

PARTICIPATION OF LATINO COMMUNITY-BASED ORGANIZATIONS IN THE RWCA PROCESS: A STUDY OF TWO METROPOLITAN AREAS

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Abstract

This study examines implementation of the Ryan White CARE Act (RWCA) in two Title I jurisdictions in order to better understand the participation of the Latino community in the Planning Council decision-making and allocation processes. Data were obtained from two Eligible Metropolitan Areas (EMAs) through surveys and a total of 27 in-depth, in-person interviews with executive directors and HIV/AIDS service staff from 14 Latino community-based organizations, Planning Council Chairs, RWCA Title I Administrators, and HRSA Project Officers. Results provide insight into the factors that facilitate or hinder effective participation of the Latino community in the RWCA process and highlight the need for support in the building of infrastructure and capacity within Latino agencies. This analysis also contributes to the growing literature addressing the processes of coalition-building.

Keywords: HIV/AIDS, Ryan White Care Act, Latino Services, Coalitions, mediating institutions

INTRODUCTION

A central theme in sociologic inquiry over the past 40 years has been the participation of marginalized groups in policy development and implementation. Resource mobilization theory suggests that individual and institutional resources such as time, money, influence, or expertise are key elements in policy implementation and change. (See, for example, McAdam, McCarthy, Zald 1996; Tilly, Tilly 1981; McCarthy, Zald 1977.) The age, size, and structure of an organization are also key factors in its ability to participate in and influence public policy—especially when these organizations represent communities of color (Minkoff 1995, 1997).

One of the recent policy initiatives that have the specific goal of increasing participation of marginalized groups in public policy development and implementation is

The Ryan White Comprehensive AIDS Resources Emergency (CARE) Act. This article explores the effort to increase participation by Latino community-based organizations in local community planning, priority setting, and service coordination for individuals and families with HIV/AIDS under the provisions of the Ryan White Comprehensive AIDS Resources Emergency (CARE) Act.

The article begins with a brief description of the CARE Act and the research methodology used in the study. Key findings are presented. The article concludes with a discussion of the ways in which the CARE Act increased representation, participation, and capacity for Latino community organizations, as well as discussion of the obstacles to more meaningful and effective participation.

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Background of the Ryan White CARE Act

The Ryan White Comprehensive AIDS Resources Emergency (CARE) Act (Ryan White Comprehensive AIDS Resources Emergency Act, 1990) is one of the largest and most recent federally funded health initiatives that require local community planning, priority setting, and service coordination. This legislation was enacted to improve the quality and availability of care for individuals and families with HIV-related disease. One specific goal of the Ryan White CARE Act (or RWCA, as used in the rest of this paper) was to improve access to needed services for under served populations with HIV/AIDS. Established to finance comprehensive systems of care for people living with HIV/AIDS, the RWCA prescribes broad participation by affected communities in much the same way as required for the federally-funded Health Systems Agencies (HSAs), which evolved over 20 years ago. Just as the HSAs invited scrutiny regarding the extent to which required representation actually occurred and was meaningful (see Marmor Morone 1980), so too have the Title I Planning Councils and Title II Consortia established under RWCA invited close assessment regarding the extent and impact of participatory planning. Title I of RWCA provides direct assistance to Eligible Metropolitan Areas (EMAs) with the largest number of reported AIDS cases as determined by a statutory formula. All Title I-funded EMAs must have a Planning Council made up of a diverse range of consumers and providers representative of the people affected by the epidemic and their service needs. Title II of RWCA provides assistance to all states to improve the quality, availability, and organization of health care and support services for people with HIV/AIDS and their families. Among its components is a mechanism for states to develop local service planning and coordination consortia. A review of the consortium process is particularly crucial now because RWCA faces the end of its first

decade, its second reauthorization cycle, and rising challenges to its programs' responsiveness to the needs of affected populations (Kierler, Rundall, Saporta, Sussman, Keilch, Warren, Black, Brinkley, Barney 1996). Among the many recent indications of challenges to the inclusiveness and responsiveness of RWCA programs have been the 1998 Congressional Black Caucus' initiative on HIV/AIDS and the 1999 General Accounting Office program and fiscal audit report requested by the U.S. House of Representatives.

This article focuses on one particular aspect of representation and participation in RWCA activities: the experience of the Latino community as exemplified in two Title I EMAs. This analysis contributes to the growing literature that reviews implementation of the RWCA (Bowen, Marconi, Kohn, Bailey, Goosby, Shorter, Niemcryk 1992; Mor, Fleishman, Piette, Allen 1993; McKinney 1993; Marconi, Rundall, Gentry, Kwait, Celentano, Stolley 1994; Health Resources and Services Administration 1996) by providing a perspective from a particular community of color living with the challenges of HIV/AIDS. It is thus specifically responsive to a national call to diversify research and evaluation efforts focused on HIV/AIDS service planning and delivery participation under the RWCA (Weissman, McLain, Hines, Harder, Gross, Marconi, Bowen 1994).

The Latino Community, HIV/AIDS, and the RWCA

The Latino community in the United States has been disproportionately affected by HIV/AIDS. Although Latinos represent only 10 percent of the national population, they made up a disproportionately high 17 percent of Americans diagnosed with AIDS during the year of this study (Centers for Disease Control and Prevention, 1994). Furthermore, the annual AIDS rates for Latino men (145.9), women (32.2), and children (3.6) have been significantly higher than those for non-Latino white men (57.3), women (5.0), and children (0.4)

since the early 1990s. In addition, studies regarding the Latino population have indicated for some time that they are more likely than non-Latino whites or African-Americans to lack access to health care (Ginzberg, 1991).

In its *1992 Report on Communities of Color* (National Commission on AIDS 1992), the National Commission on AIDS identified four critical barriers that prevent Latinos with HIV/AIDS from obtaining needed services: 1) low rates of health insurance coverage; 2) linguistic and cultural barriers in accessing care in the health delivery system; 3) lagging knowledge and continued misconceptions about HIV/AIDS and its treatment; and 4) attitudes about HIV/AIDS that may place Latinos at greater risk for infection and for delay in seeking care.

Creating yet a further challenge to the development of accessible and appropriate services for Latinos with HIV/AIDS is the fact that the Latino community is not a monolithic population. Country of birth and place of residence in the United States both contribute to major differences observed in the epidemiology of HIV/AIDS among Latinos (Diaz, Buehler, Castro, Ward 1993; COSSMHO 1991). In addition, there are significant variations in Latinos' approach to and receipt of health care. Finally, the experience of both legal and illegal immigration has shaped Latinos' trust and interaction with health care providers. These factors, along with those noted by the Commission, have critical implications for the development and implementation of appropriate HIV/AIDS prevention and care programs for Latinos in this country.

Encouraging the development of culturally competent and accessible HIV/AIDS health care providers is thus crucial to the successful abatement and treatment of the epidemic among this population. The availability of RWCA resources, as well as its concomitant obligations for representative and participatory planning processes, creates the opportunity for developing tar-

geted and responsive models of health care. While non-Latino agencies certainly play an important role in addressing the HIV-related needs of Latinos, Latino community-based organizations (CBOs) are uniquely situated to deliver HIV/AIDS-related care effectively because they provide services in culturally and linguistically appropriate settings. Moreover, Latino CBOs in different regions of the country are aware of the epidemiologic characteristics of their local communities regarding HIV/AIDS. Therefore, the expansion of their role under RWCA funds is a necessary and critical component of an effective response to the hard-hit Latino community.

Latino CBOs have been involved in responding to the HIV/AIDS needs of their local communities for over a decade; many were active well before government funding became available to support HIV/AIDS prevention and care efforts in ethnic minority groups. The extensive efforts of these CBOs have been documented by the National Commission on AIDS (National Commission on AIDS 1992) and other groups (Amaro, Gornemann 1992; Singer, Castillo, Davison, Flores 1990; Latino Health Network 1989). Nevertheless, as the Commission also noted, Latino CBOs have often been at a particular disadvantage in their ability to accrue the resources and support necessary to mount an effective response in their communities, even after the passage of RWCA:

The Hispanic/Latino community is still facing tremendous programmatic challenges in its response to the HIV epidemic. Hispanic/Latino organizations have had difficulties in accessing the financial resources needed to operate successful HIV/AIDS programs . . . They lack experience in accessing current information about funding sources. Other organizations because of limited infrastructure, insufficient work force, and limited management expertise, also lack the capacity to successfully respond to requests for proposals. Thus, even when organizations have received information about funding opportunities, they may also need technical assistance in order to submit a

competitive proposal. (National Commission on AIDS 1992, p.44).

The current study was undertaken to delineate further the concerns raised by the National Commission regarding Latinos' participation in and benefit from the implementation of RWCA. The study design was also informed by the 1992 research recommendations of the HIV/AIDS Workgroup on Health Care Access Issues for Hispanics convened by the federal Health Resources and Services Administration, which administers RWCA (Health Resources and Services Administration 1991). The Workgroup recommended research on three questions: 1) Does a more representative and open planning council process result in increased access to RWCA services by diverse populations?; 2) Does involvement of Hispanic organizations on HIV planning councils result in allocations that target care to Hispanic communities? and increased use of existing Hispanic medical, home care, housing, food, and other services?; and 3) Are planning councils representative of the Hispanic communities they serve more effective in filling existing gaps in HIV/AIDS services in that community?

Specifically, by looking at the experience of Latino CBOs in two Title I EMAs, this study seeks to provide a more detailed assessment of the barriers to effective participation faced by Latino CBOs in the planning and delivery of HIV/AIDS health care services through RWCA.

METHODS

Study Period and Description of Study Sites

The study was conducted during 1994. The data presented below on the communities where the study took place are for the years of the study.

The particular sites were selected for two major reasons: They reflected both the diversity of the American Latino community and the varied dynamics of the HIV/AIDS epidemic among Latinos, and they were of suitable size to facilitate com-

pletion of the study within a relatively short period of time. For this reason, medium-sized EMAs rather than large EMAs such as New York City or Los Angeles were selected. In order to protect the confidentiality of individuals in participating sites, the EMAs are referred to as Site X and Site Y.

Site X was a single county EMA with a population of 2.6 million comprised of the following ethnic/racial groups: 55 percent non-Latino white, 20 percent Latino, 8 percent Asian or Pacific Islander, 6 percent African-American, one percent Native-American, and 10 percent Other. As of January 31, 1994, 5,483 cases of AIDS had been reported in this EMA, with 73 percent of cases reported among non-Latino whites, 15 percent among Latinos, 10 percent among African-Americans, 1 percent among Asians and Pacific Islanders, and less than 1 percent among Native-Americans. About 79 percent of the Site's AIDS cases were reported among gay men, 8 percent among injection drug using (IDU) gay or bisexual men, and 7 percent among IDU individuals who were not gay or bisexual men. Five percent of all reported AIDS cases occurred among women and six percent among children. Unlike the national case reports, Latinos in this EMA appeared to be under-represented among those diagnosed with AIDS; however, during the study year, Site X noted in its RWCA application that under-reporting of Latino AIDS cases was suspected.

The Planning Council in Site X at the time of the study was comprised of 30 members, among whom 47 percent were persons of color and 30 percent were persons living with HIV/AIDS. To promote community involvement, the Planning Council gathered data through the following means: an annual client and provider needs assessment survey conducted by the County AIDS Office in the local health department; widely publicized general community meetings; and focus groups led by community members. County AIDS Office staff reported the data and recom-

mentations from these sources to the Planning Council, which presented service-funding recommendations to the Board of Supervisors. Health department staff developed the contracts, negotiated final contracts with the selected agencies, and monitored the signed contracts.

Site Y had a population of 4.2 million persons. The population was comprised of 73 percent non-Latino white, 10 percent Latino, 15 percent African-American, 2 percent Asian or Pacific Islander, and less than 1 percent Native-American. As of December 31, 1993, a total of 3,174 AIDS cases had been reported within this EMA, with 54.2 percent of AIDS cases reported among non-Latino whites, 9.8 percent among Latinos, 35.3 percent among African-Americans, and less than 1 percent among Asians/Pacific Islanders and Native-Americans. About 54.2 percent of the EMA's AIDS cases were reported among gay men, 3.2 percent among IDU gay or bisexual men, and 25.1 percent among IDU individuals who were not gay or bisexual men. Sixteen percent of all AIDS cases occurred among women and 1.5 percent among children.

The Planning Council in site Y had 31 members, of whom 19 percent were African-American, 13 percent Latino, 3 percent Asian/Pacific Islander, and 37.5 percent individuals self-identified as living with HIV/AIDS. The planning process included a needs assessment conducted by the Public Health AIDS Program of the local health department and overseen by a subcommittee of the Planning Council. Additional data were gathered through public hearings. The Planning Council reviewed the assessment data and prioritized categories of needed services. The Public Health AIDS Program developed a request for proposals (RFP) based on these recommendations and conducted a review process with a committee selected by Program staff and approved by the Chair of the Planning Council. Staff of the Public Health AIDS Program developed contracts after reviewers selected the agencies recommended for funding.

Procedures

In order to study the participation and planning process in each site, a combination of methods were used including a survey questionnaire mailed to Latino CBOs and interviews with individuals.

Agencies were mailed a survey questionnaire, and open-ended interviews were conducted with persons who met different criteria: 1) two individuals from each agency participating in the study (e.g., the agency executive director and the HIV services coordinator or the direct services coordinator); 2) the Planning Council Chair; 3) the Title I Administrator; and 4) the HRSA Project Officer for each EMA. Interviews lasted from 40 minutes to one hour and 45 minutes. (Interviews with non-funded sites required less information and tended to be shorter.) With the exception of 5 interviews conducted by telephone, interviews were conducted in person at each site.

Sampling Plan

The universe from which the sample of agencies was drawn in each EMA consisted of 17 nonprofit health and human services CBOs that met all of the following criteria: 1) the client population was at least 51 percent Latino; 2) the Board of Directors was comprised of a minimum of 50 percent minorities; 3) the agency was identified in the community as a Latino agency; and 4) the agency provided services to persons with HIV/AIDS or who were at high risk for HIV/AIDS.

To identify all potentially eligible CBOs, two steps were taken. A complete list of all agencies that were members of the Coalition of Hispanic Health and Human Services Organization (COSSMHO) in each EMA was obtained, and calls were made to local agencies on the list in order to identify agencies not on the original list. Calls were made to all potentially eligible agencies in order to ascertain if they met the criteria for participation. Of the 17 eligible agencies, 14 (82 percent) agreed to participate.

Agencies in each EMA were selected to represent 1) agencies that did not apply for

Title I funds in 1992 (in order to assess barriers in applying for and receiving Title I funds); 2) agencies that applied for, but did not receive, Title I funds in 1992; and 3) agencies that received Title I funds in 1992.

Description of the Sample

As shown in Table 1, survey questionnaires were completed by 12 of the 14 agencies that agreed to participate (86 percent), and interviews with agency executive directors were conducted with 12 agencies (86 percent). An additional 15 interviews (total = 27 interviews) were conducted with other agency staff and RWCA Title I personnel. Of the 14 participating agencies, survey information is missing for two, and interview information is missing for two others.

In Site X, all six eligible agencies agreed to participate (100 percent). Three of the agencies received Title I funds in 1992, whereas the other three had never applied for Title I funding. No Latino CBOs were identified that had applied for but did not receive Title I funds in 1992.

In Site Y, 8 of 11 (73 percent) eligible agencies agreed to participate; three refused to participate. Of the eight participating agencies, two had received Title I

funds in 1992, one had applied for but not received funds, and five had not applied for Title I funds in 1992. The three that refused to participate were agencies that had not applied for funding. Seven of the eight participating CBOs returned the self-administered survey questionnaire. One executive director was unavailable for interview.

Instruments

Data were gathered through a 16 page close-ended survey questionnaire completed by each agency's executive director or designee and in-depth interviews conducted with the executive directors, HIV/AIDS services agency staff, Planning Council Chairs, RWCA Title I Administrators, and HRSA Project Officer. All instruments were designed by the research team and revised according to results of a pilot test and the suggestions of project advisors.

Survey data included the number and composition of agency staff, clients, and board directors; a description of available services, including those which were HIV-specific; the total budget, including RWCA Title I funds; services funded by Title I during the period 1991-1993; and HIV-related policies established by the board of directors.

Table 1. Sources of Data from Each EMA

	<u>Site X</u> <u>N</u>	<u>Site Y</u> <u>N</u>	<u>TOTAL</u> <u>N(%)</u>
Agencies in Sample	6	8	14
Agencies with Completed Surveys	5	7	12 (86)
Agencies with Completed Interviews			12 (86)
Executive Director	6	6	
Services Director*	4	5	
Council Chair	1	1	
Title I Administrator	1	1	
Project Officer	1	1	
Total Interviews	13	14	

*In most agencies the interview was conducted with the HIV/AIDS Services Coordinator. When no such position existed, the Direct Services Coordinator and/or Substance Abuse Services Coordinator were interviewed.

The interview protocol asked participants to discuss the following: 1) agency background and history; 2) participant's knowledge of and experience with the Title I application process in the local area — including degree of participation, obstacles experienced, technical assistance received, and efforts to include the Latino community; 3) the impact of Title I funding on agency systems and capacity (this, for funded agencies only); and 4) suggestions for making the Title I planning and funding process more responsive to the needs of Latino CBOs. The interviewer kept detailed notes on each respondent's answers and recorded other observations made during the interview and agency visits.

Approach to Data Analysis

Data from survey questionnaires were coded, and analysis focused on descriptive characteristics. Qualitative data from interview notes and field notes were used to identify common themes and unique issues that emerged across sites and between funded and non-funded agencies. Analysis of interview data focused on identifying 1) intra-site differences and discrepancies in responses obtained from the respondents; 2) inter-site differences and similarities in information obtained; and 3) differences and similarities in responses from funded and non-funded agencies. Two research staff reviewed the interview data to verify categories developed for the interview data. A database for each interview question was prepared so that responses could be compared for different agencies, sites, and type of respondent, as well as by whether a given agency applied for or did not apply for funds. All interviews were reviewed to identify the major factors that affected the application, funding, and procedural experiences for agencies.

RESULTS

Description of Agencies

The sample included a broad array of agencies: five multi-service agencies, three

health/medical facilities, a substance abuse treatment center, three agencies that focus primarily on HIV/AIDS advocacy, care services, and prevention education, one agency that provides housing development, and one agency that provides services for immigrant women.

Ten of the 14 agencies (71 percent) had been providing services to their communities for over 20 years and represent well-established organizations. The remaining four agencies (29 percent) were established from the mid-1980s through 1991. The budgets of the 14 agencies varied greatly in resources and scope. The 1993 operating budgets ranged from \$245,300 to more than \$8 million, with a median operating budget of \$750,000.

Agencies varied significantly in the number of full-time staff members (ranging from 0 to 250 staff members, median = 25). In most agencies, the majority of the staff were Latinos; in ten agencies (83.3 percent), at least 70 percent of the staff was reported to be bilingual.

Together, the agencies served 126,555 clients in 1992, with the number of clients served by each agency ranging from 82 to 31,287. On average, more than half (62.3 percent) of the clients served by these agencies were monolingual Spanish speakers with little or no ability to communicate in English.

A total of 6,215 clients with HIV/AIDS were served by the agencies; they represent from 1 percent to 44 percent of the census at each site. The majority (86.2 percent) of clients with HIV/AIDS were Latino, of whom most were Puerto Rican (82.2 percent) and male (82.6 percent); they ranged in age from 20 to 60. Clients with HIV/AIDS were somewhat more likely (67.7 percent) to be monolingual Spanish speakers than other clients served in these settings (62.3 percent).

Eight of the 14 agencies in the sample had applied for RWCA Title I funds prior to 1994, the year the study was conducted; their success rate is summarized in Table 2. A total of five Latino

agencies, three in Site X and two in Site Y, had been funded by the end of 1993 for a total of \$586,000. This represented 12.3% of RWCA Title I allocation in Site X and 3% in Site Y.

Table 2

Total Dollar Amount and Percent of Title I Funding Received by Latino Agencies (1991-1993)

(N = 12 Agencies)

Year (N)	Site X (%)	Site Y (%)
1991 (2)	\$141,000 (9.7%)	\$0 (0%)
1992 (4)	\$316,138 (11.4%)	\$38,400 (1.4%)
1993 (5)	\$462,459 (12.3%)	\$124,240 (3%)

Information on Title I funding awarded to the sites was provided by HRSA; information on funding received by Latino agencies was obtained through the agency survey questionnaires.

Interview Findings

The major challenges faced by respondent agencies in becoming effective contributors to the planning and delivery of RWCA services centered around four core areas of the program: representation, participation, capacity building, and administrative process. The following sections summarize the findings from 27 interviews conducted with the staff of Latino CBOs and RWCA personnel drawn from the two sites. (See Table 1 for a breakdown of interviews by site.)

1. Motivation for Becoming Involved with the CARE Act Programs

Before examining the difficulties Latino CBOs faced in Title I activities, it is important to appreciate their motivations for becoming involved in and seeking funding from RWCA programs. Like agencies working with other affected communities, Latino CBOs expressed a diversity of compelling interests. Most felt their organizations had an obligation to respond to the challenges of the epidemic in their communities. Some were concerned about apparent discrimination and inadequate care-giving experienced by Latinos with

HIV/AIDS in existing service settings; others were looking for funds to expand the capacities of their existing institutions.

Some reported wanting to "help Latinos and kids" meet "the needs of the community" . . . "the patients." Others, like two of the primary care sites participating in the study, wanted to be able to address the increasing caseloads their programs were facing. One setting "had an HIV specialty [clinic] and wanted to increase outreach"; another site "wanted to develop a satellite clinic."

Some agencies, particularly in Site Y where there were few Latino-specific services, were particularly concerned about the quality and the cultural sensitivity of the existing "Anglo" programs serving Latinos with HIV/AIDS. In one case, an agency was developing a new counseling program because the local program serving Latinos had "done a terrible job doing HIV testing."

Like organizations responding to other populations hard hit by HIV-related disease, Latino CBOs had motivations that were informed both by particular community experiences and consciousness and by real institutional needs and burdens.

2. Representation: Understanding, Access, and Respect on the Title I Planning Council

From some of the earliest analyses of RWCA implementation, the challenges of creating diverse Planning Councils have been noted (Bowen et al. 1992; Mor et al. 1993; McKinney 1993; Salem, Horwitz, Lennihan 1992). The under-representation of affected people of color has been characterized frequently (Marmor, Morone 1980; National Commission on AIDS 1992; Weissman, Wolfe, Viruell, Ortiz, Torres, Hughes, Shelton, Worth 1995). This is a critical concern, because, as in other community planning processes, there is an intricate web among representation, participation, and acquisition of funds for particular organizations or population bases (Marmor, Morone 1980; Marconi et al 1994; HRSA 1996). As stated by one respondent in this study: "If you're not in

the loop and are new, you won't know about the funds."

Interviewees identified problems of representation at multiple levels of RWCA process: Lack of a critical mass of Latinos in the Title I Planning Councils had an effect both on the knowledge base in the local Latino community and on the internal operations of the Councils themselves. When there was little or no Latino representation, Latinos and their CBOs were unfamiliar with the "key players" in the local RWCA structure and had little knowledge of the planning and funding application processes. The counterparts who knew and had frequent contact with many of the "key players", including Planning Council members, who understood the planning and application processes, and who, in many cases, had already received Title I funds, were almost all from CBOs that had representation on the Council itself.

Although the effects of under-representation on community awareness, knowledge, and Latino CBO funding were seen in both sites, interviewees reported a considerably more responsive situation in Site X. In that site, there was more Planning Council outreach to community groups and consumers, including Latinos; more involvement in the community via focus groups and other mechanisms; and greater efforts to involve different constituencies in all levels of the process.

Lack of representation on the Title I planning groups also affected the internal function of both Councils. The diversity of the planning members had implications for what issues were given top priority and what services were funded. Respondents felt that the needs of immigrants, women, and children, especially those from minority communities, were insufficiently addressed in the planning process. Similarly, they reported that support services identified as essential within the Latino community, particularly transportation, childcare, and housing, often went unfunded.

Along with the impact on prioritized services, study respondents detailed lin-

guistic, cultural, and affective aspects of the effects of under-representation in their planning groups. Most meetings were monolingual in English; there were no translation services; and "AIDS-speak" was prevalent, further compounding linguistic problems. Meetings could feel "hostile." One respondent reported that the Planning Council "... is not a welcoming atmosphere." And, especially for people with English as a second language, the gatherings could be incomprehensible: "People talk with acronyms all the time."

Title I administrators and Planning Council Chairs did not always concur with the perspectives of the Latino CBOs in their areas. In Site X, for example, these respondents considered the Latino input to be substantial and the process inclusive and responsive. In Site Y, there was agreement among the Title I administrators and chairs that the "Planning Council is not diverse," but among this group there was concomitantly a perspective that the process itself was "well organized" and did ultimately address the needs of different communities in its final decision-making. Two of these respondents were apparently unable to differentiate in their answers between the concerns of the Latino community and other communities of color; this suggests that these administrators and chairs may be conflating responsiveness to at least one minority constituency with inclusiveness of all.

3. Participation: Power Relations in the Council and in the Funding Process

Representation on the Council was only the first step of shaping the participation of Latino CBOs in both RWCA planning and funding processes. Once involved, Latino Planning Council participants and other colleagues in the community perceived serious obstacles to their ability either to have Latino concerns heard or to affect the historical allocation of resources. Not unlike the experience of participants in the HAS planning groups twenty years ago, CBO respondents encountered entrenched patterns of decision-making: "The agencies that initially took over are holding

tight to the power." Said another interviewee: "Power is the name of the game."

Power was differentially reported to be situated in various key players, provider agencies, or affected populations. In Site X, health care agencies and their providers dominated the local RWCA process and funding acquisition. Community-based organizations providing economic, social, and other systems of support were reportedly "left out in the cold." In Site Y, respondents perceived funding and decision-making to be closed to all but a few constituencies. Said one respondent: "Planning needs to get away from the universities." Another commented that "the power of the gay community is asserted and controls the process." Interviewees noted that feeling excluded from meaningful participation in the planning process was discouraging to Latino agencies, even to those that had received Title I funds.

The dominance of one or several constituencies in the Planning Council was seen as intimately affecting the flow of dollars to CBOs. Agencies with a "track-record" tended to be the ones that received Title I dollars. They were also usually the ones that had previously been funded and those that held membership on the planning groups. As one respondent characterized the situation: "The Council picks agencies it knows, not new agencies." In circumstances where the historically funded agencies were primarily health care facilities, the allocation practices led social and other non-health providers or community-specific CBOs to believe they were not eligible for Title I grant funding.

Sometimes patterns of funding reinforced perceptions that preferably, or only, large and well-established agencies could become RWCA providers. Illustrating this perspective, one respondent indicated that his Planning Council "tenía principios que parecían un mantra [had guidelines that seemed like a mantra]: 'large before small, old before new'."

Some of the five Latino agencies that had received Title I funds felt that the

process had been responsive to them, usually because they fell into the category of large and well-established CBOs and had been able to become an insider by having a representative on the Planning Council. As one funded Latino agency said, things went well "because our agency is well known and part of the process." Nevertheless, even when Latino and other minority, small, or non-health care-providing CBOs did receive RWCA dollars, respondents often perceived the Council process and decision-making as superfluous. As one respondent noted, the historically funded [big] agencies "get the funds and throw some small funds to other agencies." Other respondents agreed with one Latino CBO representative who said that the Planning Councils seemed to have "an unspoken agreement" about how to allocate resources. Concomitantly, they felt that community meetings and public discussions about funding priorities were a sham, held to "show that the Council is politically correct."

Whether or not these perceptions are fully accurate is less important than the extent to which they speak to the inability of the RWCA Councils to build a sense of inclusive, responsive, and effective participation within the Title I planning and funding activities.

4. Capacity Building: Making Representative Service Provision Possible

Capacity building issues emerged for respondents in their discussions about infrastructure in Latino CBOs, especially as such issues affected the competitiveness of those organizations in the Title I funding process. It should be noted that there are also capacity building concerns relevant to the effective function of Title I Planning Councils themselves. In this study, however, when interviewees described capacity problems, they were discussing the serious barriers faced by Latino CBOs who wanted to become effective and competitive RWCA providers.

The most frequently noted problems were associated with the threshold capaci-

ty needed to apply for the Title I grant funds. Many agencies experienced the application process as difficult and complex, problems that were often compounded by short turnaround timeframes. Although the burdens of these structural requirements fell more heavily on small or less experienced agencies, even the larger Latino CBOs faced challenges with the application process. It was often difficult to shift the existing work-loads of agency staff to accommodate the grant development and writing needs. Other agency obligations suffered: "[It] requires staff to write proposals and be taken away from regular jobs."

Even for those Latino CBOs that had the funds to hire a grantwriter, the Title I application effort exacted fiscal and administrative tolls on their organizations. Though perhaps more established and financially secure than their smaller counterparts, these Latino organizations were often over-burdened and under-funded for their existing program activities. Said one respondent: "We had to hire someone to write the grant. The process taxed the agency. It would have been impossible for a new agency with less experience writing grants."

Most respondents noted that technical assistance at the point of application would address some capacity problems in newer and smaller agencies and would help to increase the competitiveness of Latino CBOs. Recommended support included: grant writing training; assistance in identifying experienced grant-writers; and accessible and responsive technical and other advice from Title I administrative staff during grant preparation.

Once funded, there continued serious concerns about ongoing capacity for new service provision. Respondents indicated that administrative and overhead costs associated with Title I HIV/AIDS service provision were insufficiently funded; this was a more serious concern in Site Y where the Planning Council had decided not to fund indirect costs at all. Under-

funding administrative support disproportionately affects those newer and smaller agencies that have yet to develop a sustainable infrastructure.

Further stretching the capacities of many of the CBOs was the fact that proposed HIV/AIDS services were often only partially funded. This partial funding of planned services and the absence or underfunding of associated overhead costs put some agencies in precarious positions. Having made a commitment to HIV-related care, these CBOs found they were putting at risk the stability of the rest of their organizations by creating yet another circumstance where their agencies were performing tasks for which they were under-funded. The consequences, as one individual explained, are that CBOs commit to more than they can do, staff get burned out, and, as a result, the scope and quality of the service provided declines—it becomes, at best, a "band-aid."

5. Administrative Procedures

Though many of the challenges addressed in the last three sections relate to various aspects of the administrative procedures, it is crucial to re-iterate the administrative activities of the Title I program that functioned to the detriment of the Latino CBOs.

All responding agencies acknowledged similar problems with the administration of the application and grant-making process. Applications were often burdensome, sometimes unclear, and frequently problematic because of short turnaround time. Technical assistance for understanding or responding to the application was largely unavailable. This problem was noted by all agencies except the largest and most experienced in grant writing.

Respondents also reported problems with the production, dissemination, and management of understandable and clear grant writing and grant making procedures. Inconsistent application of eligibility and funding guidelines left agencies unsure about whether rules were applied fairly and whether resource decisions actu-

ally reflected community input. Frequent cancellations and rescheduling of meetings during planning periods further augmented a sense of distrust.

The lack of reliable administrative procedures was not confined to the application period. Once agencies received their contracts, many encountered a lack of uniform and reliable record-keeping at the local RWCA administrative offices that sometimes required the re-submission of reports and data. Some Latino CBOs also experienced delayed reimbursement of program invoices, a circumstance that further exacerbated the negative fiscal effects of underfunded service and administrative categories. Others felt particularly burdened by the timing of contractual agreements that sometimes forced agencies to begin providing services upon receipt of their award letter, which could occur as much as several months before actual payment would begin. If an agency did not have other funds to use during the interim, it might face returning some of the contracted amount because of "late start-up."

These administrative problems eroded both trust in and compliance with Planning Councils processes. Site Y was seen as particularly inflexible, arbitrary and problematic; Site X's Council did not develop administrative responses sufficiently responsive to non-medical agencies. However, it was apparent in both settings that leadership and attentiveness from the Council and the Title I staff could do much to alleviate the challenges faced by Latino CBOs.

Latino CBOs felt greater ease with administrative procedures, even with cumbersome and sometimes ineffectual structures, when they experienced the Council as accessible. Council Chairs appeared to play a critical role in creating and sustaining responsible, respectful, and responsive environments. "The Chair of the Planning Council . . . helps to keep the process open," opined one interviewee. When that is not the case, noted another respondent,

the procedures are experienced as difficult and the process is "not user friendly."

Similarly, when Title I staff were sensitive to the priorities and the burdens of different populations, Latino CBOs felt less overwhelmed by the administrative process. In Site X, which the CBOs experienced as more responsive, the Title I staff supported the Latino agencies programmatic concerns by urging attention to special populations such as undocumented immigrants; administratively they increased outreach efforts during the planning and application process, understanding that "the CBOs need technical assistance."

DISCUSSION

Among the primary goals of community health coalitions like the Title I Planning Councils, Butterfoss and colleagues (Butterfoss, Goodman, Wandersman 1983) emphasize the ability of these groups to mobilize diverse constituencies in a process that "can increase the 'critical mass' behind a community effort by helping individuals achieve objectives beyond the scope of any one . . . organization" (p. 317). Successful local coalitions enable crucial organizational partners to respond to needs beyond narrow agency missions without necessarily overburdening the management or service-providing capacities of individual institutions (Black 1983). Butterfoss and colleagues (1983) believe that this kind of collaborative health planning and administration has evolved as an ecological response to "the severity and complexity of chronic health conditions that are rooted in a larger social, cultural, political, and economic fabric" (p.315).

Though focused on other health arenas, Butterfoss and colleagues provide a developmental and theoretical framework applicable to the evolution and struggles of the community-planning components of RWCA. They suggest, as we have found, that the absence or under involvement of critical organizational partners will limit the ability of an affected community to

benefit from a coordinated health response—including limiting the community's access to program funding or other support which may flow through the coalition. Representation and participation in RWCA Title I Planning Councils created critical pathways for the Latino community in the sites we surveyed. Information access was brokered through Planning Council membership or through relationships with Latino community representatives on the Councils. Planning group discussions and service priority setting were shaped by the diversity, or lack thereof, of the Title I partners. Latino community concerns penetrated the environment to the extent that there were: effective community outreach; sufficient Latino Council membership; committed Council and RWCA program staff leadership; and an open, respectful, and accessible communication environment. Finally, substantial representation and meaningful participation, along with critical leadership support, significantly shaped access to RWCA funding for Latinos with HIV/AIDS and their CBOs. The interface of representation and funding allocation has been noted by the Health Resources Administration in a number of documents and reports addressing RWCA process (Goosby, McKinney, Eichler, Gomez 1993).

Improving the inclusiveness and responsiveness of Title I Planning Councils requires more than simply increasing the representation of diverse communities. Latino CBOs identified numerous procedural, linguistic, and affective components of the Title I process that functioned as impediments to their communities' effective participation. Among the most challenging concerns they faced were the dominance of pre-existing provider and consumer groups, and the differential, though not always explicit, frameworks that inform historic funding patterns.

CBO respondents located the possibility of institutional change largely in the quality and sensitivity of Planning Council leadership. But the multi-faceted obstacles

to more meaningful and effective participation faced by small and minority CBOs (Arnstein 1986; Marmor, Morone 1981) must be addressed from a group development perspective. Butterfoss and his colleagues (1993) characterize a quality-of-readiness that all coalition members need to have in order to work meaningfully across their diverse interests and histories. He considers the "capacity to participate" a requisite skill for effective coalition membership, one that often requires skills training, facilitation, and technical assistance for the partner organizations. Emerging literature in coalition processes reflects the need for similar developmental and capacity building interventions (Parker, Eng, Laraia, Ammerman, Dodds, Margolis, Cross 1998; Chavis 1995; Pierce-Lavin Fresina 1998; York 1985). In this study, the following mechanisms emerged as critical for addressing the inclusion and participation challenges 1) training of Planning Council members to address diversity, cross-cultural understanding, and representation issues; 2) technical support for assessing service needs, integrated program development, and resource allocation concerns; 3) translation capacity for non-English speaking coalition members; and 4) other coalition development and management services.

Capacity building needs also exist at the level of individual CBOs, as was noted by all Latino agency respondents. Some of the challenges faced by these agencies were a function of size or developmental status. Nevertheless, Latino CBOs, large and small, noted that the chronic under-funding of the service sectors in which they were already involved made them particularly vulnerable in their efforts to effectively participate and compete in RWCA process. The institutional vulnerability of many of the Latino CBOs further exacerbated their experience of problematic or ineffectual administrative practices within the sites.

If, as the National Commission on AIDS noted in its 1992 report, minority

CBOs, are "essential participants in the prevention and care of HIV in hardest hit communities," the problem of assuring their effective participation in RWCA programs is fundamental. This study has provided further insight on the challenges of facilitating meaningful participation of Latino CBOs in the Title I process. Its results suggest several conclusions. First, there are lessons in history regarding community-planning efforts that should be applied to further the development of RWCA relationships and functions. Second, if, as Latino respondents noted, RWCA personnel and Council co-chairs are critical to creating more receptive and responsive planning environments, federal technical assistance and training around inclusion, effective leadership, and collaborative decision-making may facilitate improved inclusion of Latino and other minority CBOs. Third, other group development and individual agency capacity building appears to be necessary to improve minority Planning Council representation and minority CBO competitiveness in Title I funding cycles. Funding needs to be made available to support technical assistance and program monitoring targeted to CBOs. Technical support should include grant writing assistance, institutional strategic planning support and other agency-based development. Finally, administrative procedures within EMAs should be examined for their disproportionate burden on small and minority CBOs and appropriate technical and financial remedies should be investigated.

The RWCA is only the latest in a number of federal government health initiatives that define local coordination and collaboration as central to effectuating change and addressing complex health problems. As a critical response to one of the most challenging public health problems in this century, it demands continuing review, assessment, and refinement. All the more so for Latinos, and their organizational representatives, who continue to face a disproportionate burden of HIV disease.

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