Overcoming Historical and Institutional Distrust: Key Elements in Developing and Sustaining the Community Mobilization Against HIV in the Boston Haitian Community

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The Metro Boston REACH 2010 HIV Coalition needs to develop innovative processes aimed at overcoming a history of distrust that has led to limited cooperation from the Haitian community. Among the key elements being implemented are the development of a community vision through a community mobilization process; the development of an innovative working group process, in which coalition members worked together to develop and implement culturally and linguistically appropriate HIV prevention curricula; participatory leadership and joint accountability processes, manifested in decision-making approaches, such as the fund allocation system, and in the provision of technical assistance workshops on team building, designed to engender cohesion, skills, and resources sharing among coalition members. The success of this venture is measured through the growing expectation that this coalition could serve as a community planning body for all HIV-related services aimed at reducing HIV infection in the Greater Boston Haitian population. (*Ethn Dis*. 2004;14[suppl 1]: S1-46–S1-53)

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Introduction

Alternative approaches to health education and promotion, which utilized aspects of community organizing and mobilization, have produced promising results.[1] However, in order for community organizing and mobilization to occur, and to be lasting and responsive to developing conditions, changes should be rooted in a social and political base that comes from organization and leadership within the community itself.[2] Coalitions to promote health have been lauded in recent years as a tool to foster community involvement in health promotion and to combat complex health problems.[3,4] Likewise, to maximize resources, many foundations and governing agencies have found community coalitions to be an essential component of resolving major community public health concerns. However, for many communities, particularly for some ethnic communities, the formation and implementation of a community coalition represents a significant challenge, and, to some, a new approach to collectively and effectively address local health problem. For the Boston Haitian community, an inherent culture of distrust based on past political, institutional, and social experiences in Haiti, has paralyzed all efforts to implement sustained collaboration and partnership initiatives.

A coalition approach to addressing the HIV public health crisis in the Metro Boston area is warranted, given the cultural, social, political, immigration, language, discrimination, and biological factors and challenges this community has to overcome. Further, a coalition that brings together diverse providers to address these challenges provides the opportunity for cross-fertilization. The Metro Boston REACH 2010 coalition funded by the CDC has gained significant insight in developing effective mechanisms for coalition building in the Haitian community. Through the early phase of this coalition, specific interventions were developed to engage all local stakeholders in identifying and responding to gaps in HIV services and prevention in the Haitian community. This paper is an attempt to capture the elements that could explain the successful implementation of the Metro Boston Coalition.

Background

Massachusetts has the third largest Haitian population in the United States, with an estimated 80,000 Haitian residents. Haitians live primarily in the city of Boston; the Haitian population also spreads north of Boston to Cambridge, Somerville, and Malden, and to the South Shore in Randolph and Brockton. Based on our community survey of 3500 households, the Haitian adult community is a middle-aged immigrant population with 97% of the population being foreign-born. The mean age of the adult population is 41 years. Fifty-six percent of the adult population have lived in this country for more than 10 years, and 76% for more than 5 years. Haitian Creole is the preferred language of the adult population. Females outnumber males, and the population is primarily heterosexual.[5]

Haitians make up more than 6% (796) of reported AIDS cases in Massachusetts, although Haitians represent slightly more than 1% of the population. Among Haitian adults, 48% of

these cases are female, an increase of 8% from 1993. The proportion of Haitian women with AIDS is very high, compared with figure for the general population. The high rate and rapid rise in the number of Haitian women and children with AIDS further highlights the course of the HIV epidemic in the Haitian community.

As of September 2003, there were 641 HIV/AIDS cases among Haitian born individuals living in Massachusetts; of these, 343 are male, and 298 are female. 165 males reported their mode of exposure as presumed heterosexual, 63 contracted the virus through heterosexual contact, 20 through males having sex with males (MSM), 12 through IDU, and 60 were not aware of how they contracted the virus. For female mode of exposure, 165 stated they contracted the virus through presumed heterosexual contact, 162 through heterosexual contact, 4 through IDU, and 21 through unknown means.[6]

In the Boston area, various attempts to mobilize the community for action have been short lived, and had limited results. The Haitian Youth Congress on HIV funded by the Massachusetts Department of Public Health has been the only successful community venture implemented between a collective of 3 Haitian youth organizations; however, this program was terminated due to budget reduction. In order to fill this identified gap in service coordination, and to provide leadership for comprehensive HIV prevention, the Center for Community Health, Education and Research (CCHER), in 1999, applied for and was funded by the Centers for Disease Control and Prevention (CDC) Racial and Ethnic Approaches to Community Health (REACH) 2010 as the leading agency on behalf of the Metro Boston HIV Coalition to reduce the HIV disparities in the Haitian population. Nevertheless, in order to be successful in this endeavor, the Haitian community providers in this coalition must first overcome the history of distrust, and create new practices of collective behaviors.

HAITIAN COOPERATIVE BEHAVIORS

Public health practitioners of the state and city government of Massachusetts have acknowledged the difficulties in working with Haitian providers to develop a comprehensive HIV prevention plan in Massachusetts. The absence of community coordination has resulted in the duplication of programs with disparate messages targeted to all subgroups in this community. The community response to HIV was truly not in proportion to the devastating impact of HIV in the Haitian community.

Empirical data derived from research on Haitian collective behaviors have demonstrated that Haitian immigrants in America tend to reproduce deep-rooted patterns of non-cooperative behaviors acquired from their experiences in Haiti.[7] The predominant mental models for cooperation support the view that Haitians are not to be trusted, and that the collective behaviors among Haitians are doomed for failure. That predisposition to disengage is manifested, even when agreements of cooperation have been signed and implemented.[8]

Commenting on the community's predisposition toward non-cooperative behaviors, Pean[9] suggested "that the Haitian history moved from hostility to hostility, revenge against revenge, feeding hate in all cleavage of the Haitian society." Fatton[10] concurred with the insight that "the persistence of old patterns of abuse are rooted in the early days of independence . . . they form the Haitian political 'habitus'—the system of 'dispositions acquired through experience' that shapes particular types of behavior.'" Pean[9] concluded that in the Haitian environment "made of hostitilities, confrontation, jealousy where the otherness is perceived as danger and where all actions are perceived as a threat, corrupted behaviors represent a derivative of social order" (translation offered).

Two independent community surveys, conducted by the CCHER, states that community leaders emphasized lack of trust and cooperation as major obstacles to the effectiveness of community initiatives in the Haitian community. As opposed to the well accepted concept of ethnic enclave in immigrant communities, the Haitian communities in the major urban areas are divided around social class, political affiliation, geographical positioning, and similar constructs. The deep-rooted patterns of distrust, the social class positioning, and the tendency for fierce competition between individuals, have combined to create conditions that effectively hinder community mobilization against the HIV epidemic.

In addition to this historical distrust, the discriminatory policies adopted by the FDA and the American Red Cross in classifying Haitians as at high risk for carrying HIV in the early 1980s have made it even more difficult to mobilize the Haitian community against HIV. The process of disengagement in HIV issues presents a significant challenge to securing the necessary motivation for community mobilization against the spread of HIV. It is from this background that the Metro Boston Coalition was designed, with the goal of creating the momentum necessary for change.

The Metro Boston REACH 2010 HIV Coalition is a coalition of health and social service providers, clinicians, consumers, epidemiologists, and community members mobilized to assess and respond to the identified gaps in HIV/AIDS services and prevention in the Massachusetts Haitian community (see Figure 1). The Coalition focuses on reducing HIV infection among Haitians in Massachusetts by designing, implementing, and evaluating a comprehen-

sive HIV prevention strategy in the Greater Boston area. Funded by the REACH program in stage I for the development of the community action plan, the coalition has been in existence for the last 5 years and has successfully developed a community action plan. How could this coalition of Haitian organizations, or Haitian public health professionals, be successful where others have failed over the years? What are the elements of this collaboration that could explain the success of this collective venture in this community?

Among other things, we have retained 4 main processes or elements that could explain the successful implementation of the coalition-building process in this community. Following is a brief description of the implementation of each of these processes, and an attempt to explain why these were essential in the successful implementation of the coalition in the Haitian Boston community. We have retained the following elements:

1. The creation of a community vision through a comprehensive needs assessment for HIV services and prevention;
2. Participatory leadership and joint accountability development;
3. An innovative working group model; and
4. The provision of capacity building to enhance our collective capacity.

Creating a Community Vision for Change

One of the ultimate goals of Reach 2010 Phase I was to engage a significant proportion of the community in a full assessment of our collective response to HIV. The needs assessment included: 14 key informant interviews with providers; group interviews with consumers; written surveys of HIV care and prevention providers; community surveys; community forums; a review of recent epidemiological, demographic and service utilization data for the state; and a literature review of recent research on AIDS among Haitians in Massachusetts. All data were compiled, analyzed, and incorporated into a community action plan.

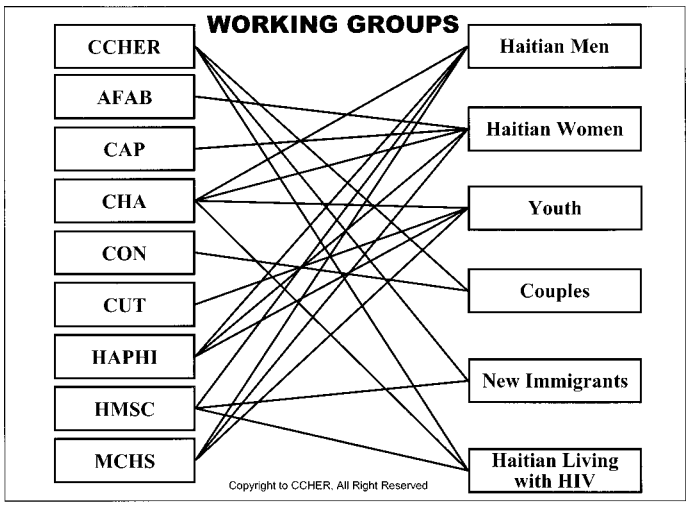

Fig 1. Coalition members

According to our assessment, AIDS mortality continues to cause silent casualties in the Haitian community. It affects the most productive members (average ages of 20–49 years) of the Haitian population. Many are recent immigrants who entered the United States with great expectations of upward mobility. Haitians remain a traditionally under-served population in Metro Boston, due to specific key characteristics that influence and exacerbate their risk of HIV. These include language, social and cultural characteristics, and the unique epidemiology of HIV in the Haitian community. Language issues create barriers for Haitians seeking and utilizing services, and receiving HIV/AIDS prevention, education, and services. There is a lack of linguistically appropriate services for Haitians, or other services that take into consideration the fact that a large proportion of Haitians are illiterate.

A coordinated and sustained approach to HIV prevention is our unique chance of dealing with the HIV epidemic. Appropriate written prevention and health care messages must be tailored to meet these linguistic needs of the community within Metro Boston.

The community action plan (CAP) addresses the unmet HIV prevention needs of Haitians affected by HIV in Metro Boston. This CAP includes a description of the size and characteristics of the Massachusetts Haitian population, identifies specific behaviors/modes of transmission that place Haitians at risk for HIV infection, and provides a list of recommendations to address unmet HIV prevention needs.

This process was essential in not only creating momentum for change, but also in presenting enough evidence of a community crisis to necessitate the pairing of resources and the coordination of disparate strategies on HIV prevention. In addition, this process was a non-risky endeavor in developing a working relationship and developing appropriate partnership. The success of this process was the development of a comprehensive community action plan, and a sound research plan, aimed at identifying and prioritizing the unmet prevention needs of Haitians in Massachusetts.

Effective Leadership and Joint Accountability Development

Studies of coalition development have identified effective leadership as an

important factor of coalition action and sustainability.[11] Effective leadership is defined as the ability to create and sustain participation and commitment, and to enhance coalition success in acquiring funding to sustain efforts.

The Center for Community Health Education and Research (CCHER) has the delicate responsibility of balancing a drive for coalition effectiveness, and sustaining the commitment and ownership of the coalition. Moving from planning to implementation represents the most delicate task of any coalition. Often the structures for planning are not adequate for implementation. How do we distribute resources among coalition members? Who will oversee the implementation of the programs? As the lead agency, CCHER needed to develop the structures of operations toward achieving the goal of the coalition.

The Center for Community Health Education and Research (CCHER), as the lead agency, has developed in partnership with coalition members' criteria for fund allocation, resulting in a competitive request for proposals that is open to all organizations serving Haitians. The request for proposals process defined the parameters for funding, and the expectations of all subcontracted agencies. A panel comprising primarily non-Haitian providers served in the review process. Eight subcontracts were funded, based on their current target population and area of expertise on HIV prevention.

The request for proposals process played the ultimate role of providing a level playing field for all partners of the coalition, diluting the concerns about equity and favoritism in funding allocations. However, this process had the unintended consequence of reinforcing the concerns over power dynamics between CCHER, as lead organization, and the other subcontractors, as members of the coalition.

The symbiotic relationship between the coalition and the lead agency is an inherent paradox.[12] It is imperative for the lead organization to foster commitment, which allows the coalition to develop some structure of mutual accountability between members. The working group model has been an innovative process of the coalition aimed at reinforcing commitment, coordination, and fostering joint accountability.

The Working Group Model

The working groups were designed as interagency collaborations of providers targeting similar sub-populations (Figure 2). Six working groups were convened to develop curriculum content tailored to meet the HIV preventive education needs of Haitian women, men, adolescents, individuals living with HIV, couples, and new immigrants.

Coalitions are believed to have greater effectiveness as they increase the time spent working toward common goals. The working groups played an important role in reinforcing commitment to the work, and increasing trust in the possibility of collective endeavors in this community. The relationship building that occurred during time spent on a common agenda decreased turf fights, and improved communication and a sense of group effectiveness. This sense of accomplishment has motivated the working groups to move from curriculum design to program implementation. Each working group is responsible for teaching the curriculum at all sites, thus guaranteeing uniformity of content and reinforcing the cohesion of the group.

The preliminary evaluation findings indicate that the working group process was successful in meeting the predetermined goals. Some of the key elements that made the working group experience successful were: 1) it allowed organizations to share information and expertise; 2) it provided an opportunity for agencies to become more acquainted with each other's services; 3) it provided a designated time for agencies providing similar services to reflect and create new ideas; 4) it provided an opportunity for agencies that had never worked together to develop a trusting relationship; and 5) it created leadership to guide future community-wide public health interventions.

The immediate result of the working groups was a curriculum developed by Haitians, tailored to meet the unique HIV/AIDS preventive education needs of Haitians. However, the broader accomplishment of the working groups was that the process provided the Haitian community with an opportunity to develop the capacity to mobilize local resources and to develop long-term collaborative relationships to address future public heath issues. The working groups demonstrated the power of Haitians coming together to accomplish a common goal. The evaluation data reveal that prior to participating in the working group, most of the participants had not worked together individually, nor had their agencies worked together on community-wide initiatives. Almost half the participants had never participated in a community-wide service planning effort. Participants who had participated in interagency advisory and planning group activities described the experience as less formal and less intense than the working group experience. As a result of the working group experience, participants expressed a desire to create interagency working groups to address other issues important to the quality of life in the Haitian community.

The working group process played a significant role in dealing with suspicion, mistrust, and doubt on the collaborative capacity of the coalition. However, the working groups have not lived up to their potential to generate innovative ideas around HIV prevention in the Haitian community. In order to increase the collective capacity to innovate, strategies to enhance individual skills and collective thinking have been developed, implemented, and evaluated.

Coordination of Capacity-Building Initiatives

Through the first stage of implementation, CCHER has dedicated sig-

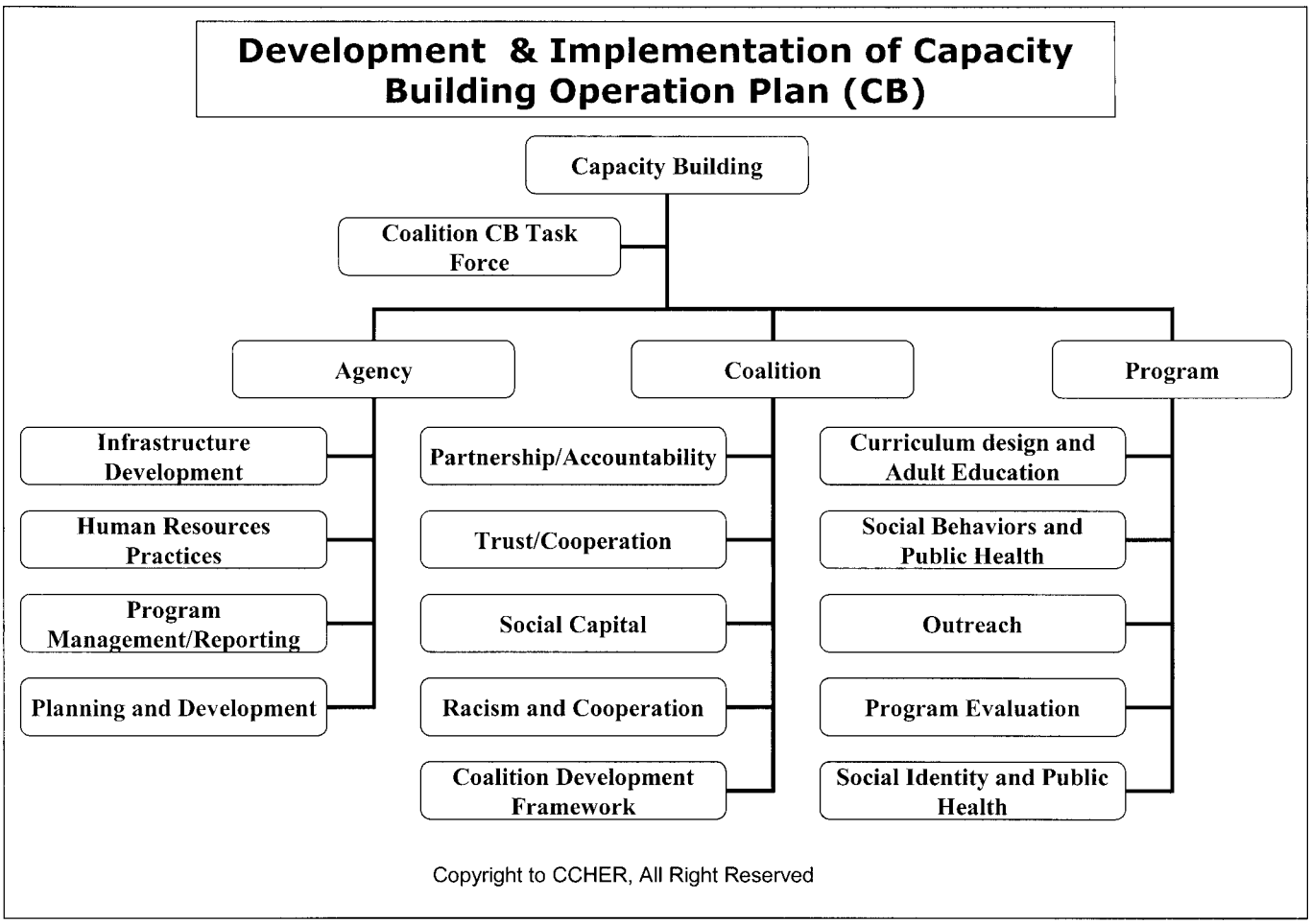

Fig 2. The working groups

nificant resources for management training, program development, and program evaluation. Capacity-building trainings have focused on theory of change, epidemiology and health planning, social and behavioral theory, financial management and human resources. Due to the fact that coalition partners are mostly grass roots organizations, a comprehensive capacity-building program had to be developed in response to both management issues and program development. A comprehensive capacity-building process also had to include a focus on coalition building and coalition effectiveness. The following 3 components were developed as part of the capacity-building process: program development, organizational management, and coalition development.

This dedicated plan for technical assistance and capacity building has been implemented and incorporated as part of the program implementation process. It has been assessed through the organizational analysis of the first phase of the implementation, during which most sub-contractors need specialized attention in program development and overall management capacity. Management development also represented a strategy to strengthen the partnership in the coalition, and lessen the tension between large organizations vs grass roots emerging entities.

Three levels of intervention have been identified and implemented:

1. Agency management development focusing on the general management practices, human resources, and program development at each organization;
2. Coalition program interventions: curriculum development, presentation and facilitation skills, social behaviors and public health practices, program evaluation; and
3. Coalition sustainment: partnership and accountability, cooperative and non-cooperative behaviors, social capital and trust, social capital and coalition building (see Figure 3).

Our coalition must continually assess its organizational strengths to remain viable. As we have learned, capacity building needs to focus on individual skill development, organizational development, and coalition building and sus-

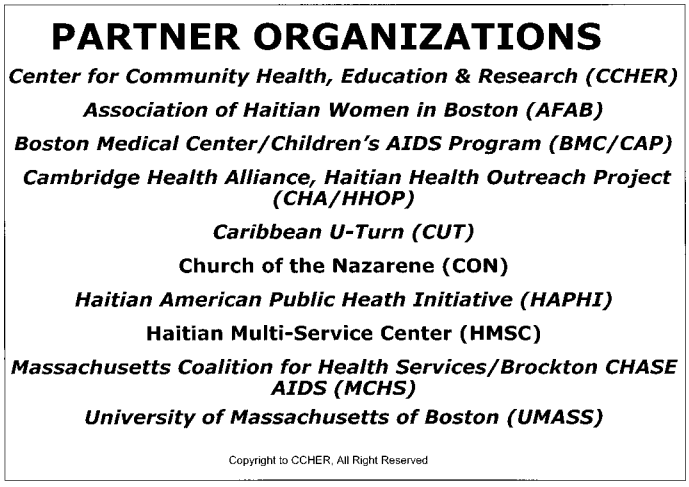

Fig 3. Overview of capacity building initiatives

tainability. The partnership with local technical assistance providers has significantly enhanced our capacity to respond to the identified needs of capacity building. However, the resources are limited to cover the growing needs for deeper dialogue on community empowerment, or to respond adequately to the emerging fundamental issues on coalition structure and sustainability.

DISCUSSION

As defined by many social scientists, coalitions represent inter-organizational alliances to advance common purposes. As a network of institutions, coalition effectiveness could be hampered not only by the limitations of each partner organization, but also by dynamics manifested in the development of meaningful relationships among the partner organizations. We have moved far from the idea that the simple act of bringing people together is sufficient to develop effective strategies in dealing with complex social problems. Creating a coalition, as we are presently learning, necessitates attention and nurturing to meet expectations of coordination, cross-fertilization, and innovation.

In the current article, we want to extend the discussion on coalition beyond the organizational factors that we know to negatively affect coalition effectiveness. We have known and understood that organizational barriers need to be overcome by sharing a common purpose, and by developing a stake for all organizational partners of the coalition. Proper facilitation skills, and the processes of visioning and planning, are known to be helpful in effectively dealing with power struggles, and, further, help define structures and accountability. In the context of the Haitian community, while all those organizational barriers remain serious challenges, they are nonetheless insufficient to deal with the deep-rooted patterns of distrust based on social classes, geographical provenance, and political affiliations.

A greater understanding of the structured sociological limitations on organizing is essential in developing a proper framework to facilitate dialogue dealing with the group's instinctive inclination to derail collective endeavors. Current dialogue and research on the social dimensions of organizing could provide currency in America to the beleaguered social constraints that have limited the formation of institutions in many developing nations, such as institutional distrust, divisiveness, and social classes. Those same constraints limit the effectiveness of institutional and other collective behaviors of immigrant groups in the United States.

The development of coalitions to respond to public health challenges provides an essential vehicle to developing partnerships, and mobilizing community leaders in sharing accountability for the health outcomes in their respective communities. For the Haitian REACH 2010 Coalition in Boston, we have witnessed the impact of the group synergy in HIV prevention. The HIV media campaign is a definite result of this coordinated effort to develop a comprehensive message about HIV prevention. Participation in HIV workshops by community participants is constantly increasing, and the level of community dialogue on HIV and HIV prevention has definitely increased, as witnessed by the media leaders in Boston.

We have made significant progress in creating an environment for dialogue, and in assessing our shortcomings in the fight against HIV. The working group model creates the necessary mechanism for sharing knowledge, building relationships, and developing trust, the instrumental element in all collective behaviors. We have moved beyond our starting point to realize that we can do even more.

Once the expectations have been raised, we must meet the new demands. We must find appropriate answers to the new challenges about balance of power, rotation of leadership, involvement of the media, and bringing the community dialogue and ownership to a deeper level of community empowerment.

The sense of cohesion, and the level of commitment, were achieved with foundational work on trust, and the development of processes to deal with the historical distrust. The understanding of those sociological limitations to organizing and collective action in the Haitian community was essential in the development of processes and structures for joint accountability and partnership building. This work is ongoing, and will

require additional attention to the development of each individual organization in meeting its potential. An emphasis on each individual partner's sense of autonomy and survival will, in fact, guarantee the sustainability of the coalition.

There is a growing expectation that the coalition will serve as a community planning body for all HIV-related services for the Haitian population. While we are deeply convinced that this coalition has taken the right path to undo our the community's deep patterns of non-cooperative behaviors, our ultimate success will be measured by how well we design and implement successful programs that significantly alter high risk behaviors in this community, and reduce the rate of HIV infection in the Greater Boston area.

REFERENCES

1. Minkler M, ed. *Community Organizing and Community Building for Health.* New Brunswick, NJ: Rutgers University Press; 1997.
2. Brown P, Mikkelsen EJ. *No Safe Place: Toxic Waste, Leukemia, and Community Action.* Berkeley, Calif: University of California Press; 1990.
3. Butterfoss FD, Goodman RM, Wandersman A. Community coalitions for health promotion and disease prevention. *Health Educ Res.* 1993;8(3):315–330.
4. Butterfoss FD, Goodman RM, Wandersman A. Community coalitions for prevention and health promotion: factors predicting satisfaction, participation, and planning. *Health Educ Q.* 1996;23(1):65–79.
5. The Metro Boston Haitian REACH 2010. *Coalition: Haitian Community Survey Report.* 2004.
6. Massachusetts Department of Public Health. *AIDS Surveillance Unit Data Report.* September 2003.
7. Metayer N. *The Politics of Marooning: Trust and Distrust in the Haitian Community* [research paper]. Cleveland, Ohio; Wheaterhead School of Management, Case Western Reserve University; 2002.
8. Metayer N. *Jan'l Passé, l'passe: The Haitian Organization in the Landscape of America* [doctoral dissertation]. Cleveland, Ohio: Wheaterhead School of Management, Case Western Reserve University; 2003.
9. Pean LJR. *Economie Politique de la Corruption: De Saint Domingue a Haiti 1791–1870.* Port-au-Prince: Editions Memoire; 2000.
10. Fatton R Jr. *Haiti's Predatory Republic: The Unending Transition to Democracy.* Boulder, Colo: Lynne Rienner Publishers; 2002.
11. Goodman RM, Wandersman A, Chinman M, Imm P, Morrissey P. An ecological assessment of community-based interventions for prevention and health promotion: approaches to measuring community coalitions. *Am J Community Psychol.* 1996;24(1):33–61.
12. Chavis DM. Building community capacity to prevent violence through coalitions and partnership. *J Health Care Poor Undeserved.* 1995; 6(2):234–244.