunities to help or fail uninfected gay men who wish to remain uninfected. This challenge has never been easy and past educational efforts may actually have made it more difficult. But as research into the prevention and management of HIV evolves, new social mores are emerging that drive the adoption or abandonment of individual behaviors and collective norms. The information provided by this study has the potential to help shape a more effective educational response to those evolving realities.

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