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Programmatic Responses to the AIDS Epidemic by Communities of Color in Massachusetts

by Ron E. Armstead

Background

The Centers for Disease Control found that minorities now account for more than half of all the HIV cases in the United States. For African Americans, the rate was more than 5 times as high as that for whites. Further, the disease has equally affected women and children in the African American community; 84% of the AIDS cases involving children age 12 and under can be found in the African American community. AIDS has now become the second leading cause of death for African American women.¹ This essay describes a research project focusing on the factors involved in developing and implementing AIDS programs in three different agencies and cities aimed at prevention and education. The project, Programmatic Responses to the AIDS Epidemic by Communities of Color in Massachusetts (PRAECC) offered planning assistance that might be utilized to enhance the overall delivery of AIDS-related services. The concept for this research project arose from a number of concerns: 1) my practical experience as a social worker in the federal government; 2) the increasing publicity around minority community HIV drug users' high risk behavior; and, 3) the alarming national statistics regarding the high prevalence rate of AIDS among African American communities. (This case study concerns itself with thematic issues rather than medical/research questions of cure and treatment.)

PRAECC offers a contextual framework within which one can analyze both positive and negative aspects of the community AIDS programming problems. It is a case study which provides a community-based organizational perspective that can serve to inform policy makers and administrators as to the front-line issues and concerns. In addition, it is also a planning process (i.e. planning, implementation and evaluation) involving various parties in collective problem-solving, community consensus-building, information sharing and exchange, bargaining and negotiating, analysis and reassessment, as a prerequisite for channeling time, energy and effort.

PRAECC targeted three major African American communities across Massachusetts to compare and contrast agencies and geographic areas. The three cities selected were: Boston, Worcester and Springfield. These three cities represented (a) the largest population



concentrations of communities of color in the state; (b) the most urban areas in the state; (c) the most active African American community-based agencies in the state; and, (d) the oldest African American communities, in most instances, in the state. The three agencies selected were: 1) For Individuals Recovering Sound Thinking, Inc. (FIRST) of Boston; 2) Prospect House of Worcester; and, 3) Northern Educational Services (NES) of Springfield. FIRST began in 1967 as a mutual support group for inmates at the Deer Island House of Corrections. This was the first self-help program in any Massachusetts Penal Institution, as well as one of the first such programs in the nation. The Prospect House started out as a storefront neighborhood drop-in center in 1967. Since then it has evolved into one of the largest human service agencies in Central New England. As of June 1988, it had approximately 218 employees, 29 programs in 13 different locations. It is a minority or community-based organization that is certified by the State Office of Minority and Women Business Assistance. NES was initially started in 1963 by a disabled African American war veteran by the name of Mr. Robert Hughes. He started the inner city tutorial service with his disability check from the military. This organization served as a tutorial and cultural enrichment program for African American students attending local preparatory schools in the area. With the assistance of federal funding, the organization has evolved into a supportive, multi-service delivery and treatment organization.

These three agencies are well recognized and, cumulatively, have a total of approximately 75 years of community service. Their agency directors, Mr. Nathaniel Askia, FIRST, Inc. and Ms. Norma Baker, NES, are well known in their respective communities, and in one instance, Ms. Bette Price, Prospect House of Worcester, held public office. Further, they have established track records of community service and are highly committed

individuals who serve as role models and advocates in their various communities. Each of them brought something unique to the discussions in terms of their insight and vision.

In order to complete this project, interviews were conducted with each director to assess their concerns, experiences, insight and vision for their particular organizations, as well as the future of AIDS programming in communities of color. The questions developed for the interviews reflected five broad categories of inquiry and involved different levels of concerns: 1) background of AIDS programming; 2) ideal scenario for future AIDS programming, and leadership characteristics for AIDS program managers; 3) evaluation of outreach; 4) strengths and weaknesses of their AIDS programming; and, 5) questions the directors would like to ask of other agencies (state agencies, medical/research institutions, etc.).

After analyzing the field data obtained from interviews, three critical themes became apparent. The agency directors felt: 1) a sense of isolation from state agencies and medical/research institutions; 2) a lack of funding and resources for organizational programs to meet expanding needs; and, 3) a level of sustained community powerlessness, which leads to the perpetuation of dependent relationships.

Currently, community-based organizations in African American communities across Massachusetts are confronted with an ever changing set of economic, social, and political circumstances. For those reasons, a few comments about each of the three themes are necessary.

The sustained character of this dependency relationship limits and fosters underdevelopment of community-based organizations.

These particular community-based organizations felt they were isolated from funding and other resources since the AIDS epidemic became paramount. These feelings were due primarily to the fact that the African American community had historically been underserved and denied access to care. Other contributing factors of this tension included the withholding of funding, institutionalizing of employment positions using research grants, tactics of "divide and conquer" among community agencies, community resource deficits, as well as exploitation.² In a very real sense, this conflict is at least a part of a larger problem of a lack of community development and self-sufficiency.

The perception was that the lionshare of dollars available for AIDS work was coming through research. Thus large scale medical/research organizations were the primary benefactors of existing funding. However, medical and research organizations thus far are still in need of community-based agencies to gather baseline data from areas otherwise inaccessible to them. Yet, given this

stated need, majority medical/research organizations have failed to explain their reluctance to provide appropriate funding for services requested and/or rendered. It is this and other funding that helps community-based organizations continue their work at the grassroots level.

It is clear that a conflict has emerged involving what these African American directors perceive as the fundamental issue of community powerlessness and the perpetuation of dependent relationships. Moreover, these directors argue that this is the root cause of the continuing underdevelopment of the African American community. According to Madhubuti's recent book, *Black Men: Obsolete, Single, Dangerous?*, the author sees community work as a struggle for the building of institutions, parties, and nations. This kind of work Madhubuti proposes is a form of empowerment and self-help.³

Of these cumulative factors the latter point is the overriding theme that needs to be addressed in the future. The sustained character of this dependency relationship limits and fosters underdevelopment of community-based organizations. As such the communities' capacities are sharply curtailed. This intrinsic conflict is seen as a microcosm of the larger issue of community development and self-sufficiency (i.e. self-determination). To plan for this type of problem, a strategic planning approach encompassing planning, field research, coordination of multi-community resources, education and developed one critical organizing resource, the Massachusetts Institute of Technology (MIT) AIDS Forum.

The MIT AIDS Forum

Dr. Frank Jones, a professor of urban studies at MIT, conceived of the MIT AIDS Forum. However, much of the idea for the forum came from the issues expressed and discussed by the agency directors and the desire to engage in dialogue with others facing similar issues. The forum's purpose was to (a) serve as a broker between the state and community-based organizations; (b) facilitate discussions among and between diverse and geographically-dispersed groups across the state; (c) act as a conduit for distributing information, soliciting mailing lists and sending information in the widest distribution range possible; and, (d) assist as a planning vehicle for reassessing the problems and determining the potential of statewide networking capacities. According to George Fraser, "it is vital for African Americans to network for their common good...joining together to have a greater impact for the good of their communities via this new form of the Underground Railroad."⁴

The day-long forum featured Dr. Deborah Prothrow-Stith and Dr. Benny Primm, as well as a panel discussion made up of representatives of the community-based organizations involved in the interviews and Ms. Shirley Gross, director of Bayview/Hunter's Point Foundation in San Francisco. Two persons living with AIDS (PWA's) were also present to recount their past and current experiences with the epidemic. At the close of the day, participants of the AIDS Forum had recommended nearly 20 specific steps that could be taken to strengthen agencies

within communities of color statewide. The four priority recommendations were suggested by Ms. Shirley Gross, who played a significant role in designing a similar plan of action for community-based organizations in San Francisco.

Strategic Plan

The forum proposed the creation of a statewide network called the Massachusetts-Black AIDS Statewide Effort (M-BASE), which would serve the purpose of an ongoing capacity building mechanism to the particular organizations and agencies. In reality, the statewide network should consist of multi-services and multi-agencies offering an organized blocking tactic—a bargaining and negotiating or leveraging tool. The key ingredient of the statewide network is not funding, but coordinated effort and interagency cooperation. If community players can cooperate and/or collaborate with one another to the extent necessary, the statewide network will work; and the result will upgrade the status of AIDS providers within communities of color to that of community brokers.

The following is a partial listing of recommendations of the MIT AIDS Forum:

- 1) establishment of a minority research unit to conduct research for leveraging co-principal investigator status, initially focusing on mainstream institutions and negotiating for paid positions in return for accessing the minority AIDS population within certain inner city communities.
- 2) development of an AIDS workshop component to provide training to enhance the capacities of the M-BASE members. The workshops, proposed by the directors of the community-based organizations, will help develop new competitive strategies and stimulate expansion of existing resources.

These workshops (i.e. on such topics as funding, programming, public and private partnerships, outreach, networking and alliance-building, publicity and marketing, and transferring business practices to non-profit agencies) were identified by the agency directors as having the most relevance to agency survival in the 1990s. This will undoubtedly be true into the 21st Century as well, due in part to the increasing competition for human services funding.

- 3) the MIT AIDS Forum will serve as a clearinghouse for the furnishing of professional expertise, information, community education, training, and research for members of communities of color and link them to those national and regional organizations addressing the issues of AIDS.

- 4) improvement of the funding environment and development of a strategy for fundraising and economic development for the agencies of the statewide network in order to fulfill their philosophy of self-determination and self-help. Thus, economic development will have to play a major role in the future.

Looking at the Future

The community-based organizations interviewed in this case study are actively involved in the community-building process as it relates to the AIDS epidemic. Collectively, FIRST, Inc., Prospect House and Northern Educational Services are a new and potentially powerful approach to the type of community empowerment mentioned throughout this article. Their collective capacity, conservatively speaking, resembles the consolidation of a giant statewide community-based organization in order to exercise newer economies of scale, improved coordination and larger opportunities for communities of color at large.

These organizations must develop more community development strategies. Project managers, administrators, directors, community activists and concerned individuals from all across the community will need to be involved in the process; they must exert leadership. At the same time, all will need to cooperate to an unprecedented degree. This strategic plan is not exclusively, nor solely Massachusetts-specific in terms of attaining the salient goal of community development. It should also be viewed as a replicable and exportable model of community empowerment to other states for ongoing utilization.

Notes

¹AIDS and HIV Infection in the African American Community. Hearing before the Human Resources and Intergovernmental Relations Subcommittee of the Committee on Government Operations, House of Representatives. 103rd Congress, Second Session. (September 16, 1994).

²For example of this kind of oppressive history, see J.H. Jones, *Bad Blood: The Tuskegee Syphilis Experiment—A Tragedy of Race and Medicine*. (New York: The Free Press, 1981).

³H. Madhubuti, *Black Men: Obsolete, Single, Dangerous?* (Chicago: Third World Press, 1990).

⁴G. Fraser, *Success Runs in Our Race*. (New York: William Morrow & Co., Inc., 1994).

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