

COMMUNITY-BASED AIDS EDUCATION AND SUPPORT SERVICES

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Address to the AIDS Forum of the Fourth National Symposium
on Doctoral Research and Social Work Practice

The Ohio State University
April 7, 1988

It is no small task to critique or summarize Community-Based AIDS Education and Support Services. These efforts have been underway since 1981, and have grown from simple efforts to provide support and friendship to the relatively few gay men diagnosed at that time, to highly complex government-funded and foundation-funded institutions that offer to thousands of individuals multiple services ranging from legal assistance to medical information, HIV antibody testing, counseling, treatment, hotlines, support groups, "buddies," skilled nursing care, advocacy, educational efforts, outreach, and research. It is rather impossible for me to summarize all of this and make any vast conclusions as to successes, failures, service gaps or funding priorities. What I can do is offer a perspective based on my experience in this field for the last five years, and bring to that perspective knowledge gained through my own errors as well as the concerns and needs of the AIDS-affected individuals who have touched my life and educated me during that time.

We all know that AIDS is a plague that entered this country through two highly stigmatized but very different social groups, homosexually-active men and IV drug users. I have no doubt, however, that stigma has dictated the course of this disease. It has also dictated the course of social work intervention. It is not my task to address this particular thesis here. Randy Shilt's book, And the Band Played On, addresses that issue fully.

Rather, I wish to look at the actual course which that intervention has taken, and analyze it from the perspective of clients and communities. I will focus in particular on the experiences of homosexually-active men, as those are the experiences with which I am most familiar. You will note, by the way, that I use two different terms here, "gay males" and "homosexually-active men." This distinction is rather socio-politico-psychological in nature, in that the term "gay" is used to refer to an individual who self-identifies as such, and has achieved a degree of intrapsychic and social integration as such, whereas "homosexually active" encompasses gay men as well as those who engage in same-sex behavior but do not self-identify as gay and/or have not achieved that level of identity integration.

Services to homosexually-active men were necessarily community-based simply because all levels of government and other mainstream institutions failed to act. In addition, those who were dying were already alienated in large part from their families and home communities. Of the two populations affected, IV drug users and homosexually-active men, only the latter obtained some response from an organized, albeit stigmatized community, that of lesbians and gay men. Only that community had the initial will and capacity to respond. (I include lesbians in this because so many lesbians have been involved in AIDS from the start for very good and logical reasons which I will address later.)

The way in which the lesbian and gay male community responded is noteworthy in a number of ways. The community quickly identified the basic needs of AIDS-affected individuals: emergency housing, food, transportation, medical care, education, and equally important, friendship. They then established remarkable volunteer-based systems for responding to these needs:

"buddies" to befriend PWA's, take them to the hospital, run errands, do laundry, cook, clean, and otherwise tend to their basic human needs, lawyers to assist PWA's in delegating Powers of Attorney, executing wills, dealing with discriminatory acts; others to do advocacy, nursing care, massage, activity programs, educational efforts, and so forth. One of the great untold stories about this disease, in fact, has been the level of volunteer response within this community. Literally thousands of individuals who had never considered charitable acts to be anything more than signing their United Way commitment card at work were caring for and caring about these lepers of our day and seeing them to their death. It is an astounding phenomenon that is perhaps one shining light in the darkness of this disease.

If there is one area where the community stumbled, it is in the area of education. I say "stumbled" and not "fell" because educational programs and efforts in the gay male community have significantly reduced the seroconversion rate in that population, in some places to zero (San Francisco). However, AIDS is entirely preventable, and we have failed to the extent that we are unable to reduce the incidence of HIV infection to zero throughout this country. The barriers to this will become readily apparent as I discuss the current challenges to adequate community-based AIDS education and support.

The nature of AIDS itself poses some of these challenges. AIDS is, first of all, a syndrome that describes the last stage of apparent infection. It is not the infection itself. By the time individuals are diagnosed with AIDS, they may have travelled down a long continuum of illness, whether they knew it or not. At any point along the continuum, an individual may be faced with complex legal, medical, social, and political decisions.

Allow me to take you through this continuum. On one end of the continuum, I may be asymptomatic, not know my antibody status, but wonder if I am at risk. What determines if I am at risk? Am I at risk because I belong to a "high-risk group" or because I have engaged in some behavior that has put me at risk? Does the time that I engaged in that behavior (10 years ago, two months ago) or the geographical location (Midwest vs. West Coast) have any bearing on determining whether I am at risk? Or am I at risk more because of who my sexual partners are, and who their partners have been?

If I somehow determine that I am at greater risk, what do I do? Should I change my behavior? How so? If I am gay and am aware that monogamy with a seronegative individual is, short of celibacy, the safest alternative, will I receive any social or familiar support for establishing and maintaining such a relationship? In couplehood, one's sexual orientation is less easily concealed. How then, will I manage this potential risk to my employment, housing, familial support? If I choose to establish a closeted lifestyle with a partner, what price will I pay for that in my relationship with that person? Or should I become celibate, or reduce my number of sexual partners and change the kind of sexual activities I engage in?

If I think I may be at greater risk, should I submit to a test for antibodies to the virus thought to cause AIDS? If so, how can I be certain that the results will be accurate, or that they will remain confidential or anonymous? If I choose not to get tested, what happens if the insurance carrier at my next workplace requires an HIV antibody test? If I get tested, how will I react to a positive (or negative!) test result? What about treatment even if I have no symptoms? Should I take the test so that I can consider experimental treatment with AZT or AL 721 or so-called "workalikes"?

What, if any, side effects could I encounter? How do I weigh side effects and toxicity with potential benefits?

Then there is the issue of disclosure of antibody status. Who should know, and how do I balance the need to tell others for emotional support or, in the case of sexual partners, ethical purposes, with the need to protect my own civil liberties and my need to feel accepted? Should my family know? Should I tell my friends? My sexual partners? When?

Finally, if I am diagnosed with AIDS or ARC, what sort of legal protection is there for me and for my lover? How do I insure that my lover, and not my parents or siblings, will be able to make decisions for me if I am incapacitated? How do I cope with changes in my appearance? At what point do I consider my will? How do I cope with increased dependency on institutional care systems? How do I hold onto life and simultaneously prepare for the possibility of death?

If you are not yet overwhelmed, consider that throughout this fabric of AIDS-related dilemmas run the threads of mortality at a young age, experiences of gross discrimination and rejection by family, friends, and community, shame and despair that often re-ignites unresolved conflicts over sexual orientation, increased financial and emotional dependence, and constant and intensely focused uncertainty over one's health.

AIDS challenges the social work profession as no other disease has done. It forces us to consider ethical, psychological, medical, legal and cultural issues that compound the human experience of illness and death seemingly beyond human dimensions. We are called upon to face issues and make decisions we have had little experience making, and AIDS compels us to think in politi-

cal terms not unlike those that nourished the social work profession in its early stages and have since all too easily been discarded.

AIDS however, is an opportunity for our profession to do what its mission has always been, to mend the fabric of a society, to not just fill the gaps, but to make whole, to renew. We can do this by addressing at least the following.

First, it is incumbent upon our profession to eliminate stigma associated with AIDS. We must examine our own attitudes not just toward illness and dependency, but toward sexual orientation, drug use, and death. We can begin by simply understanding that AIDS risk is not a function of membership in a group but of engaging in high risk behaviors. We must infuse AIDS education efforts with this fact. Gay men are not at risk for AIDS. Men or women who engage in high-risk sexual behavior such as unprotected (receptive) anal or vaginal intercourse are at risk.

Educating homosexually-active men about AIDS involves more, however, than simply providing them with a list of do's and don'ts. It involves addressing the very real homophobia in this culture and offering support to homosexually-active men in combatting the crude and destructive effects of internalizing this repugnant aspect of our culture. We cannot allow AIDS to re-ignite those passions. We must resist our own tendency to make heterosexuality better than homosexuality. One implication of this is that we must support the viability of same sex couples, and assist such couples in managing the effects of living in a homophobic society. We must also become as comfortable with the erotic and sexual aspects of our lives as we are with brushing our teeth, particularly if we are to make any real inroads into educating those at risk.

This is a tremendously important point that should not be lost in all of the discussion over the content of educational programs. Real education is derived not from learning facts but from encountering knowledge at a personal level. Real knowledge is derived from one's experience. Education is the complete communication of experience. We are therefore called upon to experience change in ourselves before and during our attempts to educate others. We must speak from experience. I am not talking here about sexual experiences per se, but rather the experience of becoming conscious of such issues as homophobia and heterosexism when they appear. I am speaking of allowing ourselves to be confronted on those matters and of confronting it in others. We simply must develop, at a very personal level, the capacity to surrender our professional pretenses and communicate to others real comfort with sex and sexuality.

This is particularly critical in educating our youth. We cannot for a moment hesitate because of some Victorian consideration that they might learn what they may not know but already may do so that they won't know what they shouldn't do when they do what they're not supposed to know how to do and not tell anyone they did it! Large numbers of our youth are at higher risk for a number of reasons. They are often even less knowledgeable, more sexually active, more resistant to behavior change, more likely to feel omnipotent and therefore less vulnerable to illness and misfortune, more likely to exercise bad judgment or engage in behaviors like alcohol and drug consumption that impair judgment, more likely to be negatively influenced by peers and less empowered to assert themselves with exploitative adults. Subgroups of this population, such as homosexuality active youth and homeless youth are at even greater risk without adequate education and support. I am most fearful for

this population. Our efforts to educate youth are too muddled, too little, too focused on content issues, and too late.

We must furthermore confront our attitudes about death and dependency. Here we pay a price for our generational preference to remove death from our lives. We have neatly excised it from our everyday experience. We have placed death at a distance. Death rarely occurs at home with family, but at nursing homes and hospitals (and for those who prefer to exercise complete control over this reality, there is television). For PWA's, death all too often occurs alone. We must incorporate the dying into the fabric of our society, and must find meaning and value in that experience. Many volunteers and community-based AIDS service organizations have truly mastered this. Places like the Shanti Project in San Francisco or Chicago House come to mind. There, dying is not distinct from living in the hearts and minds of volunteers and PWA's. We can learn from people and places such as these.

We must also reconcile the mainstream community and its institutions with those affected by AIDS. It is in our own communities that the rending of our social fabric is most apparent. Families, churches, schools, and local mainstream organizations are more often than not rejecting of AIDS-affected individuals. The ill and dying cannot return home, and are sometimes shunned even when they are home. The experience of Ryan White or the three hemophilic brothers in Florida who tested positive reflect the very worst aspects of this. Nor is this a matter of ethics alone, for a receptive and supportive community can truly make a life and death difference to the person who is ill, or who has tested positive for HIV antibodies.

Finally, we must absolutely surrender our professional bias that dictates that only professionals, physicians, nurses and social workers can help. Our

experience over the last several years proves otherwise. Human beings, very human beings, help. Our role as social workers is to understand this, and create opportunities for such help to occur.

There are reasons to be hopeful. The models of intervention and, increasingly, the resources are available. The women's health movement is one such model. It is a model that emphasizes equality in the examining room, the right to informed consent, prevention, access to knowledge, the right to make decisions about treatment and control one's own destiny, and the right to be treated respectfully and with dignity. Lesbians have been integrally involved in this movement. It is therefore no surprise that so many lesbians became immediately involved in the community response to AIDS. They recognized that the issues were the same, that a minority was facing the same issues that women have faced in the medical profession--disdain, dehumanizing treatment, discrimination and inequality. Their contributions have immensely influenced the shape of community response.

Alternative approaches to health have also flourished in this response, and are increasingly recognized as being of value by the medical profession. These approaches, ranging from nutritional guidelines to meditation, yoga, massage, acupuncture and acupressure, rolfing, herbal therapy, and experimental naturalistic drug therapies have in some cases appeared to fortify individual immune responses and reduce the suppression of T-cells. These approaches are not offered as cures, per se, but as adjuncts to traditional Western medicine that may assist in improving the quality of life of AIDS-affected individuals.

Hope can also be found in the acknowledgement by mainstream institutions that community-based AIDS efforts are essential. Research institutions,

government, universities are all in fact dependent on these community-based efforts to further their work in the field. As a result, these mainstream institutions are increasingly sensitized to the realities of serving at-risk populations. This, in turn, is contributing to government's ability to overcome narrow moralistic concerns and understand that we all have an interest in the well-being of those previously thought of as disposable. The initial reports from the President's Commission on AIDS reflect this more pragmatic and useful approach.

There are many useful avenues for research that can be inferred from all of this. For example, much is not known about the relationship between various so-called co-factors and susceptibility to HIV. Some research has been done in the area of stress and immunosuppression, but results are far from conclusive in terms of this disease. Clearly, however, a traditionally stigmatized population such as homosexually-active men faces stressful situations daily. Other suggested co-factors include substance abuse and exposure to CMV or syphilis. In addition, initial research indicates that knowledge of antibody status does not necessarily induce positive behavioral change. This has some implication for the educational and counseling approaches applied to the issue of testing.

Educational approaches are themselves worthy of serious investigation. It is extremely difficult to determine the kind of educational approaches that best promote prevention and behavior change. My own particular concern for educating youth is paramount here.

Finally, we must begin to look at ways to sensitize local communities and help them support the AIDS-affected in their midst. Minority neighborhoods and rural small towns are called upon to educate themselves and create a

positive environment for the AIDS-affected. I welcome research into the relationship between community sensitivity and knowledge about AIDS and the well-being of AIDS-affected members of that community. I believe that a positive correlation exists.

Community-based AIDS education and support is not the responsibility of any one individual community. Ultimately, it is the responsibility of us all. As a profession, social work has an immense role to play in this. We can educate, advocate, serve, confront, and conduct research that is both meaningful and useful. I congratulate you on your dedication to this profession, and welcome your good work.