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Factors Affecting the Delivery of HIV/AIDS Prevention Programs by Community-Based Organizations

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Community based organizations (CBOs) play a frontline role in HIV/AIDS prevention activities. CBOs face formidable challenges to effective delivery of HIV prevention services including client characteristics such as homelessness and CBO characteristics such as limited resources and staff turnover. Despite these obstacles, CBOs are generally well positioned to deliver services to specific high-risk populations because they understand their local communities and are connected to the groups they serve. [C1]This qualitative study illustrates that structural, sociocultural, organizational, and individual client factors both facilitate and act as barriers to delivery of HIV prevention services. These challenges and successes help identify critical technical assistance needs.

Community-based organizations (CBOs)[1] face formidable challenges to the effective delivery of HIV prevention services to the populations they serve. These challenges in-

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1. The term *community-based organization* encompasses a wide variety of local organizations staffed by persons familiar with the needs of high-risk populations or specific communities (e.g., particular racial/ethnic minorities). Examples of CBOs include primary health care agencies, drug rehabilitation centers, homeless shelters, grassroots AIDS service and prevention organizations, and community centers. To be eligible for direct CDC funding, CBOs must have been tax exempt, as determined by 501(c)(3) status, nonprofit organizations, with an established record of service to the communities of interest.

clude client characteristics such as homelessness and injection drug use and CBO characteristics such as limited resources and high staff turnover. Despite these obstacles, CBOs are especially well situated to serve specific high-risk populations in local communities because they frequently are familiar with and connected with them (Kelly et al., 2000).

Since 1988 Congress has mandated direct funding of CBOs to provide support for the HIV prevention infrastructure in underserved communities. [C2]In 1997 the Centers for Disease Control and Prevention (CDC) directly funded 94 CBOs under Program Announcement 704 to develop HIV prevention interventions. These organizations were funded to conduct one or two of the following types of interventions: individual-level, group-level, community-level, and street and community outreach (CDC, 1997).[2]

To assess the implementation of HIV prevention services delivered by CBOs, CDC initiated an exploratory, qualitative study of 26 of these CBOs as part of a larger evaluation. We report structural, sociocultural, organizational, and individual client factors that facilitated or acted as barriers to the delivery of HIV prevention services as described by managerial and "frontline" staff of the directly funded organizations. [C3]Our report highlights CBO staff perspectives, provides examples of successful strategies used by CBOs to deliver HIV prevention programs, and identifies technical assistance needs to improve program delivery.

METHODS

PARTICIPANTS

The 26 CBOs were selected (Devers, Kelly, & Frankel, 2000; Patton, 1990) to include a variety of intervention types, populations, and geographic locations. The mean number of years of CBO operation was 22.34 (range = 5-48 years). Although all the CBOs offered multiple intervention types, the CDC funding supported 12 individual interventions, 13 group interventions, 12 community interventions, and 16 street and community outreach interventions. The racial/ethnic populations served by the sample CBOs included African Americans (n = 15), Hispanic/Latinos (n = 9), Asian/Pacific Islanders (n = 4), and Native Americans (n = 1). The sample CBOs represented 23 distinct geographic locations, and 21 were located in metropolitan statistical areas with high AIDS prevalence.

Participants from 18 CBOs [C4]were selected to participate in either a focus group or in 1 of 10 site visits. Representatives from eight additional CBOs participated in a second focus group after the completion of the site visits. All CBOs solicited for recruitment in the study agreed to participate. Participants reviewed and signed consent forms outlining the scope and purpose of the data collection and the potential risks and benefits of their participation.

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2. Individual-level interventions include one-on-one client services such as counseling to assist clients in assessing their own behavior, and planning, supporting, and sustaining behavior change to prevent the transmission of HIV. These services could include prevention case management. Group-level interventions include education and support in group settings to promote and reinforce safer behaviors and to provide interpersonal skills training. Community-level interventions have as a central goal changing community norms (e.g. media campaigns to increase community support of the behaviors known to reduce the risk for HIV infection and transmission). Street and community outreach is designed to reach persons at high risk, on the street or in community settings, and provide them with prevention messages, information materials, and other services.

PROCEDURES

Information about the study was provided to the CBOs via letters and conference calls. During focus groups and site visits, interviewers used a semistructured topic guide. Each focus group was conducted in 1 day and consisted of two sessions of approximately 2 hours each. Site visits were mainly 2 days per site, with interviews ranging from 45 minutes to 1.5 hours. The number of staff members interviewed at each CBO ranged from two to seven. Two interviews were conducted by telephone, as the respondents were unavailable at the time of the site visit.

Interviewers were three master's level CDC contractors who received 2 days of training in focus group techniques. Respondents were asked to describe their organization's history, range of services provided, mission, staff, HIV prevention program implementation including the provision of referrals, technical assistance needs, and efforts to collaborate with other local organizations and communities. Information about the barriers as well as facilitating factors for reaching populations of interest and delivering interventions were collected.

DATA ANALYSIS

Interviews were audiotaped and transcribed verbatim; identifying information was removed. The interviewers met after each site visit to identify thematic content. To increase consistency in the use of thematic codes, all interviewers coded the first focus group transcript and one site visit interview (Bernard, 2000; Miles & Huberman, 1994). Then 17 site visit interview transcripts were coded independently by two interviewers and the rest by a single interviewer. The final focus group was coded by two interviewers.

A preliminary list of themes was created prior to data collection and then modified as fieldwork progressed. Transcripts were further analyzed using computer software QSR NUD*IST (QSR International Pty. Ltd., 1988) to assign thematic codes to text sections. This text was read by three additional readers at the CDC, who identified no new themes. All transcript texts describing access to the populations and delivery of prevention services were reread for review of each theme as described by CBO staff (Creswell & Miller, 2000; Strauss & Corbin, 1990). Quotations that reflected the most commonly offered themes were selected.

RESULTS

CBO managerial and frontline staff described critical structural, sociocultural, organizational, and individual client factors that facilitated and acted as barriers to the delivery of HIV prevention services. Structural factors include legal, policy, and broad economic issues and are frequently outside the direct control of CBOs and the clients they serve (Gollub, 1999; Sweat & Denison, 1995). Sociocultural factors in general concern norms and issues associated with ethnicity, stigma, and bias toward behaviors or groups; values and beliefs about sexuality; and attitudes about health care professionals and other authority figures (Cruise & Dunn, 1994; Stevenson & White, 1994; Valdiserri, West, Moore, Darrow, & Hinman, 1992). Organizational factors include characteristics associated with CBO infrastructure, such as budget, relationships with communities and populations of interest, location, staff satisfaction, and scope of the CBO's mission (Mercer & Liskin, 1991). Individual client factors include

TABLE 1. Barriers and Facilitators to CBOs' Delivery of HIV Prevention Interventions

Factors	Barriers	Facilitators
Structural	• Legal and policy issues (e.g., federal ban on needle exchange funding, changes in welfare laws and managed care, laws that limit services to immigrants) • Economic issues (e.g., poverty, gentrification, lack of affordable housing)	• Positive political climate • Supportive law enforcement and other state/ local agencies
Sociocultural	• Stigma/bias (e.g., homophobia, racism, sexism, attitudes and beliefs about HIV/AIDS) • Distrust of social service providers, system, dominant culture • Shame about sexuality • "Conservative" political environments	• Knowledge of cultural norms • Entrée/credibility of CBO staff members • Well–organized population of interest • History of activism
Organizational	• Bureaucratic/unwieldy organization, • High staff turnover and "burnout" • Difficulty recruiting staff who reflect the population of interest • Lack of resources	• Clear mission and strong identity • CBO provision of comprehensive services • Accessible location
Individual	• HIV not perceived as a priority • HIV/AIDS fatigue • High rates of poverty, unemployment, drug use, mental health issues, alcoholism; sexually transmitted diseases, teen pregnancy, domestic violence • Transient nature of clients; illegal activity of clients	• Strong social networks • CBO attention to clients' needs other than HIV • Provision of incentives

such characteristics as homelessness, other illnesses such as depression or sexually transmitted diseases, undocumented alien status, and illegal activity.

BARRIERS

Structural, sociocultural, individual client, and organizational factors affecting delivery of services by CBOs were intertwined and created similar barriers (Table 1). Structural factors such as poverty may underpin sociocultural, individual, and organizational factors. In general, these factors caused clients to disperse or become difficult to locate, rendered HIV and HIV prevention less important relative to other life concerns, undermined the credibility of CBOs among populations served, and directly prevented CBO staff members from providing services to clients.

Structural Factors. Several major changes in laws and policies affected client access and intervention delivery for the sampled CBOs. These included changes in immigration laws (e.g., passage of Proposition 187 in California;[3] Carrasquillo, Carrasquillo, & Shea, 2000; Families, U.S.A., 1999); passage of the Personal Responsibility and Work Opportunity Reconciliation Act (1996; Health Care Financing Administration, 1997), commonly known as "welfare reform"; changes in HIV reporting practices[4] (e.g., HIV name-based reporting; Kassler, Meriwether, Klimko, Peterman, & Zaidi, 2001; Osmond et al., 1999); prohibition of federal funding for needle exchange programs (University of California Berkeley School of Public Health & University of California San Francisco Institute for Health Policy Studies, 1993); and changing policies toward homeless persons (e.g., antivagrancy policies and laws; National Law Center on Homelessness and Poverty, 1996).

3. Proposition 187 required publicly funded health care facilities to deny care to undocumented persons and report them to authorities.

4. Morin (2000) characterized recent trends as being "toward more mandatory testing for broader classes of people and away from protecting the confidentiality of HIV test results" (p. 1).

CBO staff members reported distrust and fear as a direct consequence of changes in immigration laws. This represented a particular barrier in relation to referrals. One program, for example, offered HIV counseling, testing, and referral (CTR) but was unable to successfully refer undocumented persons to services outside the CBO. As a result, these persons did not participate in the CTR program. This example shows how structural factors and individual client factors intertwine and undermine HIV prevention efforts. Welfare reform most commonly affected access and delivery by rendering HIV and HIV prevention less important relative to other life concerns. One CBO staff member commented:

> The community is getting tired of hearing about HIV and AIDS. . . . It's not an urgency anymore. . . . When you look at about 60% or more of [the] population being on public assistance, with the public policy now surrounding public assistance, welfare reform. . . . people are just looking to try to find where their next meal [is], and HIV is just not on the priority list if it [is] even there.

Changes in HIV reporting practices, such as name-based reporting, designed to improve tracking of the epidemic and facilitate more timely entry into medical care, may discourage at-risk persons from seeking CTR (Osmond et al., 1999).

Economic structural factors identified by CBO staff included the effects of poverty, lack of affordable housing, and gentrification of neighborhoods. One staff member said, "One of the things that I've found [is] if someone's homeless or a substance abuser or they're hungry, they're not going to think about risk reduction." Another staff member described the effects on an outreach program of local policies dealing with homeless persons:

> Mainly in the beach area, wherever there is heavy tourism mainly you don't find homeless folks out in the open as much as you would. . . . [Name of city] has new rules concerning homelessness. You either have a choice to go to this facility or possibly go to jail, so that puts a lot of pressure on finding folks as well.

Sociocultural Factors. Sociocultural factors described by CBO staff concerned community norms, values, attitudes, and beliefs. Sociocultural factors that presented barriers to delivery of services included racism, sexism, homophobia, attitudes about drug users and other marginalized groups, stigma associated with HIV/AIDS, shame/secretiveness about sexuality, absent or poor social networks, and language and literacy difficulties.

Attitudes and beliefs about risky behaviors can affect access to target populations. A CBO program manager commented:

> Women substance users have to be more underground than male substance users. It's not socially acceptable to be a female substance user. I've had people say to me a man can lay down in the gutter and get up in the morning and he's still a man. A woman who lays down in the gutter at night, when she get up in the morning, she now a ho [whore]. She's no longer a woman. . . . Women substance users are harder to access because it's not socially acceptable to be open about your substance use.

Another CBO staff member described how stigma associated with HIV/AIDS affected delivery of prevention services:

The other thing is that we operate in a political climate. . . . we have presidents of major local corporations and vice presidents of banks and that sort of thing. And we also have to keep them, you know, they read [the local newspaper]. And if the CBO name is splashed in there, I don't think we're going to be getting them $100,000 from

[Company] because they're going to want to shy away from controversy. . . . We feel like we've established some protections for our agency. But at the same time, those protections also inhibit us from delivering the services in the way we want.

Organizational Factors. Organizational barriers include an unwieldy or overly bureaucratic structure, weak leadership, staff burnout/turnover, and lack of resources. Staff characteristics, whether negative or positive, seemed to be most important in determining the success of access and delivery. Staff burnout presented a frequent problem:

> I think there is a great deal of burnout in this work. . . . I've always felt that if nonprofits could be like some of the [department stores] of the world, they'd recognize you've got to support the frontline workers first. But you've got to be supporting, I think, the folks who are doing the work at the delivery level. That's training and that's extra time. They don't usually fund it.

Occasionally, having staff members from the populations being served created difficulties. These individuals may lack other important attributes for the job such as an appropriate academic background. Absenteeism due to illness for those living with HIV was sometimes cited as a problem, as was loss of boundaries or overidentification with the populations being served. A CBO program manager explained:

> I've seen [it] happen where staff get comfortable to the point where they start talking about when they used to, when they used to do this or that and whatever, just to try to identify with that particular population to make the message get across and it turns into like more of a joke . . . glorifying the behavior that we are trying to really, really get people to think about in a different light, not to laugh and joke.

Individual Client Factors. Individual client factors mentioned included unemployment, homelessness, drug use, being an undocumented person, illegal activity, complacency or fatigue with HIV/AIDS, and distrust of health care professionals or other authority figures. As with structural factors, most individual client factors described were barriers to successful access to clients and delivery of services. In addition, many individual client factors were strongly related to structural factors—policy, legal, and broad economic issues. Many clients had multiple characteristics that challenged the abilities of CBOs to adequately provide services. One staff member described such a situation:

> We work with a significant sex-working population, and we also work with a lot of low-income clients, many of whom have limited English and many of whom are undocumented. And so many of the clients we see in prevention have never had legal employment.

Ironically, the well-organized, highly identified population of gay men who have a long history of activism also are more likely to have "HIV/AIDS fatigue." A CBO staff member said, "We're operating at a time in the epidemic where most gay men are over it, most gay men are tired of hearing about condoms. They're tired of hearing about AIDS. They don't want to go to another condom-on-a-banana demonstration."

FACILITATORS

In general, factors facilitated access and delivery by helping to identify, locate, and attract new clients and by making programs more relevant to populations served.

Structural Factors. Structural factors may be the most difficult for locally based CBOs to directly address. Nevertheless, because these legal, policy, and economic is-

sues contribute to day-to-day work of CBOs,[C5] creative and locally appropriate strategies indirectly addressed them. CBOs were sometimes able to capitalize on a relatively positive political climate or develop local relationships that help to directly address structural factors. A CBO staff member commented, "They've [outreach workers] worked out relationships with the cops so the cop's don't bust outreach workers [conducting needle exchange]".[5] Others maintained relationships with local politicians:[6]

> Whenever a problem surfaces, we have to get on the telephone with our congresswomen and different politicians to say "Explain this to us" because you know they are speaking a different language . . . "explain this to us so we can explain it to the critical masses" . . . . Then we take it out to the streets because we are out in the streets anyway.

Sociocultural Factors. Sociocultural factors that facilitated access and delivery included strong social networks and a well-organized, highly identified population with a history of activism (e.g., gay men). CBO staff members sometimes enhanced their entrée into and rapport with these populations through knowledge of cultural norms:

> Because I am of Mexican descent, I get a lot of Mexican kids that come, you know for that. . . . So I began to include more cultural stuff too, you know, bring in all those myths about sexuality. Like, you know, how big your feet are compares to how big your penis is, to if you kiss a boy when you are on your period, you know, you're bound to get pregnant.

Organizational Factors. Facilitators included a strong mission and leadership, committed staff members, CBO infrastructure that was supportive of staff needs, creative strategies for accessing populations and delivering services (e.g., interesting incentives such as T-shirts or theater/musical concerts), entrée/credibility among the populations served, and comprehensive service delivery.

A program manager described the importance of committed staff members, as well as those with entrée/credibility:

> Most of our employees are indigenous workers. They have been in prison, they have been substance abusers, they work very well with the HIV population; and I think the motivation comes from the fact that they had these backgrounds. They turned their lives around, and they are very interested in helping someone else do that.

A staff member described creative strategies:

> We'll use different styles of information and education that make it seem like you're not being educated so people know when they come to these things that it doesn't feel like AIDS intervention. . . . We'll have a game show to get out some information facts, or when we did the drug and alcohol forum we had a fashion show with 12 guys dressed up as different kinds of drugs and they ran down the runway.

CBOs with comprehensive services are better able to access and deliver services to clients with priorities other than HIV prevention. Said one:

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5. The CDC does not fund needle exchange; however, some CBOs receive other funds to do so.

6. CBOs cannot lobby using federal funds. This is not a comment on this CBO's activities.

> In terms of our program [I don't think] it would be as successful as it's been if we didn't have the other pieces in place that we have. If we didn't have a grant that paid us to do outreach, if we didn't have a grant that had on-site HIV testing and counseling, HIV-positive case management, or a food pantry.

One staff member described CBO-tailored strategies:

> In our target population, we deal with immigrants. We do help immigrants in getting their green cards. So we have an open door for them to come to address that need. When we fulfill that need, they are open to listen to the message. We do need to do something for our target population for them to trust us.

Individual Client Factors. CBO staff attempted to ascertain and address individual client factors that hindered client receptivity to HIV prevention interventions. A CBO staff member said, "The case managers do...an assessment and figure out where this individual is. Once they get the individual immediate need satisfied, then we...enroll them." In one instance, a CBO staff member reported that the fact that clients have other pressing needs may facilitate receptivity:

> A lot of the women, they are in treatment. . . . they are real needy. Because they are right on the edge, they are ready to lose their kids, and so they will really reach out then. . . . So those cases are a little more easy. Because I let them know that I am here to help . . . but then when they are out in the community, in their homes, it takes a lot longer to get that message across.

Recruiting for or conducting interventions in settings comfortable to the populations served may help to ameliorate the effects of some individual client factors. A CBO staff member commented:

> Do you realize the homeless is scared of going into a big fancy building? Just seeing all that fancy building and those fancy people, they don't want to go there. . . . But if you meet them where they're at, and you can serve them and keep going to them, you can bring them in.

DISCUSSION

To overcome the barriers identified, long-term strategies focusing on infrastructure and client factors are needed. CBOs are unlikely to directly influence the structural factors that affect access and delivery, but they are able to mitigate the effects of these factors through, for example, delivery of comprehensive services that address the range of clients' HIV-related and other needs. To most effectively address structural and sociocultural factors, strong leadership and coordination are needed at the federal level. Initiatives such as National Minority AIDS Initiative (CDC, 1999) and the Minority Health and Health Disparities Research Act of 2000 (2000; Betancourt, 2001) may help to address structural and sociocultural factors over the long term. The Committee on HIV Prevention Strategies in the United States of the Institute of Medicine, National Academy of Sciences, recommended specific strategies to diminish the effects of structural and sociocultural factors. These strategies are best undertaken by the federal government and other policymakers and include increasing funds for substance abuse treatment, removing legal and policy barriers to needle exchange programs, eliminating requirements for public funding for abstinence-only sex education

programs, and providing comprehensive sex education in schools (Institute of Medicine, 2001).

CBOs can play an important role in organizing and coordinating efforts in community mobilization and participation to increase access and delivery of program services to high-risk and HIV-infected populations. For structural and sociocultural barriers, CBOs can collaborate with their community partners and advocate for policy development and social change. CBOs may partially address lack of resources by tapping human and other resources in their communities where they have strong existing ties and linkages. If funded directly by CDC or indirectly through their local health departments, they may also access state and federal technical assistance in program development and implementation. Because CBO frontline staff members play key roles in the success of their programs, staff training and development, including burnout prevention, must be stressed.

Programs designed to address racism and the stigma of homosexuality are critical, as are programs targeted to the specific needs of young, minority gay and bisexual men, women, the economically disadvantaged, and others. CBOs can and do play critical roles in programs for those disproportionately affected by HIV/AIDS. Recent reports have shown continuing high and in some cases, rising incidence of HIV infection in young gay and bisexual men. Seroprevalence rates are highest for African American young gay and bisexual men and high among other minority men who have sex with men, including those of other ages (Catania et al., 2001; CDC, 2001; Karon, Fleming, Steketee, & DeCock, 2001). Regardless of behavioral risk factors, persons of color or lower income are disproportionately affected by HIV/AIDS (CDC, 2001; Karon et al., 2001). Women, particularly African American women, for whom AIDS has become the third leading cause of death, are increasingly affected by HIV/AIDS (Hader, Smith, Moore, & Holmberg, 2001).

Federal and other funding agencies should consider continued and increased development, evaluation, and funding of comprehensive service delivery in CBOs that also provide HIV/AIDS services. Funding agencies also have a role in providing technical assistance. The scope of this technical assistance can include helping CBOs to recruit, support, and maintain quality staff; developing data collection and maintenance systems for [C7]tracking referrals; and documenting "best practices" from which CBOs can model programs (Kelly et al., 2000).

Although the AIDS epidemic has clearly had an enormous effect on the United States, local organizations continue to persevere, maintaining an energy and sense of purpose that has allowed them to create innovative strategies, tailored to their communities, in spite of the many challenges associated with the provision of HIV/AIDS prevention services.

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