THE STATE OF LATINOS

IN

HIV PREVENTION

COMMUNITY PLANNING

National Association of People with AIDS

CDC SAFER • HEALTHIER • PEOPLE

USMBHA

AFMES

NATIONAL MINORITY AIDS COUNCIL

NASTAD
National Alliance of State and Territorial AIDS Directors

Center for Community-Based Health Strategies at the Academy for Educational Development

March 2002

Table of Contents

ACKNOWLEDGEMENTS 2

EXECUTIVE SUMMARY 3

INTRODUCTION 4

METHODOLOGY 5

THE HIV/AIDS EPIDEMIC IN THE LATINO COMMUNITY 6

IMPORTANCE OF LATINO REPRESENTATION 9

BARRIERS AND CHALLENGES 11

ADDRESSING THE BARRIERS AND CHALLENGES 13

EXAMPLES OF LATINO INVOLVEMENT IN COMMUNITY PLANNING 14

CONCLUSION 16

REFERENCES 17

GLOSSARY 18

RESOURCES 19

PUBLICATIONS 21

Acknowledgements

This document evolved from charlas (discussions) among Latino staff, at organizations funded by the Centers for Disease Control (CDC) to provide Technical Assistance (TA) in community planning, to a collaborative project that spanned close to a year and involved numerous conference calls, face-to-face meetings, and hard, but rewarding work. During the time spent together, members of this project have developed endearing professional relationships, as well as friendships.

We are thankful for the support our agencies and supervisors have provided us throughout this process and to those who provided assistance in the editing of this document. Muchas gracias to NASTAD for taking on the printing task, and a special gracias to Rosendo Corral, who is responsible for the design and layout of this document.

We extend our sincere agradecimiento (thanks) to the Latino community and their State and Local Health Departments that support and encourage Latino participation in HIV Prevention Community Planning, especially to those that provided such valuable input—son sus palabras y experiencias que han hecho este trabajo posible! (it is your words and experiences that made this work possible).

The group, affectionately dubbed the "Superamigos " by its members, will continue to work side-by-side with Latino communities for positive change in the HIV Prevention Community Planning process. Aqui estamos para servirles—we are here to serve.

J. Gabriel Rendón jrendon@aed.org
Academy for Educational Development Center for Community-Based Health Strategies (AED-CCHS)

Carmen Villar cvillar@cdc.gov
Centers for Disease Control and Prevention (CDC)

Alberto Santana asantana@nastad.org
National Alliance of State & Territorial AIDS Directors (NASTAD)

Joseph Lovato jlovato@napwa.org
National Association of People With AIDS (NAPWA)

Ruben Cantu rcantu@nmac.org
National Minority AIDS Council (NMAC)

Maria Chaparro chaparrm@usmbha.org
U.S.-Mexico Border Health Association (USMBHA)

March 2002

Executive Summary

In HIV Prevention Community Planning, communities and health departments come together to address HIV prevention through an established planning process. This collaborative process was developed according to the principle that local HIV prevention priorities and needs are best identified by a local planning body.

In late 1993, the Centers for Disease Control and Prevention (CDC) issued the Guidance for HIV Prevention Community Planning. The Guidance was intended to affect the HIV prevention cooperative agreements to state and territorial health departments, as well as the health departments of six cooperative agreement cities. Although some health departments had already been working directly with local communities to make decisions on the allocation of HIV prevention funding, the implementation of the Community Planning Guidance formally brought local communities and health departments into a partnership called the community planning process. Although community planning group (CPG) membership recruitment processes are different in each jurisdiction, there is one constant: the requirement that community members involved in this process reflect the epidemic in each jurisdiction.

The Latino community is the fastest growing population in the United States and the group with the second-highest risk for HIV/AIDS. In 2000, Latinos made up 13% of the United States population but accounted for 19% of the total number of new U.S. AIDS cases reported among adults and adolescents. The annual reported AIDS rate, per 100,000 persons, among Latinos in 2000 was 30.4. This was almost four times the rate for Whites (7.9), but lower than the rate for African Americans (74.2). Large populations of Latinos reside in California, New York, Florida, and Texas. Data from CDC indicate that the geographic distribution of reported AIDS cases among Latinos follows similar population patterns.

Latinos are a diverse group composed of a mix of ethnic groups and cultures. In the United States, the largest Latino groups are Mexicans, followed by Puerto Ricans, Central and South Americans, Cubans, and other Latinos from the Caribbean. This diversity requires that Latinos be actively involved in the community planning process to ensure accurate representation and communication of needs.

Latino staff of the CDC National Technical Assistance (TA) Providers' Network for Community Planning facilitated sessions on the Latino experience in community planning at various meetings and conferences in 2001. This document is a compilation of information from these meetings and various other sources. It was created to serve as a tool to help CPGs, health departments, and other stakeholders understand the issues behind Latino participation in community planning, as well as to increase Latino participation in the process. For further explanation of the methodology used, please refer to the methodology section of this document.

To ensure representation in the local planning process, Latinos must be involved in their local CPGs. Numerous barriers prevent or hinder Latino involvement in the planning process. These include language differences, cultural beliefs, and socio-economic status. Various individuals and CPGs have addressed these barriers in creative and innovative ways. Participants in the sessions that informed this report identified initiatives that CPGs and health departments may undertake. Specifically, the Florida, Michigan, New Jersey, and Texas state health departments provided examples of Latino involvement in community planning (these are included in this document).

Throughout the aforementioned meeting sessions, participants also expressed frustration with elected Latino leadership regarding HIV/AIDS issues. Many expressed the need for national and local Latino leadership with a stronger voice in the development of HIV prevention policy and program design. Although the issue of leadership merits an entire discussion, it will not be addressed in this documen However, this document may serve as a catalyst for further work.

INTRODUCTION

HIV Prevention Community Planning is a process by which communities provide input into the development of the Comprehensive HIV Prevention Plan in their area, including identifying priority populations and interventions for the jurisdiction. Local demographic and epidemiologic data drive the design and development of an HIV Prevention Plan. It is a collaborative process, a partnership, and a method for involvement in HIV prevention. Community planning is an outgrowth of the belief that determining responses to local HIV prevention priorities and needs is best carried out through local participatory planning.

Prior to 1993, communities were involved in carrying out HIV prevention services, but were not always involved in the planning of comprehensive state and local prevention programs. However, several cities and state health department HIV prevention programs were working closely with the community. Federal prevention dollars flowed to CDC, which administered funds through cooperative agreements with state, local, and territorial health departments. In 1993, CDC acknowledged that local communities should be more involved in the planning process to address local HIV prevention priorities and needs. Thus, community and state/local community planning groups were born. These partnerships are made up of community members and health department officials, including infected and affected communities. They are usually known as community planning groups (CPGs). Participation of communities in this process became required for all project areas receiving federal funds for HIV prevention programs.

In December 1993, CDC issued a guidance document on HIV Prevention Community Planning to the health departments in all 50 states, 8 U.S. territories (American Samoa, Commonwealth of Northern Mariana Islands, Federated States of Micronesia, Guam, Republic of Marshall Islands, Palau, Puerto Rico, and U.S. Virgin Islands), 6 local jurisdictions (Chicago, Houston, Los Angeles, New York, Philadelphia, and San Francisco) and the District of Columbia. All these health departments receive federal HIV prevention funds. In accordance with the guidance, each CPG engages in nine steps to develop a comprehensive HIV Prevention Plan for its jurisdiction. These steps follow a logical process to build the plan and include: (1) developing an epidemiologic profile; (2) conducting a needs assessment; (3) assembling a resource inventory; (4) conducting a gap analysis; (5) identifying potential strategies and interventions; (6) prioritizing populations and interventions; (7) developing a plan; (8) evaluating the planning process; and (9) updating the plan.

Though each CPG has different membership processes for recruitment, determined by individual bylaws, some factors are constant. Membership must be reflective of the epidemic in each jurisdiction. New members need to be solicited through an open process. Once selected, members should receive a thorough orientation.

The Latino community, the fastest growing population in the Unites States, is at increasing risk for HIV, due to a variety of issues. These include population growth, cultural beliefs, language differences, and religious beliefs. For these reasons, it is of paramount importance for Latinos to be involved and to have a voice in the community planning process. The inclusion of Latino members in the community planning process is an issue that all CPGs and all members of the community need to address.

METHODOLOGY

This document is a result of an ongoing dialogue with and within the Latino community. Latino staff of the CDC National TA Providers' Network for Community Planning collaborated at various regional/national meetings to facilitate workgroups and conference sessions on the Latino experience in the community planning process. These individuals represented the Centers for Disease Control and Prevention, the Academy for Educational Development, the National Association of People with AIDS, the National Alliance of State and Territorial AIDS Directors, the National Minority AIDS Council, and the U.S.-Mexico Border Health Association.

The workgroup and conference sessions produced input on barriers and recommendations for recruitment and retention. In addition, there was an open call to solicit other models of Latino involvement. The U.S. Census Bureau and CDC contributed census and epidemiologic data. In addition, this report contains CPG membership data complied from membership grids submitted to CDC by the health departments. All of this information was compiled into this document for CPGs; Latino CPG members; health departments supporting the work of their state, local, and territorial CPGs; and members of the Latino community who are not yet members of CPGs. It provides information on barriers to Latino recruitment and retention on CPGs; suggests strategies to increase Latino representation; and provides recommendations for an inclusive process.

THE HIV/AIDS EPIDEMIC IN THE LATINO COMMUNITY

According to U.S. Census 2000 data, 35.3 million, or 12.5% of United States residents are Latino/Hispanic. Of the 35.3 million Latino residents, 7.3% are Mexican; 1.2% are Puerto Rican; 0.4% are Cuban; and 3.6% are from "other" Latino groups. These figures do not include the 3.8 million residents of Puerto Rico.

The growth of the Latino population in the U.S. has been dramatic over the last 10 years. From 1990 to 2000, the Latino population increased by 57.6%, from 22.4 million in 1990, to 35.3 million in 2000. This is significant when compared to the 13.2% growth of the overall U.S. population during this same time period.

Geographically, half of all Latinos living in the United States reside in two states: California and Texas. However, different Latino groups are concentrated in different states. For example, the largest Puerto Rican population (outside of Puerto Rico) resides in New York and Florida, whereas the largest Mexican populations are reported to be living in California and Texas.

The impact of HIV and AIDS in Latino communities is disproportionate when compared to other racial and ethnic groups.

Although current numbers of HIV and AIDS cases among Latinos are not increasing as quickly as the population figures reported by the Census, the impact of HIV and AIDS in Latino communities is disproportionate when compared to other racial and ethnic groups. In 2000, Latinos represented 13% of the U.S. population (including residents of Puerto Rico), but accounted for 19% of the total number of new AIDS cases reported among adults and adolescents (8,140 of 41,960 cases). The annual reported AIDS rate per 100,000 population (the number of new cases of a disease reported during a specific time period) among Latinos in 2000 was 30.4. This was almost four times the rate for Whites (7.9), but lower than the rate for African Americans (74.2). As demonstrated in the Census data, Latinos in the United States include a diverse mixture of ethnic groups and cultures. Similarly, as reported in the CDC HIV/AIDS Surveillance Report, Volume 12, Number 2, exposure/transmission categories for U.S.-born Latinos and Latinos born in other countries vary greatly (see chart below). As a result, there is a need for specifically targeted prevention efforts.

Latino	U.S.	MEXICO	PUERTO RICO
Men who have Sex with Men	30%	44%	14%
Injection Drug Users	24%	9%	48%
Heterosexuals	11%	14%	25%

According to the HIV/AIDS Surveillance Report, Volume 12, Number 2, between 1993 and 1999, the characteristics of persons living with AIDS in the U.S. were changing. The epidemic was expanding, particularly in minority populations. In 1993, 18% of those estimated to be living with AIDS were Latino, while in 1999, 20% were Latino. By comparison, non-Latino whites represented 46% of people estimated to be living with AIDS in 1993, but that number had fallen to 38% by 1999. Cumulatively, males account for the largest proportion (77%) of AIDS cases reported among Latinos in the United States, although the proportion of cases among women (23%) is rising.

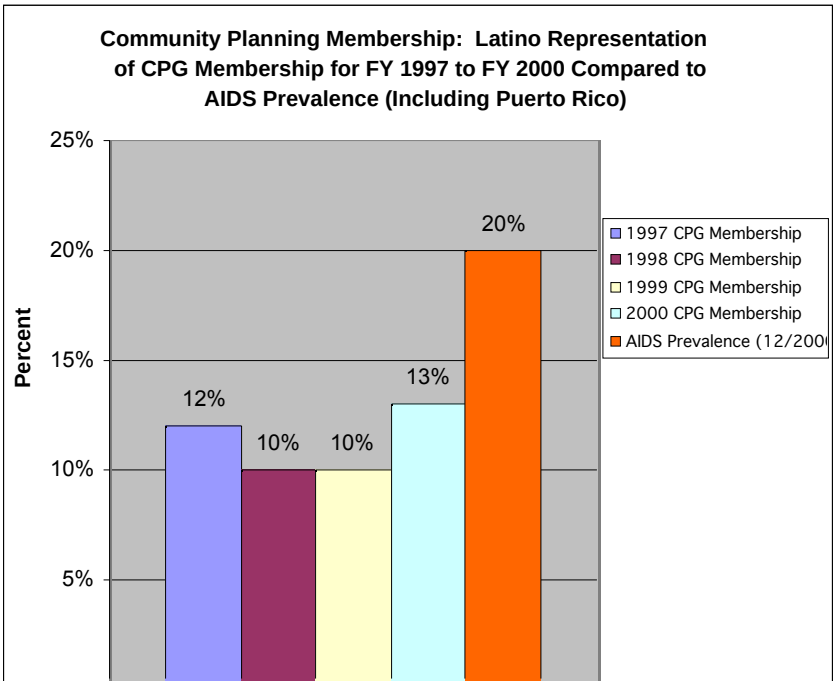
From the beginning of the epidemic through December 2000, 114,019 Latino men have been reported with AIDS in the United States. Of these cases, men who have sex with men (MSM) represent 42%,

injection drug users (IDUs) account for 35% of cases; 6% of cases were due to heterosexual contact. About 7% of cases are among Latino men who both had sex with men and injected drugs. Among men born in Puerto Rico, however, injection drug use accounts for a significantly higher proportion of cases than male-to-male sex. For adult and adolescent Latinas, heterosexual contact accounts for the largest proportion (47%) of the 25,643 cumulative AIDS cases. Among Latinas, most cases are linked to sex with an injection drug user. Injection drug use accounts for an additional 40% of cumulative AIDS cases among U.S. Latinas.

Large groups of Latinos reside in states such as California, Florida, New York, Texas, and the territory of Puerto Rico. Data from CDC's HIV/AIDS Surveillance Supplemental Report, Volume 7, Number 1, indicate that the geographic distribution of reported AIDS cases among Latinos follows a similar pattern. (See chart below.) This type of data is just one example of the information used to develop epidemiologic profiles for each state and locality through the HIV prevention community planning process. These epidemiologic profiles, in turn, inform the development of a comprehensive plan for HIV prevention appropriate to that jurisdiction. (For more information on the impact of HIV/AIDS in a jurisdiction, contact the state or local health department.)

States/Territories with Highest Number of Latinos Living with AIDS. Through 1999	
New York	17,242
California	11,109
Puerto Rico	9,195
Florida	5,527
Texas	4,967

According to CDC's Guidance for HIV Prevention Community Planning, each Comprehensive HIV Prevention Plan, accompanying a jurisdictional health department application to CDC for prevention funds, must include accurate demographic data on the racial and ethnic make-up of each CPG. The Division of HIV/AIDS Prevention at CDC compiles this demographic data on racial/ethnic minority group CPG members and analyzes it on an aggregate basis. Data specific to Latino CPG membership during the last four years are compared here with AIDS prevalence among Latinos, through 2000. (See chart on Community Planning Membership.)



The CDC Guidance for HIV Prevention Community Planning states that the CPG process should "…attempt to accommodate a reasonable number of representatives without becoming so large that it cannot effectively function." While the national data in this chart is disappointing, it may not represent what may be happening in each state or

locality in terms of Latino representation on planning groups. For example, some planning groups may be using Latino advisory bodies or other avenues to obtain input on community planning. However, the Guidance also states, "HIV prevention programs developed with input from affected communities are likely to be successful in garnering the necessary public support for effective implementation and in preventing the transmission of HIV infection." Considering this statement, the disparity between Latino CPG membership and AIDS prevalence, and the disproportionate impact of the AIDS epidemic on Latinos, it is clear that increased Latino representation on CPGs would contribute to more effective prevention programs targeted to Latinos.

It is clear that increased Latino representation on CPGs would contribute to more effective prevention programs targeted to Latinos

Key factors in design and development of HIV prevention programs and interventions for Latinos include population and demographic information as reported in Census 2000, disproportionate numbers of new AIDS cases reported among Latinos, and disproportionately representation of Latinos on CPGs. With the majority of Latinos living in areas where AIDS case rates are relatively high, infection is likely to continue to increase among Latino groups (Carpio, 2001). This, along with continuing trends in new infections among Latinos, underscores the importance of Latino involvement in the HIV prevention community planning process.

Importance of Latino Representation

To ensure that HIV prevention community planning is accomplished in a participatory manner, CDC requires that all CPGs address the principles of HIV prevention community planning as stated in its supplemental Guidance for HIV Prevention Community Planning. The first of the fifteen principles recommended by CDC states the following:

> HIV prevention community planning reflects an open, candid, and participatory process in which differences in cultural and ethnic background, perspectives, and experiences are essential and valued.

Participatory planning for HIV prevention is designed to secure a broad range of perspectives, build consensus, and mobilize resources to make decisions about HIV prevention programs. The participation of Latinos in HIV Prevention Community Planning is crucial to identifying effective prevention interventions for Latinos. Given this reality, Latino communities must take three crucial steps in becoming part of territorial, local, state, and federal responses to HIV transmission.

The first step is to provide more local expertise to support prevention programs that consider the special characteristics, needs and preferences of the communities these programs are designed to reach. The second step is to assist in the development sign of Comprehensive HIV Prevention Plans, which require multifaceted input from communities affected by HIV, including those experiencing disproportionate rates of infection and those at disproportionate risk. The third step is to change behavioral norms. The strategy of changing risk-taking behaviors is more likely to be successful if people are involved in the initiation and promotion of safer behaviors.

How Latino communities can participate in HIV prevention planning:

1. Provide local expertise to support prevention programs that consider the special characteristics, needs, and preferences of the communities these programs are designed to reach.
2. Assist in the development of Comprehensive HIV Prevention Plans, which require multifaceted input from communities affected by HIV; including those experiencing disproportionate rates of infection, as well as those at disproportionate risk.
3. Change behavioral norms.

Participatory planning for HIV prevention requires both balance and integration of perspectives such as epidemiologic information, programmatic experience, and perspectives from affected communities, including Latinos. HIV prevention programs developed without this collaboration are unlikely to be successful in preventing the transmission of HIV infection or in garnering the necessary public support for effective implementation. Latinos at risk for HIV infection and living with HIV/AIDS should play a key role in identifying prevention needs not adequately being met by existing programs and planning for needed services that are culturally appropriate (CDC, 1998).

A CPG can be carefully constituted in terms of membership, but if Latinos at risk for HIV infection and Latinos living with HIV/AIDS do not have parity, inclusion, and representation (PIR) and participate actively and fully – attend, speak, listen, and are heard – then being “balanced on paper” will have little impact in the HIV Prevention Community Planning process (NCLR, 1994). Some CPGs have found it difficult to recruit such individuals – or to retain them once selected – because they may not find the planning group a comfortable environment.

It is imperative that CPGs demonstrate to Latinos that their involvement will make a difference. If, for example, a Latino member is encouraged to provide the unique perspective of his/her population, and shown that others will listen to what is said, then participation will appear important. If, on the other hand, it appears that membership will be largely passive or reactive, then participation will not seem worthwhile. Current CPG members can be important in dispelling these concerns for potential Latino members. Latinos are likely to consider CPG participation worthwhile if they believe it will lead to a better

understanding of their community's needs, and, ultimately, to an equitable response to Latino needs within the HIV prevention system. However, when Latino members believe that priorities have already been set, or that the overall CPG will not be sensitive to the needs of their communities, they may conclude that participation is not worthwhile.

> Often those who most need to be heard [in the Community Planning process] are those least likely to participate.

The community planning process can provide opportunities for personal and professional growth, including: training and practical experience through testifying, chairing a committee, facilitating a meeting, public speaking, conducting media relations, performing research and analysis, and developing materials. It can also provide an environment in which prevention can be discussed openly. Community planning facilitates access to information and facts, which in turn may be widely disseminated to local Latino communities. The inclusion of Latino members may increase the likelihood that the HIV/AIDS-related information will be provided in a culturally- and linguistically-appropriate manner.

Often those who most need to be heard are those least likely to participate. Examples of such unheard voices may include persons with limited experience of working in large forums, persons already infected with HIV, and persons from culturally different backgrounds. The first of many challenges for the CPG is to understand these differences. The second challenge is to integrate Latinos into the group. Despite the best of intentions, diversity can create stumbling blocks for a CPG in three key areas:

- Process – Latinos may think about and act upon projects and tasks differently. There may be marked differences in decision-making styles, timeframes, and methods for planning and acting.
- Language – in addition to the potential of Spanish being a first or second language, various Latino subgroups communicate with each other in different, unique ways, using particular words and figures of speech to express themselves.
- Etiquette – Latinos have certain norms for acceptable and unacceptable behavior, particularly when conflicts arise. These may differ from the norms of other members of a CPG.

Latino members, like members of other ethnic/racial minority communities, may lack prior experience and therefore, may not initially have the capacity to participate fully in the planning process. As such, the planning effort, to fully benefit from the community's involvement, should undertake efforts such as group training members in decision-making and should make provisions to allow for active participation. Attention to parity and an orientation to community planning will result in Latino members having the capacity to participate fully, thus providing a balanced and accurate reflection of community HIV prevention needs.

Membership in the CPG can provide other benefits. Certainly, one of the most valuable benefits of planning group involvement is the opportunity to learn more about the local community and networks with dedicated colleagues. While the process can be difficult, the information and understanding gained should prove useful for everyone involved. Keeping this in mind can help make the challenges worth overcoming.

BARRIERS AND CHALLENGES

The fact that a number of CPGs lack adequate Latino representation can affect the development of a comprehensive plan and, in turn, the quantity and quality of HIV prevention programs in Latino communities. Given this premise, the question remains: What are the factors that limit Latino participation in HIV Prevention Community Planning?

With this question in mind, Latino staff of the CDC National Technical Assistance (TA) Providers' Network facilitated sessions — "The Latino Experience in Community Planning" — during two national conferences and one regional meeting in 2001 (Community Planning Leadership Summit in Houston, TX; CDC Capacity Building for HIV Prevention in Atlanta, GA; and Enlaces: Skills Building for the Latino Community in El Paso, TX). Participants were asked:

> What are some un-addressed barriers to gaining and sustaining Latino involvement in your CPG?

What are the factors limiting Latino participation in HIV Prevention Community Planning?

Latino staff documented the answers and synthesized them into barrier-related themes below. The following themes describing barriers encountered by Latinos in the HIV Prevention Community planning process appear in order of greatest to least number of comments provided by participants.

Social/Cultural

- Stigma associated with AIDS "rechazo" (rejection)
- Diversity among different Latino sub-populations
- AIDS impact on Latino communities not known within the community
- Interlinked issues of religion, fatalism, machismo, gender, and denial ("AIDS doesn't happen to us!")
- Limited educational background
- Cultural issues: stigma associated with being identified as gay, a man who has sex with men, or AIDS-infected and resulting reluctance to identify as one of these

Recruitment/Retention

- Lack of knowledge of CPG process and CPG members' roles and responsibilities
- Lack of Involvement and participation of women and seasonal migrant workers
- Lack of inclusion of Latinos in HIV prevention plan (Latinos not a priority)
- Lack of information and orientation; the CPG process needs to be marketed to Latinos
- Inconsistency of CPG process, lack of knowledge of the goal of the CPG process
- Failure to address barriers to meeting attendance: needs and challenges of potential members (childcare, transportation, cost, multiple jobs, incentives, and meeting times); location of meetings, urban vs. rural (distance some members must travel to meeting)
- Lack of role models, especially peer role models

Self-efficacy/Skills

- Lack of orientation to community planning and skills building which results in the lack of sustaining Latino participation
- Lack of belief on the part of the CPG leadership in Latino participants' skills and abilities
- CPG leadership and Latino participants' need to believe in the importance of participation
- Lack of mentoring and orientation for Latinos in the CPG process

Cultural Sensitivity/Cultural Competency

- Lack parity among Latino participants
- Generalizations of Latinos; lack of recognition and awareness of diversity (different backgrounds of Latin America, i.e. South and Central America and the Caribbean);
- Lack of awareness and recognition of Latino varying social distinctions by region and/or country
- Lack of sensitivity to Spanish-only speakers
- Lack of Spanish-language materials; not recognizing the difference between translation and interpretation; not producing materials that are culturally targeted to the local Latino groups (i.e., Mexican, Puerto Rican, Cuban, Dominican, etc.)

Trust

- Lack of trust in and negative experiences with health departments, governmental agencies, and AIDS Service Organizations (ASOs)
- CPG membership policies of disclosure and confidentiality fail to recognize the risk and stigma of Latino association with homosexuality, having AIDS, or non-documented immigration status

Conflict

- Victimization
- Competition among different racial/ethnic groups
- Contentiousness of the community planning process; lack of skills in resolving conflict appropriately; internal conflict among Latino community members
- Classism

Reactive/Proactive Orientation

- Crisis-orientation among some Latino CPG participants
- Fatalism
- Lack of access to and flow of information

Lack of Results & Outcomes

- "puro hablar sin acción" (all talk no action); lack of interest due to intangible results
- Perception that others focus on process to the detriment of results

Representation of Agencies, Not Community:

- Conflict of interest due to dual representation
- Perception of tokenism/lack of power; arbitrary assignment by community-based organizations (CBOs) or ASOs to the CPG

Marginalized Population Not Being Served:

- Lack of representation of migrant/seasonal farmworkers, injection drug users, people living with HIV/AIDS, and non-gay identified men who have sex with men

The challenges listed do not solely pertain to the Latino community. Moreover, while social and cultural factors exist in limiting participation, the community planning process itself requires regular maintenance to ensure inclusive and productive results. The next steps could include CPGs using this information to address Latino membership. More importantly, Latino members should understand both the challenges they face and the role they can play in achieving PIR in their CPGs.

ADDRESSING THE BARRIERS AND CHALLENGES

Participants in the sessions also recommended strategies to foster Latino recruitment and approaches to sustain Latino participation in the HIV prevention community planning process. Some participants stated that some of these recommendations were already being implemented in their jurisdiction. The following themes describe initiatives that address the issue of Latino participation in the HIV prevention community planning process:

- Co-sponsoring roundtable discussions with other planning groups to discuss barriers; making personal efforts to reach Latinos (e.g., phone calls, mail).
- Providing capacity-building assistance to CBOs on community planning to encourage their participation in the community planning process.
- Pursuing conversations with stakeholders and key HIV/AIDS community players outside of the community planning process to encourage participation.
- Developing an effective process for reviewing community planning guidelines and community planning group by-laws.
- Fostering coalition building within community planning groups; educating community leaders on the community planning process.
- Facilitating roundtable discussions in Spanish and/or providing language translation.
- Making commitments or resolutions to involve more Latinos in the community planning process.
- Providing comprehensive orientation and mentoring to new and ongoing members.
- Rotating meeting places and creating spaces for informal meetings.
- Holding meetings during hours that accommodate community participation (e.g., time, day, and locations).
- Providing incentives for participation (e.g., child care, transportation, meals, etc.).

In addition, some members of CDC's National Technical Assistance Providers' Network for HIV prevention community planning have provided PIR technical assistance relating to Latino involvement. As a result, the following can be added to the previous list:

- Marketing the importance of community planning in Latino communities
- Developing a Latino or People of Color committee within CPGs to address recruitment and retention issues
- Providing cultural sensitivity and competency workshops/training to CPG members
- Advertising CPG meetings as a public meeting for the community at-large
- Developing marketing tools that document the accomplishments of past CPG processes

These activities are not exclusive to achieving PIR among Latinos in the community planning process. Other communities of color may be using some of the same strategies. As documented in the following section, several CPGs have implemented strategies to address the barriers that limit Latino participation in community planning.

EXAMPLES OF LATINO INVOLVEMENT IN COMMUNITY PLANNING

Many community planning groups have been or are starting to address the issues of PIR for Latinos. The following are some examples of how health departments and community planning groups are addressing PIR for Latinos the community planning process. The four examples below come from responses to a questionnaire sent to a number of jurisdictions with large Latino populations. The survey asked for a description of activities and strategies used to recruit and retain Latino CPG members. (Please refer to the appendix for contact information.)

Texas: Regional Representation

In 2000, Texas completed a restructuring from 11 prevention planning groups to 6. The resulting six CPGs represent a widely diverse population and epidemic across this large state. Each group strives to achieve CPG representation that reflects that area's unique epidemic; therefore, Latino representation is more crucial in some areas of the state than in others. In the most recent PIR report sent to the CDC, Latino representation on all six CPGs met or exceeded population and epidemic profile estimates by geographic area, reflecting success in recruitment of Latinos to community planning.

Texas conducts community planning through the partnership of the CDC, the Texas Department of Health (TDH), a contractor to provide technical assistance on community planning processes, and CPG leadership comprised of one TDH-appointed co-chair and one community elected co-chair for each of the six areas. Two contractor consultants who are Latino also serve these three plan areas. All six areas have Latinos in leadership roles, such as community co-chair-elect, intervention selections committee, and core group leaders (for defined areas within the larger planning areas). A Price Fellowship was awarded to a Latino CPG member from Texas in 1999. (The fellowship allows representatives from three non-governmental, community-based organizations to spend a month at the CDC in Atlanta. Price Fellows explore with CDC professionals the latest, most effective approaches to HIV prevention.) Latinos are also recruited as CPG members through involvement with CBOs who target Latinos and/or address Latino issues related to HIV and STD prevention.

New Jersey: Recruitment Efforts

New Jersey has steadily maintained a 15-20% Latino representation on its CPG. This is equivalent to the Latino proportion of the epidemic in New Jersey. Representation includes Latinos at risk for infection and those living with HIV/AIDS.

There are generally adequate numbers of applications for CPG membership from the Latino community in New Jersey. As a result, when nominations occur, and Latino representation needs to be maintained, there are community members waiting to fill vacancies. Latinos have served as community co-chairs, and Latino committee chairs serve as leadership role models. One reason for the proportional representation on the New Jersey CPG is that the CPG makes an effort to maintain strong collaborations with CBOs and community leaders.

Michigan: Membership Committees

The Michigan HIV/AIDS Council (MHAC) – the statewide planning group – and regional planning groups rely on membership committees and individual members and member organizations for recruitment of Latinos to the community planning process. Members identify and invite potential members to attend CPG meetings. They try to assess potential members' interest in joining and encourage those interested to submit a formal application. The Latino workgroup, a membership committee, provides recommendations to the MHAC on issues affecting Latinos. In addition to providing important input to the larger body, the Latino Workgroup facilitates recruitment and retention of Latino members by providing an opportunity to influence policies that affect Latinos.

The Latino Workgroup is currently compiling a resource inventory of health and human service agencies serving Latino communities. The inventory will serve as a foundation to assess gaps in HIV-specific resources and guide priorities for capacity building relative to HIV services targeting the Latino community.

Florida: Minority Network

In Florida, they recruit members into the community planning process through newsletters, newspaper advertising, posters and flyers, television, outreach workers, radio, word-of-mouth, and sponsorship of public events at parks and other social gathering places. Another recruitment strategy the community planning partnerships have used is rotation of meeting sites throughout an area to facilitate accessibility by community members who may not have a means to travel to a meeting due to financial, health or other reasons.

The Florida HIV/AIDS Minority Network actively recruits Latinos into the Network from areas of the state where they represent a significant proportion of the total population or where HIV prevention efforts among the Latino population are minimal and warrant local initiatives. These volunteers, who act as liaisons, are responsible for a number of activities that include participating in the local community planning process. Once active on the local level, liaisons are in a position to be nominated and appointed to the Florida Community Planning Group (FCPG).

CONCLUSION

National community planning membership data indicate Latino CPG membership has remained at 10 –13% over the last four years. However AIDS prevalence data through June 2000 show that Latinos represent 20% of AIDS cases.

"Camaron que se duerme se lo lleva la corriente."

Latino involvement in the HIV prevention community planning process is a necessary step towards the development and prioritization of appropriate interventions to stem the tide of HIV/AIDS in Latino communities. With the dramatic rise of the Latino population in the United States, and the disproportionate increase in HIV and AIDS in the Latino community, health departments and CPGs must take a leadership role in ensuring PIR of Latinos and other communities of color**. The Latino community must also take responsibility for its own involvement and representation on CPGs.** Communities have the ability to make their voices heard beyond their immediate surroundings. Barriers and challenges facing the Latino community that hinder the development of targeted prevention programs can be overcome. Initiatives for PIR, as described in this document, can assist the community in surmounting some of these barriers and challenges.

Some Health Departments and CPGs across the country have implemented innovative strategies to recruit and retain Latino involvement in their community planning processes. These examples include minority networks, membership committees, enhanced recruitment efforts, and regional representation. The data and examples described in this report should serve as a springboard for developing and implementing initiatives in other jurisdictions that need to increase Latino representation. In order for this to occur, the CPGs should take the following actions:

- Communities that lack Latino representation should communicate with CPGs that are fostering Latino participation (networking is crucial for change);
- Become informed about the variety of Technical Assistance and Capacity Building services available to CPGs, especially knowledge of TA providers that specialize in cultural diversity issues to involve/retain Latinos; and
- Raise your voices — CPGs that have made the initial steps in getting Latinos to the planning table and support for the Latino community should share their efforts and disseminate their results. (e.g., conferences, workshop presentations, etc.).

Without Latino representation on CPGs and other planning bodies, the Latino community will continue to be underserved and underrepresented, and will continue to be disproportionately affected by HIV/AIDS. There is a dicho or saying:

"Camaron que se duerme se lo lleva la corriente."

In the context of HIV prevention community planning, this dicho can be interpreted to mean that if Latinos do not wake up and realize the impact of HIV/AIDS in their community and the importance of their voices, then they will be swept away by the tide of complacency. The message is clear—the Latino community must take an active role in community planning, and that time is now.

REFERENCES

Academy for Educational Development. HIV Prevention Community Planning: An Orientation Guide, January 1999, p 3.3.

Carpio FF. Social, Cultural, and Epidemiologic Considerations in HIV Disease Management in US Latino Populations. Topics in HIV Medicine. 2001; 9 (No.2). Available at http://hivinsite.ucsf.edu/InSite.jsp?doc=md-04-01-11. Accessed on July 11, 2001.

Centers for Disease Control and Prevention. HIV/AIDS Among Hispanics in the United States. Available at http://www.cdc.gov/hiv/pubs/facts/hispanic.htm. Accessed on June 11, 2001.

Centers for Disease Control and Prevention. HIV/AIDS Surveillance Report; 12 (No.2).

Centers for Disease Control and Prevention. HIV/AIDS Surveillance Supplemental Report, 2001; 7 (No.1): 9.

Centers for Disease Control and Prevention. Supplemental Guidance on HIV Prevention. 1998.

Centers for Disease Control and Prevention. Guidance: HIV Prevention Community Planning. 1993.

National Council of La Raza. Do's and Don'ts for an Inclusive HIV Prevention Community Process: A Self-Help Guide. 1994.

U.S. Census Bureau. The Hispanic Population: Census 2000 Brief. Washington DC. U.S. Census Bureau. Available at http://www.census.gov/main/www/cen2000.html. Accessed on July 10, 2001.

GLOSSARY

Term	Definition
AED*	Academy for Educational Development
AFY*	Advocates for Youth
AIDS	Acquired Immunodeficiency Syndrome
APA-BSSV*	American Psychological Association Behavioral and Social Scientist Volunteer Program
APIAHF*	Asian and Pacific Islander American Health Forum
ASO	AIDS Service Organization
Bright Ideas	A compilation of noteworthy practices from selected states, including strategies for supporting the community planning process as well as innovative approaches to HIV prevention program service delivery
CBA	Capacity Building Assistance; see TA
CBO	Community-based Organization
CDC	Centers for Disease Control and Prevention
CPG	Community Planning Group
CPLOT	Community Planning Leadership Orientation and Training is a joint regional skills-building training program presented by NMAC and NNAAPC.
CPLS	Community Planning Leadership Summit is an annual national skills-building conference for those involves in the HIV Prevention Community Planning Process. CPLS is sponsored by AED, CDC, NASTAD and NMAC.
ENLACES	ENLACES is a skill building course designed to increase Latino participation in the HIV Prevention Community Planning process at the local, state and regional levels, strengthen skills, promote stronger linkages between Latinos in the region, and create new strategies for collaboration and support. ENLACES is presented by the USMBHA in partnership with Latino CBOs.
EPI	Abbreviation for Epidemiology
GMOC	Gay Men of Color
Guidance	Provides the basic framework for CDC HIV prevention grantees (state and local health departments) to implement HIV prevention community planning. In December of 1993, the CDC officially initiated HIV Prevention Community Planning. In the summer of 1998, CDC issued a revised Guidance for HIV Prevention Community Planning
HIV	Human Immunodeficiency Virus
IDU/IVDU	Injection Drug User / Intravenous Drug User
Inclusion	The assurance that the views, perspectives, and needs of all affected communities are included and involved in a meaningful manner in the community planning process
MSM	Men who have Sex with Men
NAPWA*	National Association of People With AIDS
NASTAD*	National Alliance of State and Territorial AIDS Directors
NMAC*	National Minority AIDS Council
NNAAPC*	National Native American AIDS Prevention Center
Parity	The concept whereby all members of the community planning group are provided opportunities for orientation and skills building to participate in the planning process and to have equal voice in voting and other decision-making activities
PIR	Parity, Inclusion, and Representation
Representation	The assurance that those who are representing a specific community truly reflect that community's values, norms, and behaviors
STD	Sexually Transmitted Disease
TA	Technical Assistance; TA is designed to support your CPG and its members to accomplish the necessary steps and principles of Community Planning in a helpful and positive manner
USMBHA*	U.S. – Mexico Border Health Association

***National Technical Assistance Provider**

CDC National TA Provider's Network for Community Planning

The Academy for Educational Development Center for Community-Based Health Strategies
www.healthstrategies.org
www.hivaidsta.org
1825 Connecticut Avenue, NW
Washington, DC 20009-5721
Phone: (202) 884-8862

Advocates for Youth
www.AdvocatesForYouth.org
Suite 200
1025 Vermont Avenue NW
Washington, DC 20005
Phone: (202) 347-5700

The American Psychological Association Behavioral and Social Science Volunteer Program
www.apa.org/pi/aids/bssv.html
American Psychological Association Public Interest Directorate
750 First Street, NE
Washington, DC 20002
Phone: (877) 754-1404

Asian & Pacific Islander American Health Forum
www.APIAHF.org
942 Market Street, Suite 200
San Francisco, CA 94102
Phone: (415) 954-9988

Washington D.C. Area:
440--1st Street N.W., Suite 430
Washington, D.C. 20001
Phone: (202) 624-0007

Centers for Disease Control and Prevention, Division of HIV/AIDS Prevention
www.cdc.gov

The National Association of People with AIDS
www.NAPWA.org
1413 K Street, NW
Washington, DC 20005-3442
Phone: (202) 898-0414

National Alliance of State and Territorial AIDS Directors
www.NASTAD.org
www.hivaidsta.org
444 N. Capitol Street, NW
Suite 339
Washington, DC 20001
Phone: (202) 434-8090

National Minority AIDS Council

www.NMAC.org
1931 13th Street, N.W.
Washington, DC 20009
Phone: (202) 483-NMAC (6622)

National Native American Aids Prevention Center
www.NNAAPC.org
436-14th Street, Suite 1020
Oakland, CA 94612
Phone: (510) 444-2051

U.S.-Mexico Border Health Association
www.USMBHA.org
5400 Suncrest Dr., Suite C-5
El Paso, TX 79912
Phone: (915) 833-6450

Internet

www.hivaidsta.org - A one-stop shop for HIV Prevention community planning materials, peer samples, hot links to CPGs, list serves and more. This site is a joint project of the Academy for Educational Development's Center for Community-Based Health Strategies and the National Alliance of State and Territorial AIDS Directors.

www.cdcnpin.org/rellinks.htm#planning - The CDC National Prevention Information Network's listing of HIV Prevention Community Planning resources and links.

http://hivinsite.ucsf.edu/InSite.jsp?page=pr-02-03 - HIV InSite's listing of HIV Prevention Community Planning resources and links.

PUBLICATIONS

Community Planning Guidance (English)
Available at www.hivaidsta.org
This CDC Guidance provides the basic framework for CDC HIV prevention grantees (state and local health departments) to implement HIV prevention community planning. In January of 1994, the CDC officially initiated HIV Prevention Community Planning. In the summer of 1998, CDC issued a revised Guidance for HIV Prevention Community Planning.

La Guía para el Planificación Comunitaria para el Prevención del VIH
(Spanish language Guidance)
Available at www.hivaidsta.org
La Guía provee un esquema para los departamentos de salud estales y locales para implementar el modelo de planificación comunitaria para el prevención del VIH. En enero de 1994, los Centros de Prevención y Control de Enfermedades (CDC, por su siglas en ingles), inicio planificación comunitaria. En el verano de 1998, el CDC revisó la Guía para planificación comunitaria. La coordinación y la traducción de esta Guía fue realizada por la Academia para el Desarollo Educativo y revisado por miembros Latinos/Hispanos de grupos de planificación y provedores Latinos/Hispanos de asistencia técnica.

Assessing the Need for HIV Prevention Services: A Guide for Community Planning Groups
(August 1999)
Available at www.hivaidsta.org
This guide developed by AED, is intended to help HIV prevention community planning groups (CPGs) design, implement, update, and manage useful needs assessments. It will also be instrumental in: (1) Furnishing the information needed to make informed decisions about priorities regarding target populations and prevention strategies; and (2) Meeting the requirements and expectations of the Centers for Disease Control and Prevention (CDC), as defined in the Guidance for community planning.

Bright Ideas 2001
Available at www.hivaidsta.org
This publication, first distributed at the Community Planning Leadership Summit for HIV Prevention in Houston (March 2000), is a compilation of noteworthy practices from 17 states and includes strategies for supporting the community planning process as well as innovative approaches to HIV prevention program service delivery. Each example provides a program description and contact information. These practices were identified during the CDC External Review of health department HIV prevention cooperative agreement applications and comprehensive plans. NASTAD and AED produced the document, with funding from CDC.

The Collaboration Continuum
Available from NMAC
Provides AIDS Service Organizations with tools for choosing and negotiating new collaborations with prospective partners or to support existing collaborations. The manual provides a description of many types of collaborations, including community planning, to assist the organization in recognizing and pursuing opportunities to better serve their communities.

Facilitating Meetings: A Guide for Community Planning Groups (August 2001)
Available at www.hivaidsta.org
This guide developed by AED, is intended to assist community planning group (CPG) co-chairs, committee chairs, members, and external facilitators in preparing for and facilitating CPG meetings. Chapters include Using Core Skills and Tools, Facilitating the Opening, Facilitating Discussions and Decisions, Facilitating the Conclusion, and Dealing With Challenges.

HIV Prevention Among Drug Users: A Resource Book for Community Planners and Program Managers (March 1997)
Available at www.hivaidsta.org
This document developed by AED, is intended to support the need of prevention planners and program managers involved in the community planning process to learn about and understand the critical issues associated with drug use, sexual behavior, HIV transmission, and their interrelationships. It is only through such understanding that wise decisions can be made about program priorities and design.

HIV Prevention Community Planning: An Orientation Guide (January 1999)
Available at www.hivaidsta.org

This guide developed AED, is meant to provide an orientation to the principal components of HIV prevention community planning for new, as well as seasoned, members of community planning groups (CPGs). The guide presents standardized, user-friendly information on HIV prevention community planning to prepare CPG members to be effective in carrying out their community planning roles and responsibilities. It is not, however, designed to provide in-depth information on the specialized planning processes used in specific project areas and CPGs (for example, how the community planning process works in a particular city or state, how decision-making is carried out, or which priority-setting approach to use).

HIV Prevention Community Planning: Successes and Challenges, (January 1998)
Available at www.hivaidsta.org
This fact sheet, produced by CDC in 1998, identifies the core objectives of community planning. Successes and challenges of community planning are then discussed. The document concludes by providing information on the types of technical assistance available for community planning.

NASTAD Issue Brief: Technical Assistance and Capacity Building (March 2000)
Available at www.hivaidsta.org
This issue brief, published by NASTAD, provides an overview of capacity building, why it is important, and the role that health departments can play in the process. The brief provides short summaries of capacity building activities conducted by five health departments: Colorado, Florida, Maryland, Massachusetts, and Rhode Island.

NASTAD HIV Prevention Update and Community Planning Bulletin
Available at www.hivaidsta.org
NASTAD produces a monthly newsletter on HIV prevention, the HIV Prevention Bulletin. Critical current issues in HIV prevention and surveillance are highlighted through specially focused issues of the Bulletin. Each newsletter features a calendar of upcoming events and conferences. More than 1,600 individuals receive the newsletters.

NASTAD TA Report: Youth of Color TA Report
Available at www.nastad.org
Case studies from several jurisdictions on efforts and strategies to involve youth of color in th HIV Prevention community planning process.

Setting HIV Prevention Priorities: A Guide for Community Planning Groups (October 2000)
Available at www.hivaidsta.org
This document developed by AED, is meant to serve as a reference guide and workbook for HIV prevention community planning groups as they perform the following tasks:
Develop a clear priority setting process that is acceptable to the community, the health department, and the Centers for Disease Control and Prevention (CDC) or reviewing and modifying the existing priority setting processes;
Orient new members and health department staff to the priority setting process;
Make explicit the factors used to set priorities; and Document the evidence used to justify decisions.

The guide is designed for individuals and committees who set HIV prevention priorities. Each chapter includes a list of priority setting tasks to complete with the relevant portion of a priority-setting scenario to illustrate the process. At the end of each chapter worksheets are provided to help you carry out the tasks.

Self-Assessment Tool for HIV Prevention Community Planning (May 1995)
Available at www.hivaidsta.org
This assessment tool developed by AED, is designed to accomplish two specific objectives: (1) To provide community planning groups with a practical, easy-to-use- instrument to assess and enhance their community planning process; and (2) To assist community planning groups in identifying their needs for technical assistance.
The individual sections of this assessment tool correspond to major planning tasks as defined in the Guidance on HIV Prevention Community Planning. Each section can be used independently — if your CPG wishes to assess progress in areas related to PIR, the CPG needs to complete only that section of the tool. Or your CPG can complete all the sections to explore the major components of the overall planning process.

Understanding the Basics: HIV Prevention Community Planning
Available from NMAC
An introduction to the process involved in forming, participating and getting the most out of HIV Prevention Community Planning Groups. It includes a list of resources available for guidance and procuring technical assistance, as well as community real-life experiences from across the nation regarding community planning.

What Intervention Studies Say About Effectiveness: A Resource for HIV Prevention Community Planning Groups (May 1996)
Available at www.hivaidsta.org
This document developed by AED, has been prepared specifically to help planning groups in using behavioral science more effectively. The document focuses on demonstrated effectiveness of interventions – one of the core considerations in HIV prevention community planning. The studies included in the document are not the only important studies, nor do they provide a comprehensive view of the evaluation literature. They do, however, represent a range of interventions, a diversity of target populations, and a mix of research designs. Examples have been selected for their utility to planning group deliberations and for their evaluation approach.

Compendium of HIV Prevention Interventions with Evidence of Effectiveness (November 1999)
Available at www.cdc.gov/hiv/pubs/hivcompendium/organize.htm
The Compendium was developed for prevention service providers, planners, and others who require science-based interventions that work. This document provides summaries of state-of-the-science interventions with evidence of reducing sex- and/or drug-related risks and the rate of HIV/'STD infections. These interventions have been effective with a variety of populations, e.g., clinic patients, heterosexual men and women, high-risk youth, incarcerated populations, injection drug users, and men who have sex with men. They have been delivered to individuals, groups, and communities in settings such as storefronts, gay bars, health centers, housing communities, and schools. To be included in the

Compendium, an intervention had to come from a behavioral or social study that had both intervention and control/comparison groups and positive results for behavioral or health outcomes.

CONTACT INFORMATION FOR EXAMPLES OF LATINO INVOLVEMENT

Lisa M. Mackey, MSW
Prevention Program Advisor
Bureau of HIV/AIDS, Prevention Section
Tel: (850) 245-4444, x 2592
Fax: (850) 487-1521
E-mail: Lisa_Mackey@doh.state.fl.us
Website: www.doh.state.fl.us/disease_ctrl/aids/

Francisco J. Michel
HIV Prevention Consultant
Michigan Department of Community Health
Division of HIV/AIDS
2747 Woodlake Circle Suite 300
Okemos, Michigan 48864
Tel: (517) 241-5900
Fax: (517) 241-5922
E-mail: michelf@state.mi.us
Website: www.mdch.state.mi.us/dch/hiv_aids.htm

Steven Saunders
Director, Prevention and Education
New Jersey Department of Health and Senior Services
Division of AIDS Prevention and Control
PO Box 363
Trenton, NJ 08625-0363
Tel: (609) 984-6050
Fax: (609) 292-4244
E-mail: esaunders@doh.state.nj.us

Shirley Broussard
Planning Branch Manager
Texas Department of Health Bureau of HIV/STD
Prevention; Health Resource Division
1100 W 49th
Austin, Texas 78756
Tel: (512) 458-2525
Fax: (512) 490-2534
E-mail: Shirley.Broussard@tdh.state.tx.us
Website: www.tdh.state.tx.us/hivstd/planning/commplan.htm