Learning from the Community

What Community-Based Organizations Say About Factors that Affect HIV Prevention Programs

Conwal, Inc.
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Acknowledgments

This summary reflects the experiences of many CBOs who were working to develop, implement, and evaluate effective approaches to decreasing HIV transmission in their communities. We want to acknowledge the CBO staff members who shared their insights and described the dynamic context in which they worked to combat HIV/AIDS. Their dedication to this work continually inspired us.

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INTRODUCTION AND GOALS

In the Fall of 1996, the Centers for Disease Control and Prevention (CDC) announced funds for HIV prevention projects for minority and other community based organizations (CBOs) serving populations at increased risk of acquiring or transmitting HIV infection (Program Announcement {PA} 704). Ninety-three CBOs were funded to conduct one or two of the following intervention types: individual level interventions, group level interventions, community level interventions, and street and community outreach interventions.

The Program Evaluation Research Branch (PERB) of CDC undertook an in-depth study of factors that help and hinder CBOs in their efforts to reach their target populations, deliver HIV prevention services, and provide referrals.

The goals of this study were to:

1. Identify and explore factors that help and hinder CBOs in their efforts to reach their target populations, deliver HIV prevention interventions, and make referrals;

2. Describe CBO collaboration;

3. Identify the critical technical assistance needs of CBOs; and

4. Provide an in-depth look at the above issues from the perspective of both managerial and front line CBO staff.

This report presents the highlights of this study. Quotations that appear in this document are included to illustrate and develop ideas, and they have been edited for clarity and to protect the confidentiality of respondents.

METHODOLOGY

As indicated in Table 1, data were collected using the following methods in the respective order, focus group one, site visits, and then focus group two. In total, there were 45 respondents and 26 participating CBOs. Sixteen respondents were selected to represent their organization and participate in the focus groups with 8 persons in each group. Ten CBOs were selected for site visits. As part of the site visits, 29 formal interviews were conducted. All respondents solicited for recruitment in the study agreed to take part. Participation was voluntary and informed consent was obtained. All participants were selected to create a sample of CBOs that varied by intervention type, target population, and region of the country. Interview guides were developed based on the research questions, and were similar for both site visits and focus groups to help keep the data collection consistent.

Table 1. Data Collection Methodology

	Focus Group 1	Site Visits	Focus Group 2	TOTAL
Number of participating CBOs	8 CBOs	10 CBOs	8 CBOs	26 CBOs
Number of individuals participating	8 (one representative from each selected CBO)	29 semi-structured, formal interviews (interviews lasted approximately 1 hour)	8 (one representative from each selected CBO)	45 individual respondents

Data Analysis

QSR NUD*IST was used to manage and analyze the data. An initial coding scheme was developed prior to data collection and codes were continually refined and clarified as interviews were analyzed. Reports summarizing themes in the data were generated, allowing for an understanding of themes across the CBOs as well as an in-depth understanding of each case.

THE COMMUNITY-BASED ORGANIZATIONS

The 26 community-based organizations who participated in the study were diverse. The organizations were of various sizes and ranged in years of operation (4-87 years with an average of 22 years). The tables and figures below describe various characteristics of participating CBOs.

Figure 1. Founding Mission or Purpose of Participating CBOs

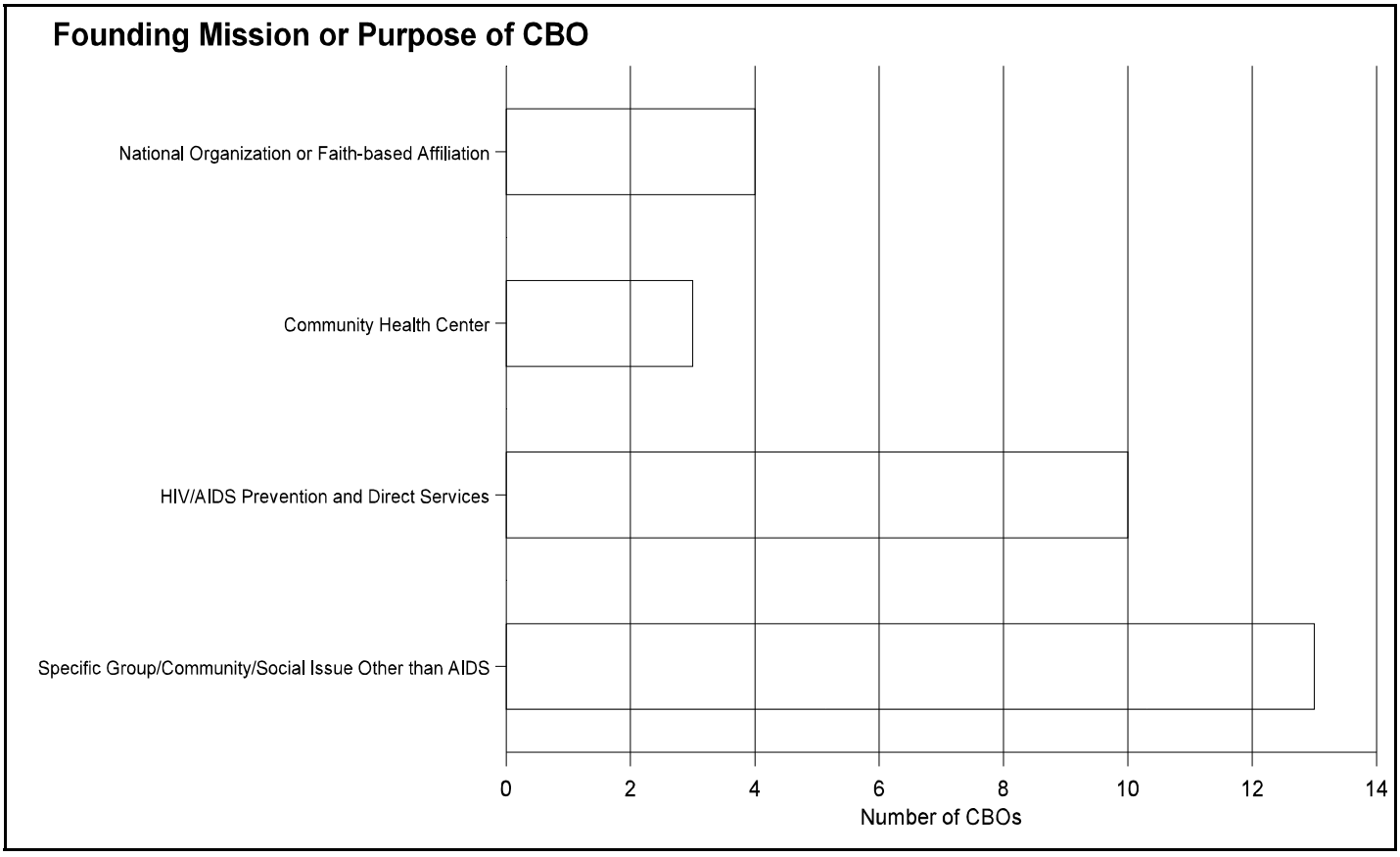
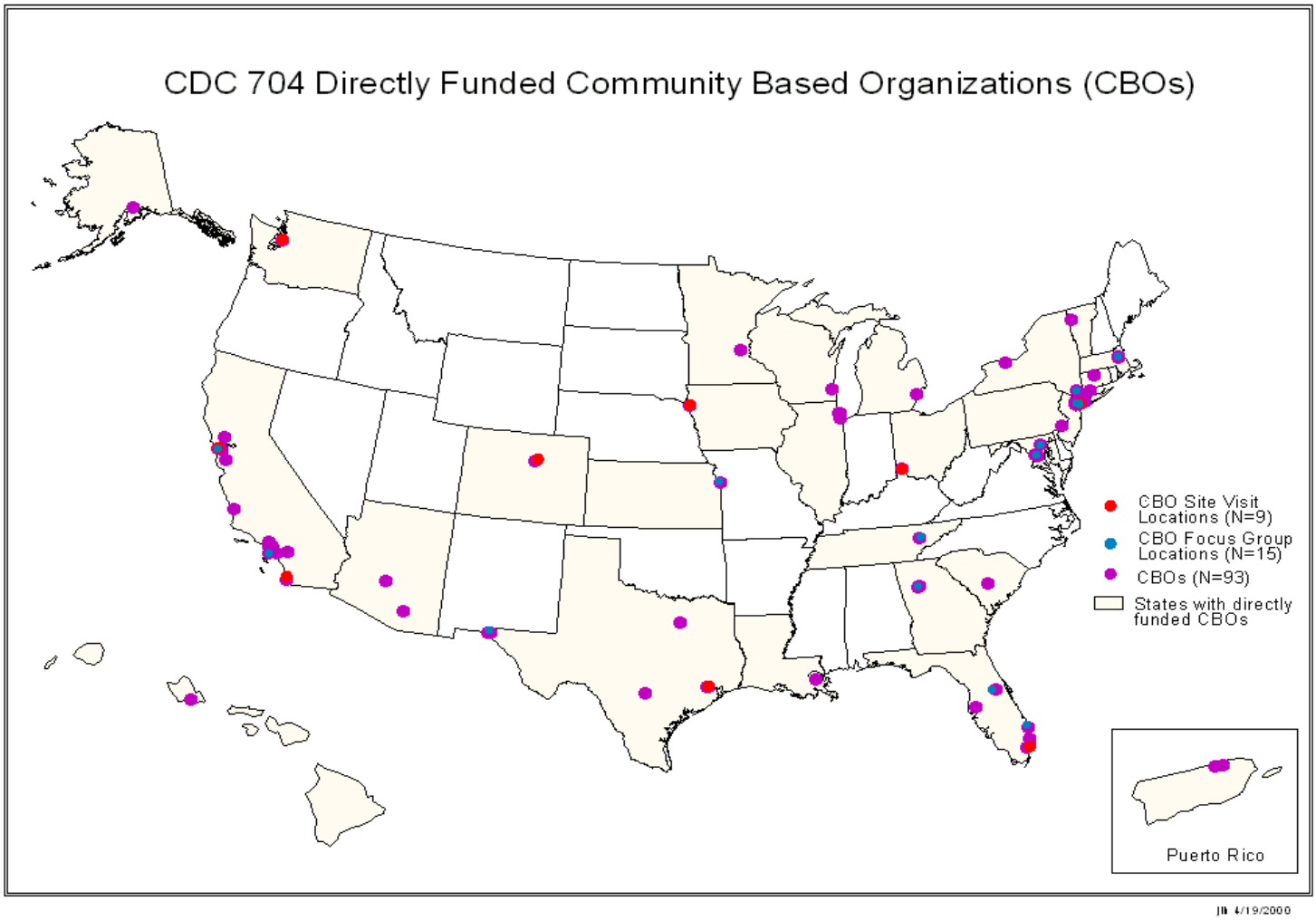


Figure 2. Locations of All PA 704 Directly-Funded CBOs, by Site Visit or Focus Group Participation



The directly-funded CBOs developed and targeted their interventions to populations at high risk for HIV. The CBOs in our study reported serving the following populations (Figure 3 and Figure 4):

Figure 3. Race/Ethnicity of Target Populations*

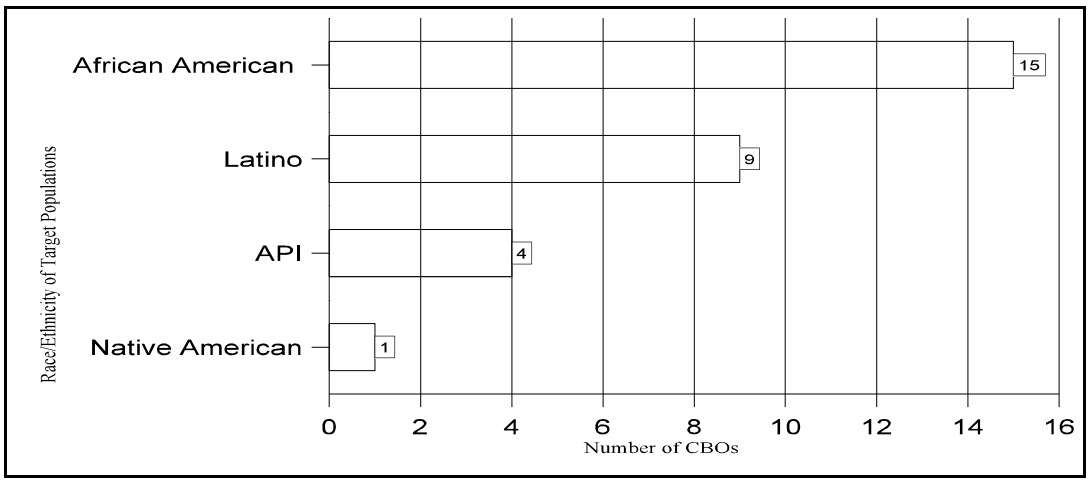
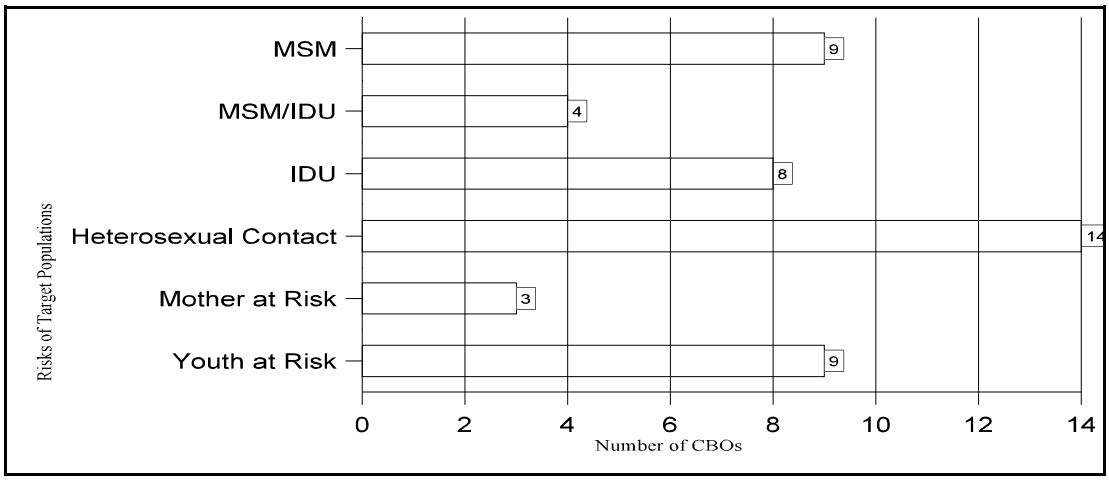


Figure 4. Risks of Target Populations*



* The categories for race/ethnicity and target population risks are not mutually exclusive. CBOs served one or more race/ethnicity and risk group.

RESULTS

Reaching Clients, Delivering HIV/AIDS Prevention Services, and Making Referrals

Table 2. Examples of Factors that Help and Hinder CBOs to Reach their Target Populations and Deliver Interventions

	Factors that Help	Factors that Hinder
Structural/ External	Supportive city and health department Well organized target population	Police harassment Limitations on the accessability of syringes Policies that prevent condom distribution Poverty Racism, sexism, drug phobia, homophobia
Cultural Norms	Strong role of families Active faith communities	Distrust of social service providers Ashamed to talk about sexuality
Client Factors	Well established social networks	High rates of drug use, poverty, unemployment, mental health issues, STDs, teen pregnancy, domestic violence, etcetera Transient nature of clients Denial/clients tired of hearing about AIDS
Organizational	Long history in the community Credibility Clear mission/strong identity "One stop shopping:" multi-services	Overly bureaucratic management Insufficient support for line staff Insufficient infrastructure Abstinence/no condom distribution policy
Staff	Charismatic leader Flexible work environment Support for line staff Staff represent community Commitment / Work as a team	High turnover/vacancies Difficulty finding staff that represent target population Conflicts between staff Not enough money to pay staff
Program	Needs assessments Market research Realistic goals and objectives Incentives Meet clients "where they are at" "Infotainment"–combining education and entertainment Flexible implementation design	Unrealistic goals and objectives Inappropriate strategies for target population No meaningful integration of evaluation data

Reaching their Target Population

Several strategies helped CBO staff reach clients by facilitating their abilities to: identify and find clients; attract new participants; and develop prevention messages, print materials, and programs more relevant to target population members. For example, one strategy to attract clients was to use incentives. CBOs used various types of incentives including money, food, clothing, raffles, music, and coupons for food and clothing.

There were other factors described by CBOs that hindered their ability to reach their target population. The hindering factors caused the target population members to disperse and become hard to find; made HIV irrelevant to the target population, or made the target population disinterested in HIV prevention programs; and/or distracted both those at risk for HIV, as well as the organizations serving them, from HIV intervention activities. For example, public policies regarding homeless persons were cited by CBO staff as hindering their efforts to reach the target population. New anti-vagrancy laws and efforts to make sure people did not sleep in parks or on beaches meant that homeless persons were harder for outreach workers to find.

> *"When you look at about 60% or more of the population being on public assistance [in the community], you know, with the public policy now surrounding public assistance, welfare reform, and all that, people are just looking to try to find where their next meal and HIV is not on the priority list if it's even there. So, it's really hard reaching a population like that and having any solid impact."*

Delivering HIV/AIDS Prevention Services

Factors helped CBO staff deliver their HIV intervention programs by: allowing staff and the organization know and do what the clients want/need; creating opportunities for behavior change; and strengthening the organization, staff, and/or program. For example, on-going training and support for staff helped them to feel confident about the work they were doing and more satisfied that they were making a difference in the lives of their clients. Also, using needs assessments and formative research to guide their program development helped ensure that the prevention messages were relevant to the people CBOs were trying to reach.

Factors hindered the delivery of services by preventing the staff or organizations from delivering services that clients wanted and needed such as distributing condoms, implementing syringe exchange programs, and/or implementing a curriculum. Some of the factors also undermined the strength, credibility, and/or coherence of the organization, staff, and program.

"If we give them a good product, they'll come back for more. So we know who the market is and what they want to buy, you know, and then we sell it to them... We're selling self-esteem, we're selling activism, we're selling hope for the future...we are selling HIV prevention."

In short, CBO staff said that in order to reach their target populations and deliver HIV interventions, they needed to navigate the changing political and policy environment; identify and respond to cultural norms that both facilitate and hinder their efforts; recruit and maintain quality staff; and innovate and create programs responding to the complex and changing needs of their clients.

Provision of Referrals

CBO staff said that referrals are an efficient way to improve program delivery and to help clients get services the CBO itself may not provide. Referrals create bridges for collaboration between agencies and can help to eliminate gaps in service. CBO staff described four steps in an effective referral process. The four steps are described in Table 3 below.

Table 3. An Effective Referral Process

	Description of the Steps
Step 1	Client centered assessment
Step 2	Give information to the client including preparing client for referral and documenting referral
Step 3	Client uses referral services
Step 4	CBO follow-up and documentation ("tracking") that services were used and an assessment of the client's experience at the referred agency

During step 1, before a referral can be made, a staff person determines which referrals are most appropriate. CBO staff clearly said that this assessment must be client-centered. After the staff person talks with the client and figures out what type of referral to make, basic information regarding the available services, agency location and cost can be given (step 2). In step 3, the actual use of services by the client, the cost of services and transportation play a crucial role in whether or not a client completes a referral. Incentives were one method used to encourage clients to access other services (e.g., coupons for discounted care at local health center, bus tokens, free cab rides and staff providing transportation). Finally, the CBO staff person tracks the referral to determine whether or not the client they referred got the help they needed. Each step has factors that help and factors that hinder, described below in Table 4.

Table 4. Factors that Help and Hinder the Four Step Referral Process

Factors that Help	Factors that Hinder
Step 1: Client Assessment	
A client centered assessment process including positive relationship established between staff and client	Assessment process not client-centered and negative relationship or no relationship exists between staff and client
Step 2: Give Information to Client	
Knowledgeable staff operating in an established referral system with access to appropriate tools and information	Untrained staff struggling against legal, individual and community barriers (such as no beds available, no services for women with children) within an informal or loose system
Step 3: Client Uses Referral Services	
Free services or incentives to go to referral and transportation is monitored by CBO staff	Individual client temperament and community barriers, cost of services and loss of clients in transit
Step 4: CBO Follow-up and Documentation	
Staff use established relationships and an established system with policies, forms, and procedures in place	Overburdened staff without time, connections or instruments to determine if client accessed services

"You have to be very creative with clients. And you have to know and understand people. And that's one thing that I think that we have expertise in. We understand how to match people with services, but first of all we have to understand the people."

Describing CBO Collaboration

CBO staff described collaboration as a complex process, influenced by program goals, politics, resource availability, and personalities. Collaboration may occur for one or more purposes: cost/resource sharing, technical assistance, joint program administration, improved program delivery, and access to a larger audience. Ultimately, it was the goal which determined what form the collaboration effort took. See Table 5 below for a list of goals of collaboration and Table 6 for examples of collaboration partners.

Table 5. Goals of Collaboration

•Increase ability to address multiple needs of target population •Gain trust of people "in the system" •Diversify staff •Share staff and resources •Link efforts; find common ground •Diversify participant base •"Build a bridge" (e.g., between clients and researchers) •Find suitable lead partners/agencies for funding application •Avoid duplication of efforts •Accommodate a political situation •Increase referrals to CBO •Receive or Provide Technical assistance •Become part of a community to improve access to target population •Expand networking opportunities •Get a better end product; program delivery •Share information; be informed •Join in research trials and projects

Table 6. Examples of Collaboration Partners

Examples of Collaboration Partners
•Community businesses: hair salons, night clubs, etcetera. •Prevention planning groups •Live theater (i.e., not movie theaters) •Criminal justice agencies: prisons, probation agencies, youth detention •Academia: universities, grammar and high schools •Medical: health centers and hospitals •Faith based agencies •Shelters: homeless, domestic violence, detox, •Departments of Public Health: state and city •Child Protective Services •Federal: CDC, CSAT, HRSA and other federal grants •Professional organizations including fraternal agencies •Radio stations •Private Voluntary Organizations •Individuals (e.g., social workers)

Collaborations help to make the work of CBOs more effective and efficient to the extent that both partners, now interdependent upon one another, fulfill their obligations and value their partner's experience as much as their own.

Unsuccessful collaborations can create frustration and waste energy in organizations and staff that already feel overwhelmed and under-supported. The factors reported to help and hinder collaboration are described in Table 7 below.

Table 7. Factors Helping and Hindering Collaborations

Help	Hinder
•Each partner clear about what they are contributing •Control issues defined and boundaries set •Commitment of each organization to fulfill responsibilities •Each agency has a specialty •Clear communication •Monitoring or systematic evaluation of the collaborative effort •Ability to choose partners •Benefits to each agency defined •Members of target population on staff •Personal relationships and professional affiliations/members	•Forced collaboration from funders •Target populations of various CBO are too diverse •Turf issues due to competition for money •Short funding cycle •Organizational systems not compatible •Lack of information •Different standards of CBO •One group does not fulfill responsibilities •Turnover of staff •Capitated payment systems

The factors described in Table 7 reflect the synthesis of information most often described by the CBO staff we interviewed. There were exceptions, however. For example, CBOs in a forced collaboration may still be able to communicate well about responsibilities and benefits. Or, CBOs in a voluntary relationship may discover that their target populations are too diverse to bring together. Despite the troubles sometimes associated with collaboration, CBOs reported that collaboration is an important and necessary activity in which to engage. The emphasis that CBOs place on collaboration, despite its difficulties, can be seen as an indication of CBO commitment to the communities and populations they were created to serve.

> *"There are natural relationships that come up as you are attempting to do your work and provide the best service to your consumers. And then there are those relationships you find yourself in because you are trying to locate funding to keep your organizations stable that winds up, you know, stretching your ability to really be effective."*

Identify Critical Technical Assistance Needs

CBO program and administrative staff identified the following technical assistance (TA) needs: evaluation, data collection, use of technology, and training for staff.

The need for evaluation and data collection relates specifically to the CBOs' ability to determine whether strategies for reaching clients, delivering services and making referrals are working. As program models change and become more sophisticated in attempts to address clients' multiple needs, the ability to successfully utilize computer technology may become more important and valuable. Finally, in order for any program to succeed, staff need to be trained in appropriate areas of expertise and this training needs to be continually updated in order to keep pace with the changing nature of the HIV epidemic.

There were several other technical assistance requests that were expressed by CBOs (see Table 8).

Table 8. Technical Assistance Interests of CBO Participants

- Evaluation
- Data collection
- Use of technology such as the Internet, creating and maintaining websites and creating interactive CDs
- Training
- Formal behavioral science theory and public health practice
- CDC language and protocol
- Contract management
- Confidentiality
- Program marketing and strategic planning
- Negotiating with contractors
- Prospective problem trouble shooting
- Improving volunteer participation
- Writing grants
- Accessing information on the latest developments in AIDS and HIV prevention
- Cultural sensitivity
- Board development

CONCLUSION

This reports provides a summary description of the context in which a group of CDC's directly-funded CBOs operated, from the perspective of the managerial and front line staff. The local communities and larger political arenas in which CBOs operate are dynamic environments, possessing factors which impact CBO programs. Understanding helping and hindering factors presents an opportunity to either harness them for greater program success or to allay their negative impact on both programs and people.

As the face of AIDS continues to change, CBOs and those who support the efforts of CBOs, must continue to be innovative, responding to the ever changing needs of those at risk for HIV while navigating complex political and policy environments. Furthermore, funders and policy makers, such as the CDC, must continue to learn from and partner with those on the frontlines of HIV prevention to bring an end to the AIDS epidemic.

RECOMMENDATIONS

Forums for Networking

The CBO representatives sought opportunities to share their knowledge and experiences with other directly funded CBOs. Participants wished to gather together to share resources and problem solve, learning from other CBOs that face similar challenges. The CBO representatives suggested CDC provide more opportunities for funded CBOs to network and share strategies.

Relationship with CDC

Staff explained a need for more consistency in the CDC program management staff, to enable more productive interactions. CBO staff also suggested implementing longer funding periods to allow for start up time and revisions to the intervention implementation. CBOs suggested changing the mechanism of payment to an electronic draw down system, as the current method is cumbersome and causes delays. CBOs asked for clear reporting requirements and expectations to facilitate a better dialogue with the CDC. Finally, CDC was encouraged to create systematic ways that CBOs could give anonymous feedback about the directly funded cooperative agreement program.

Interventions

Many of the CBO staff identified structural factors that effect their ability to implement their HIV interventions in their communities. CBOs have varied levels of understanding about how CDC can assist them in counteracting structural factors. The CBO staff requested more support to combat structural factors.

> *"If someone's homeless or substance abuser or they're hungry, they're not going to think about risk reduction. That's not top of their priority."*

Productive Collaborations

CBOs suggested that the following characteristics of collaborations be supported by the CDC: formed voluntarily and include natural relationships; clearly defined responsibilities of each of the partners; CBOs involved have similar target populations; and ways to monitor and evaluate the collaboration are in place.

Technical Assistance

Participants suggested that CDC create a user-friendly guide for CBOs to explain the various technical assistance resources available and how to access those resources. Common TA requests included how CBOs can collect and use evaluation data and assistance with referral tracking systems. A focus on qualitative rather than primarily quantitative data collection was requested. Furthermore, CDC was encouraged to allocate more funds for CBOs to provide TA to their own peer organizations.