

Report

Latino Community Consultation:

Access to HIV/AIDS Care Issues

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Doubletree Hotel and Executive Meeting Center
1750 Rockville Pike
Rockville, MD

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Introduction

The HIV/AIDS epidemic in the United States (US) disproportionately impacts ethnic and racial minorities, the poor, and other populations that are underserved by the health care system. Together, ethnic and racial minority populations make up close to thirty percent of the total population of the US.¹ However, these populations experience a disparate burden of HIV disease. In 2002, for example, ethnic and racial minority populations accounted for over three-fifths (61.6%) of the estimated number of persons living with HIV/AIDS in the US.² Despite the advances made in HIV clinical care and drug therapies, disparities in health outcomes and access to HIV treatment and care persist for ethnic and racial minorities living with HIV disease.³

The Ryan White Comprehensive AIDS Resources Emergency (CARE) Act, originally enacted by Congress in 1990, and subsequently amended, and reauthorized in 1996, and 2000, is due for reauthorization again in 2005. The CARE Act is administered by the United States Department of Health and Human Services (DHHS), Health Resources and Services Administration's (HRSA) HIV/AIDS Bureau (HAB). The purpose of the CARE Act is to improve the quality and availability of care for low income, uninsured, and underinsured individuals, and families affected by HIV disease; to reduce the use of more costly inpatient care; to increase access to care for underserved populations; and to improve the quality of life for those affected by the HIV/AIDS epidemic.⁴ CARE Act funding is distributed through grants to states, local governments, private, non-profit organizations and institutions, for primary health care and support services that enhance access to, and retention in care; healthcare provider training; and technical assistance to assist funded programs address implementation and emerging HIV care issues.⁵

CARE Act funding also supports oral health treatment for individuals with HIV disease; development and evaluation of innovative HIV/AIDS service delivery models with potential for local and national replication; and time limited planning and capacity building grants to eligible public or private nonprofit entities interested in developing, enhancing, or expanding high quality HIV primary health care services in rural or urban unserved areas and communities of color.

On an annual basis, CARE Act programs reach over 500,000 persons. These programs are an important source of HIV care and support

services for ethnic and racial minorities living with HIV disease. In 2001, more than three fifths of the persons served by CARE Act programs were ethnic and racial minorities.⁶

The Latino concept of "Familia" was mentioned by various participants as a key element in supporting access to HIV care.

Purpose of the Meeting

As part of its on-going efforts to assure input from many diverse communities across the country, the HIV/AIDS Bureau convened four, one-day meetings of representatives of different ethnic and racial minority groups, in late January and early February 2004. This report summarizes the meeting held on January 30, 2004, with a group of Latino consumers and service providers, working on the frontlines throughout the United States to address the epidemic in their communities.

The purpose of the meeting was to elicit feedback from participants on the resources that are currently available through the CARE Act in their communities, the resources that are still lacking, and their perspectives on what is necessary to improve access to quality HIV/AIDS care at the community level. The meeting was structured to examine the following:

- What is, and what is not working, in the provision of HIV/AIDS care and treatment in their communities.
- The broader systems issues that impact access to HIV/AIDS care in their communities.
- The factors and special needs that must be taken into account to assure that Latino communities receive access to quality HIV/AIDS care and treatment.
- The unique characteristics of their communities, their healthcare needs, and the service delivery system(s) that need to be taken into account -- where the CARE Act fits within this broader framework.
- Strategies that the HIV/AIDS Bureau can undertake to reduce disparities in access to care through policy and guidance development, training, technical assistance, program development, program management, and in the formulation of recommendations for reauthorization.

Participants

A diverse group of thirteen (13) Latino men and women, representing people living with HIV disease, consumers of CARE Act services, community-based service providers, and local health department staff participated in the Latino Community Consultation Group meeting. The

group was comprised of persons of diverse Latino cultural backgrounds, including Mexicans, Puerto Ricans, Cubans and Central Americans, from San Diego, CA, Miami, FL, Roxbury, MA, Las Cruces, NM, New York, NY, Salem, OR, Harlingen, TX, San Antonio, TX, Seattle, WA and Milwaukee, WI.

The participants represented a wide range of expertise and experience, and included AIDS advocates, community leaders and service providers. Some participants were members of local Title I planning councils, Title II consortia or HIV prevention community planning groups. Others had experience working in Title III funded clinics. The service providers represented key management and frontline staff such as executive directors, program managers, health educators, client advocates and case managers.

The organizations represented in the group were also very diverse in terms of size, populations served, and services offered. AIDS service organizations (ASOs), migrant health and services organizations, women-focused ASOs, Veterans' service programs, comprehensive community health centers, and state public health departments were represented. Some organizations serve multicultural populations, while others are Latino specific. Clients served include women, children and in-school and out-of-school youth, migrant and seasonal farm workers, immigrants, veterans, gay men and other men who have sex with men (MSM), prison inmates, formerly incarcerated, and homeless persons. These organizations provide a wide range of services to Latinos at risk for, and living with, HIV disease. Services provided include bilingual and culturally sensitive, street and community outreach in various venues such as migrant camps, work sites, schools, and churches, confidential and anonymous HIV-antibody testing, pre/post-test counseling, HIV/STD prevention and risk reduction education, prevention case management, primary health care, case management, financial and housing assistance support groups, substance abuse counseling, technical assistance, and translation services.

Trends of HIV/AIDS among Latinos

Latinos in the US are a growing and diverse ethnic minority population, who experience a disproportionate burden of HIV/AIDS.

Demographic Profile

According to the US Census Bureau, as of March 2002, there were an estimated 37.4 million Latinos living in the US (estimates do not include the 3.9 million residents of Puerto Rico). Latinos constitute 13.3 percent of the nation's population, making them the largest ethnic minority group in the nation.⁷ Latinos in the US are a diverse population, representing different cultural groups and national origins. Mexicans are the largest Latino sub-group accounting for 66.9 percent of all Latinos, and Puerto Ricans are the second largest group constituting 8.6 percent of the US Latino population. The remaining proportions of the Latino population are made up of Central and South Americans (14.3%), Cubans (3.7%) and other Latino national origins (6.5%).⁸ In terms of regional distribution of the population, Latinos are more likely than whites to be concentrated in the West (44.2%), and the South (34.8%), and less likely to live in the Northeast (13.3%), and Midwest. There are significant differences in the regional distribution of the Latino population by Latino origin type. For example, Latinos of Mexican origin are more likely to live in the West (54.6%), Puerto Ricans are more likely to live in the Northeast (58.0%), and Cubans are more likely to live in the South (75.1%).⁹

Overall, the Latino population is concentrated in metropolitan areas. Latinos are more likely than whites to be concentrated in the central cities within a metropolitan area (45.6% vs. 21.1%). About 45.7% of Latinos live outside of central cities, but within a metropolitan, compared to 56.8% of the white population. The proportion of Latinos living in non-metropolitan areas (8.7%) is much smaller than the proportion of whites (22.1%).¹⁰

Latinos in the US tend to live in larger family households, have significantly lower educational attainment, and experience higher poverty rates than whites. In 2002, Latinos accounted for 26.5 percent of family

households with five persons or more, while only 10.8% of white households were of this size. The proportion of Latinos that graduated from high school was only 57% in 2002, compared to 88.7% of whites. Over a quarter of Latinos (27%) had less than a ninth grade education, compared with only 4% of whites. Latinos also experience higher rates of unemployment (8.1%) than do whites (5.1%). Moreover, 21.4 percent of Latinos were living in poverty compared to 7.8% of whites. In 2002, Latinos constituted 24.3% of the total population living in poverty in the US.¹¹

Foreign-Born

A substantial proportion of the Latino population in the US is foreign-born. In 2002, 40.2 percent of the Latino population in the US was foreign-born.¹² Latinos made up more than half (52.2%) of the foreign-born population in the US in 2002.¹³ Mexico accounted for more than a quarter of the overall foreign-born population, and more than half of the Latino foreign-born in the US. In addition to Mexico, three other Latin American countries - Cuba, the Dominican Republic, and El Salvador - ranked among the top ten countries of birth of the foreign born in the US.¹⁴ The foreign born from Latin America are more likely to be concentrated in the West (40.6%) than any other region of the US. Among the Latino foreign-born, those from Mexico and other Central American countries were concentrated in the West (54.7%), and in the South (30.1%). In contrast, foreign born Latinos from the Caribbean (50.5%) and South America (45.5%) tend to be concentrated in the Northeast region.

Compared to the native-born US population, and all other foreign born groups, foreign-born Latinos are more likely to live in family households of five or more persons, less likely to have graduated from high school, and more likely to live below the poverty level.¹⁵ Moreover, the Latino foreign-born population has the lowest rates of naturalized citizens when compared to other foreign-born populations: 24% of Latinos compared to 53% of Europeans, and 44% of Asians. These low rates among Latinos is attributable to the low citizenship rates of the foreign-born from Mexico (15%).¹⁶

Language

In 2000, 47 million (18%) persons over 5 years of age in the US spoke another language at home, other than English. Spanish is the language most frequently spoken at home, accounting for 60% (28.1 million) of the 47 million persons speaking a language other than English at home. Of these Spanish-speakers, more than half (14.3 million) said they spoke English "very well" and the remainder (13.8 million) spoke English less

than very well. Consistent with the distribution of the Latino population by region, the West and South combined had about three times the number of Spanish speakers (21 million) as the Northeast and Midwest combined (7 million).¹⁷

Lack of Health Insurance

In 2002, there are approximately 43.6 million uninsured in the US. Latinos (67.6%) were less likely to be insured than whites (89.3%), and represented the population with the highest percentage of uninsured persons (32.4%) compared to all other ethnic/racial groups. Moreover, the proportion of the foreign-born population without health insurance (33.4%) was more than double that of the Native population (12.8%). Among foreign-born, non-citizens (43.3%) were more likely than naturalized citizens (17.5%) to lack health insurance coverage. Among the poor, Latinos (42.8%) were more likely to be uninsured than all other ethnic/racial groups in the country. Moreover, non-citizens living in poverty (61.4%) had the highest proportion of uninsured of all groups in this country.¹⁸

The disparities in access to insurance and quality health care experienced by Latinos are significantly related to citizenship status and English proficiency. Low-income Latinos who are non-citizens, and who have limited English proficiency, are much more likely to be uninsured, less likely to use health care services, and more likely to experience problems communicating with their health care providers than their citizen and English-speaking counterparts. Although immigrants have a high rate of labor force participation, they often have low-wage jobs with limited benefits. Consequently, they are disproportionately low-income and uninsured.

Public insurance like Medicaid could offset the limited availability of private insurance for immigrants, but coverage is hampered by eligibility restrictions enforced by the 1996 federal welfare reform law, and ongoing confusion about eligibility and the effect of benefits on their immigration status. These barriers make it more difficult for immigrants to obtain primary and preventive health services.¹⁹

HIV/AIDS among Latinos

Latinos account for close to one fifth of the new AIDS (18.8%) and new HIV (18.5%) reported in 2002.²⁰ The overall AIDS case rate for Latinos was more than three times the rate for whites in 2002, (19.2 per 100,000 compared with 5.9). Among women, the AIDS case rate for Latinas was

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over five times the rate for white women (11.3 per 100,000 compared to 2.1). Among men, the AIDS case rate among Latinos was more than three times the rate among white men (39.7 per 100,000 compared to 12.3).²¹ An estimated 76,052 Latinos were living with AIDS in 2002, constituting 20% of the total (384, 906) persons living with AIDS in the US.²²

The distribution of AIDS cases among Latinos in the US varies by place of birth, but does not parallel the distribution of the US Latino population by sub-group. Of the estimated number of diagnoses of AIDS in adults/adolescents among Latinos reported in 2002, 38% were among Latinos born in the U.S., 21% among those born in Puerto Rico, 16% among those born in Mexico, 9% among those born in Central/South America, and 2% among Latinos born in Cuba.²³

There are also differences by exposure category and place of birth. Overall, male to male sexual (MSM) contact accounted for 39% of all estimated Latino adult/adolescent AIDS cases reported during 2002, followed by heterosexual contact (29%). Injection drug use (IDU) was the mode of exposure for 27% of the reported cases. However, except for Latinos born in Puerto Rico, male to male sexual contact accounted for the majority of estimated adult/adolescent AIDS cases among Latinos born in other countries: Mexico (57%), Cuba (50%), Central and South America (52%). In contrast, IDU was the primary mode of transmission for Puerto Rican born Latinos (45%). Among Latinos born in the U.S., male to male sexual contact accounted for 39% of the estimated adult/adolescent AIDS cases followed by IDU (29%).²⁴

Variations are also found in the distribution of AIDS cases among Latinos by gender. Males, especially MSM and young MSM (YMSM), are the most impacted sub-populations among Latinos. By the end of 2002, males accounted for 81% of the cumulative AIDS cases reported among Latinos compared to 19% among women. Males also represented 77% of the new AIDS reported among Latinos in 2002, while females accounted for 23% of these cases. MSM and young MSM account for over 50% of the total estimated number of Latinos living with AIDS in this country.²⁵ A number of factors contribute to the severity of impact among Latino MSM/YMSM, including social discrimination, homophobia, poverty, racism, and HIV/AIDS related stigma.²⁶

The largest numbers of Latinos living with AIDS are concentrated in the Northeast, West, Puerto Rico, and the South. The table below shows the distribution of cases among ten states, jurisdictions and metropolitan statistical areas with the highest number of Latinos living with AIDS:

Table 1: Ten States/Jurisdictions and MSAs with the Highest Number of Latinos Living with AIDS 2001

Jurisdiction State/Territory	# of Latinos Living with AIDS at the end of 2001 ²⁷	MSA of Residence	# of Latinos Living with AIDS at the end of 2001 ²⁸
New York	18,651	New York, NY	16,588
California	12, 772	Los Angeles, CA	6,169
Puerto Rico	10,086	San Juan, PR	6,137
Florida	6,616	Miami, FL	3,787
Texas	5,848	Chicago, IL	1,535
New Jersey	3,109	Houston, TX	1,503
Pennsylvania	1,952	Boston, MA	1,448
Massachusetts	1,863	San Francisco, CA	1,283
Connecticut	1,807	Philadelphia, PA	1,268
Illinois	1,645	San Diego, CA	1,266

HIV/AIDS Care and Latinos

Early HIV diagnosis and early entry into care are the cornerstones of successful HIV treatment. Early treatment enhances the quality of life, decreases morbidity, prolongs survival, and decreases deaths due to AIDS for many persons living with HIV disease. Unfortunately, Latinos are more likely than other ethnic/racial groups to have a late diagnosis of HIV. In one study by the Centers for Disease Control and Prevention (CDC), Latinos were reported to have the highest proportions of late HIV diagnosis (49%) compared to whites (46%), and blacks (40%).²⁹ A 2003 CDC report, on a study of HIV testing patterns in 16 U.S. sites, indicated that Latinos (23%) were significantly more likely to be late testers³⁰ than whites (18%) and to have tested negative for HIV previously before their first positive HIV test. Moreover, the majority of late testers sought testing due to illness (65%).³¹

Studies have also found that compared to whites, Latinos are significantly more likely to delay care after an HIV diagnosis. One study of health care and patient factors associated with delayed initial medical care for HIV disease, showed that Latinos were substantially more likely than whites to report more than three months' delay in receiving care. Despite the finding that having Medicaid insurance and a usual source of care reduced delays in care after HIV diagnosis, delays were still greater for Latinos compared with whites.³²

Latinos also experience disparities in access to, and quality of, HIV care received. The HCSUS study on variations in the care of HIV+ adults receiving care in the U.S. found that Latinos, African Americans, the uninsured, and those with Medicaid were less likely than whites to receive optimal HIV care on various measures of access and quality of HIV care. The study also found that Latinos with HIV/AIDS were more likely to be publicly insured or uninsured than whites in the sample. About one quarter (24%) of Latinos with HIV/AIDS were uninsured, compared to 17% of the whites, and about half of Latinos were covered by Medicaid compared to about a third of whites (32%). Those HIV+ persons who were covered by Medicaid received less optimal care, including less access to antiretroviral therapies than those with private insurance. Moreover, the study showed that Latinos, African Americans, and Medicaid and uninsured patients were less likely than other HIV patients to have enough doctors visits to assure good continuity of care, and were more likely to have gone to an emergency room for problems not leading directly to hospitalization. These disparities decreased over time (from 1996 to 1998), but were not fully eliminated.³³

The low literacy or variations in literacy rates among Latino clients was noted as a major obstacle in the delivery of services.

Publicly funded programs like Medicaid and the Ryan White CARE Act (RWCA), including the AIDS Drug Assistance Program (ADAP), are very important vehicles to access HIV care and pharmaceuticals for low income or uninsured Latinos living with HIV. Medicaid is the largest source of health care coverage for persons with AIDS in the US. Medicaid serves approximately 55% of all adults living with AIDS, and up to 90% of all children with AIDS in the US. Nearly one fifth (19%) of Latinos with AIDS are covered by Medicaid. Despite Medicaid's critical role in providing care for HIV/AIDS patients, eligibility for the largest population of HIV infected persons -childless adults that have not yet been disabled by AIDS - is limited.³⁴

The CARE Act, as the "payer of last resort," fills gaps in care not covered by other resources and therefore, plays a critical role in ensuring access to HIV care for low income, uninsured, or underinsured Latinos living with HIV, especially single adults and immigrants. CARE Act funded programs are reaching a significant proportion of Latinos with HIV disease. In 2001, Latinos accounted for 23% and 18%, respectively, of the duplicated clients reported receiving services through Title I and Title II programs, almost one quarter (23%) of clients receiving services through the Title II ADAP program, 20% of the persons receiving Title III early intervention services, and 21% of the women, children, and youth receiving Title IV services.³⁵ A study comparing access to HIV highly active antiretroviral therapy (HAART) by race and ethnicity in four states (California, Florida, New York, and Texas), found that except

for New York, the proportions of HIV+ Latino participating in ADAP was higher than, and their participation in Medicaid was lower than, their representation in the epidemic.³⁶

Conclusion

Latinos in the US are a growing and diverse ethnic minority population who experience a disproportionate burden of HIV/AIDS, and significant barriers and delays in accessing and utilizing quality HIV care, due to a combination of complex factors. These include high poverty rates, lack of health care coverage, lack of transportation, severe illness, competing psycho-social and economic needs,³⁷ limited English proficiency, problems communicating with health care providers, mistrust of government, immigrant status, and fear of deportation. In addition, lack of knowledge about HIV, denial, fear of disclosure of HIV status, and fear of stigmatization also create substantial barriers to access to care.³⁸ Further compounding these barriers, Latinos are more likely than whites to live in medically underserved areas.³⁹

The diversity of the Latino population in the US and the differential impact of HIV/AIDS on Latinos due to variations in national origin, immigrant and citizenship status, sexual orientation, mode of exposure, age, and gender pose significant challenges for program planners and service providers. An effective response to the needs of this population requires the design and implementation of linguistically appropriate and culturally competent HIV/AIDS related services that address these complex social, economic, cultural and linguistic factors.

Meeting Proceedings

Dr. Deborah Parham Hopson, Associate Administrator of the HIV/AIDS Bureau, welcomed the participants, and then provided an overview of HAB's rationale and objectives for the meeting.

Ms. Idalia Sanchez, Acting Director of HAB's Office of Policy and Program Development (OPPD), welcomed the participants, and then expanded on Dr. Parham Hopson's description of the purpose of the meeting.

Mr. Steven Young, Director of HAB's Division of Training and Technical Assistance, provided an overview of the Ryan White CARE Act.

All three speakers opened the floor to questions from the attendees following the opening presentations. A detailed description of the presentations and questions and answers may be found in Appendix B of this report.

A Community Window

Mr. Kilkelly, a consultant who facilitated the meeting, introduced and handed out the tool "A Community Window...HIV/AIDS Care from My Point of View". This tool was used to structure and guide the discussions throughout the remainder of the day, on the focus question:

What is necessary to achieve better access to quality HIV/AIDS care through the Ryan White Comprehensive AIDS Resources Emergency (CARE) Act at the community level?

The discussion was divided into three segments that required participants to work individually, and then in small groups, to address the focus question in the context of identification of:

- Community Strengths
- Community Challenges
- Barriers to, and Facilitators of, HIV/AIDS Care

Following each segment, the small groups presented the outcomes of their deliberations to the larger group, and a broader discussion of the issues ensued. The participants were also asked to define what they meant by community, and to report out their definitions to the larger group when they shared their lists of community strengths.

Key Findings

This section summarizes the key issues participants' identified regarding community strengths and challenges, and the barriers to, and facilitators of, HIV/AIDS care in their communities.

The tables that follow summarize the community strengths, and barriers to and facilitators of HIV/AIDS care identified by the participants:

Definitions of Community

The participants come from diverse communities and backgrounds and defined "community" in a number of ways.

- Latinos (affinity by national origin)
- Geographic area or place of residence
- HIV service community
- Latinos as the minority or majority population, depending on the area
- Provider community
- Sexual and Gender Identity
- Age
- Multi-ethnic communities of color in HIV community

Community Strengths

The participants identified the following community strengths:

Diversity of Hispanic/Latino Population

- Diversity by national origin and distribution of population by geographic region
- Differences in self identification (ethnicity - Latino/Hispanic or national origin)
- Variations in whether Latinos are the majority or minority population by geographic region
- Multi-ethnic
- Sexual orientation
- Religious
- Political
- Gender and age (men, women, and children)

Community Support

- Community members are versatile, determined and willing to help and learn

Political Support

- Local government's support and involvement in HIV

Family Support

- Strong sense of "Familia" (family)

Socio-economic Factors

- Good housing

Leadership

- Strong Hispanic/Latino community leadership
- Strong coalitions with other racial/ethnic minority groups
- Consumer leadership
- Statewide advisory groups
- Talent within community with potential for leadership development

Participation in HIV Planning Councils and Consortia

- Broad planning perspective inclusive of all community groups (looking beyond own group interests)
 - Work in collaboration with other ethnic and racial (E/R) minority groups
 - Work out differences with other E/R groups and build consensus
 - Speak in one united voice
 - Good response and programs from the state

Care Services System

- Availability of health care (variations across jurisdictions)
 - Availability of health insurance coverage (variations across jurisdictions)
 - RWCA filling in the gaps
- Availability of medical providers (variations across communities)
 - Capacity to provide culturally competent service and treatment
 - Collaboration between medical and social services providers
 - Providers integrate feedback from consumers to determine needs
- Known and trusted agencies
 - "Confianza" - trust is key element
 - Agency's reputation is spread by word of mouth in community

- Inter-agency collaborations
 - Between AIDS service organizations (ASOs), other organizations and faith-based community
 - With other community-based organizations (CBOs) of color
- Peer education and advocacy
 - Peer educators emerging from their own communities
 - Peer advocacy
 - Peer group counseling (face-to-face)
- Bilingual and bicultural providers
 - Excellent bilingual health providers (including HIV specialists and nurses)
 - Bilingual initiatives working
- Staff education and training
 - Available
 - Cost is free
- Prevention services
 - Good preventative health care
 - Prevention education
 - Safer sex workshops
 - Excellent prevention counseling
- Outreach services
 - Good system of outreach programs (run by different agencies)
- HIV testing services
 - Mobile testing
 - Use of rapid testing, technology
- Organizational infrastructure
 - Diverse funding sources
 - CARE Act programs
 - HOPWA funding
 - ASOs with strong organizational infrastructures

Discussion

The participants identified a number of important community strengths that were organized into eight categories: diversity, community support, political support, family support, socioeconomic conditions, leadership, participation in HIV planning processes, and care services systems care.

Diversity of the Hispanic/Latino Population

Participants viewed the diversity of the Hispanic/Latino population as an important strength. This diversity encompasses a number of variables including national origin, ethnic and racial identity, geographic distribution across the country, culture, language, religion, sexual

orientation, gender, age, and political affiliation. In some communities, for example, Latinos constitute the numerical majority of the population, while in other they are the minority. Participants felt that these differences impact providers' ability to market services to different clients, and also the accessibility of services. Where the Latino population is the majority and the predominant cultural group in a community, outreach and service delivery may be facilitated. In such cases many of the prevention messages and educational materials can be developed in Spanish and tailored to the particular Latino subgroup(s) in the area. On the other hand, the diversity of the Latino population may pose some significant challenges to serve providers, particularly when the Latino population in some geographic areas represents a mix of various cultural and national origin groups, degrees of assimilation, and where certain sub-populations such as women, children, and transgender persons are underserved.

Community Support

In some Latino communities there is a significant amount of support for HIV/AIDS issues from the general community. The diversity of the Latino populations within these communities and the mix of talent, skills, knowledge, resources, and commitment that many community members bring to the table facilitate the community response to HIV/AIDS.

Political Support

Political support was also identified as a key element in enhancing access to care. Support from, and involvement of, local and state elected and appointed officials in some communities comes in the form of providing more funding for health care, and helps to increase access to both prevention education and health services for Latinos.

Family Support

The Latino concept of "Familia" was mentioned by various participants as a key element in supporting access to HIV care. Some participants stated that when the concept of "Familia" is integrated as part of an approach to service delivery among Latinos, it can serve to mitigate the negative effects of stigma, and increase utilization of care services. For example, some participants stated that HIV related stigma plays a strong role in Latino communities. When a person is first diagnosed with HIV, he or she may experience some rejection due to stigma, but ultimately the family members will provide support to the person living with HIV. Since the concept of family in Latino culture extends beyond the nuclear family to include extended family members and non-related persons viewed as "kin", there is a wide net of persons available to provide support. Moreover, Latino cultural values place great importance on the

mutual obligations and responsibilities of family members for each other. When one member of the family is affected, all members are affected. Familial support may come from a variety of sources including spouses, parents, and children, or extended family members such as aunts, uncles, cousins, grandparents, and comadres/compadres (co-parents/godparents).

Socio-economic Conditions

Availability of good housing within their communities was identified by participants as an important element in facilitating access to care. In many communities there are housing assistance programs for people with HIV/AIDS, as well as affordable housing.

Leadership

Access to HIV care is also facilitated by the presence of strong and committed leadership. Some participants indicated that Latinos within their communities are involved in planning HIV services, and work effectively in coalitions with other ethnic and racial minority groups to advocate for enhanced services. These community leaders are able to collaborate and speak in a united voice to promote the interests all communities of color while assuring that Latinos also get the resources they need. Others noted that there is a broad range of talent and potential for leadership among Latinos within their communities with the appropriate support and mentoring. Still others noted that Latinos living with HIV and consumers of services are also strong leaders. However, some communities experience a loss of leadership through the illness and death of consumers, making leadership development in training a new generation of leaders critically important.

The rising cost of HIV related medications is a major obstacle to access to quality HIV care, especially for the poor and uninsured.

Participation in HIV Planning

Participants noted that Latino participation in HIV planning councils and consortia in their communities served to enhance services for Latinos affected by, and living with HIV/AIDS. Strong Latino participation is necessary to assure that the needs of Latino populations are addressed by Title II consortia. For example, in one community, the Title II consortia does not serve very well because the ASOs that are running them are directing the funds to themselves. As a result of community collaborations and advocacy, the state is now revising the system to require that regions reflect parity and equity in the distribution of funding and services. This demonstrates the state's responsiveness to community concerns. Another participant noted that while participation in such planning bodies may at times be contentious and difficult, when communities unite, the result is more effective in assuring the services reach the communities that need them.

Care Services Systems

The participants noted a number of strengths in their local care services systems including the availability of health care coverage, Medicaid programs that cover a range of needed HIV care and medications, and CARE Act funded programs that are filling in gaps in services. While they noted differences in the level and scope of services across jurisdictions, there was the agreement that coverage and services are available for people with HIV/AIDS.

One major issue in most communities is the lack of qualified and trained Latino staff.

Participants also identified the availability of bilingual and bicultural medical care providers in their communities as an important factor in facilitating care to Latinos. Some participants noted that they had many culturally competent providers, while others indicated that some medical providers working in underserved areas did not speak Spanish and others were inexperienced in HIV care. Medical providers that collaborate with social service providers and respond to client feedback to improve services were also seen as an important asset.

The presence of known and trusted agencies in communities was noted as key. Participants stressed the importance of "confianza" (trust and confidence) in Latino culture and indicated that community members pass information on about the responsiveness of agencies, by word of mouth. Many Latinos living with HIV will not go to an agency to obtain services if it is viewed as unresponsive and uncaring. Moreover, they may choose to travel long distances or go outside of their community for services, to an agency that is viewed with "confianza," rather than using a nearby agency with a bad reputation.

Participants stressed the importance of strong inter-agency collaborations between ASOs, CBOs and faith-based organizations, and other people of color (POC) organizations to provide seamless services to clients. The role of consumers was also viewed as valuable in facilitating access to services, and many participants noted the use of peer advocates, peer counselors, and support group facilitators in their communities' HIV service delivery system as an asset.

As noted earlier, the presence of bilingual and bicultural health providers, including nurses, pharmacists, and HIV specialists was viewed as important. Some participants noted that bilingual/bicultural initiatives in their communities were actually working well. Others noted that there is a need for more research on how culturally competent service models can be implemented effectively in other areas.

The participants stressed the importance of having staff training, education, support, and development opportunities for front line workers and managers, available free of cost. Participants also cited the presence of good preventative health services such as immunizations for hepatitis, influenza, pneumonia, TB screening, HIV prevention education, outreach, and HIV testing (especially rapid testing) as an asset in their communities

Organizational infrastructure and capacity were identified as important assets. Participants mentioned that many organizations within their communities, including ASOs and CBOs, have diverse funding sources that enable them to provide a comprehensive range of services to Latinos. They also noted the availability of funding from different titles (Titles I-IV and SPNS), as well as HOPWA funding, as important to their care delivery system.

Community Challenges

Due to time constraints the Latino Community Consultation group did not address community challenges. Instead they integrated many broad community challenges into their discussion of barriers to access to HIV/AIDS care.

Barriers to, and Facilitators of, Access to HIV/AIDS Care

The participants identified the following factors as barriers to, and facilitators of, access to HIV/AIDS care in their communities:

Socio-economic Conditions

Barriers	Facilitators
<ul style="list-style-type: none"> • Restrictive immigration policies - Residency and citizenship requirements for service eligibility - Public charge provisions - Fear of deportation - Aggressive INS/Border Patrol practices 	<ul style="list-style-type: none"> • Institute policies to protect and assist immigrants seeking HIV services • Provide legal assistance for immigrants • Waive fees and co-pays • Remove HIV from INS exclusion list

Socio-economic Conditions (continued)

Barriers	Facilitators
<ul style="list-style-type: none"> • Intimidation at health facilities • Heightened "Homeland Security" measures <ul style="list-style-type: none"> - Government assisted medical program (GAMP) charge fees and co-pays - INS HIV exclusion policy • Extreme poverty • Drug addiction • Homelessness • Lack of housing assistance • Lack of transportation <ul style="list-style-type: none"> - Mass transit only works in some areas • Lack of Life Insurance Coverage <ul style="list-style-type: none"> - Funeral expenses 	<ul style="list-style-type: none"> • Supportive federal social welfare and substance abuse prevention/treatment policies • Provide affordable housing • Provide various transportation options <ul style="list-style-type: none"> - Vans, taxis, vouchers • Provide/enhance funding to needed support services

Socio-cultural

Barriers	Facilitators
<ul style="list-style-type: none"> • Denial and fear of HIV • Sexual taboos (sex is not discussed) • Language barriers • Low literacy levels • Clients' educational levels vary • Lack of HIV literature, educational materials, and curricula in Spanish 	<ul style="list-style-type: none"> • Education and stigma reduction interventions • Community education (on HIV and sexuality) • Provide /enhance funding to support such services • Translators/interpreters • Bilingual staff, bicultural • Spanish language information and printed materials • ESL courses • Facilities that use communication media that address low literacy • Educational materials and posters • Audio-visual media (symbols/pictures, tapes, videos, cassettes, etc.)

Socio-cultural (continued)

Barriers	Facilitators (continued)
	<ul style="list-style-type: none"> • Use basic, easy to understand language to address clients and public • Collaborate with universities for Spanish language translation and material development • Develop Spanish language HIV materials or translate existing materials into Spanish

Care Services System

Barriers	Facilitators
<ul style="list-style-type: none"> • Poor translations <ul style="list-style-type: none"> - Literal translations - Culturally inappropriate - Lack meaning • Lack of culturally competent and linguistically appropriate services <ul style="list-style-type: none"> - Prevention education - Behavioral health services: mental health and alcohol and other drug abuse services • Lack of bicultural/bilingual staff (case managers, physicians, nurses, pharmacists) <ul style="list-style-type: none"> - Throughout service system: limits referrals to other agencies • Stigma • Lack of trust • "Machismo"/Sexism • Professional behavior <ul style="list-style-type: none"> - Cultural differences in 	<ul style="list-style-type: none"> • Employ or contract out to culturally competent translators (English/Spanish) • Develop culturally competent services that include: <ul style="list-style-type: none"> - Acknowledgement of human level - Client-centered focus - Non-judgmental - Understanding diversity • Train staff and volunteers • Recruit peer educators to conduct community education • Direct funds to providers who are members of the community • Compensate bilingual and bicultural staff (pay differential) • Develop skills in volunteer recruitment and retention to build a network of Latino volunteers

Care Services System (continued)

Barriers	Facilitators
<p>perceptions of professional behavior</p> <ul style="list-style-type: none"> - System is driven by statistics rather than client interests - Focus on getting new cases (numbers) compromises continuity and comprehensiveness of care for existing clients <ul style="list-style-type: none"> • Limitations of case management <ul style="list-style-type: none"> - High caseloads means less time for individual clients - Clients with multiple problems and needs require more case management services - Undocumented immigrants need more services due to legal and service eligibility issues - Flat funding - Impact of CDC's AHP • Lack of legal services to address <ul style="list-style-type: none"> - Immigration issues - Child custody issues - Permanency planning issues • Higher cost of HIV medications • Lack of treatment education resources • Lack of specialty and sub-specialty services <ul style="list-style-type: none"> - Requires patient referral to specialist outside of service areas 	<ul style="list-style-type: none"> • Flexibility for clients to select a service provider of their choice -eliminate residency or catchment area requirements • Assure privacy and confidentiality protections • Commitment to confidentiality (with service providers and in peer related activities like support groups) • Provide gender sensitivity training • Care for people at a human level • Train staff on clients' cultural norms and beliefs and on culturally appropriate approaches • Identify funding sources to increase number of case managers • Lower case managers' caseloads • Base caseload size and reimbursement for services on the severity of client need and barriers to care • Provide funding for legal services to assist clients with legal status • Identify funding sources to address needs • Collaborations with pharmaceuticals to assure drug access • Train healthcare providers • Train more Latino treatment educators

Care Services System (continued)

Barriers	Facilitators
<ul style="list-style-type: none"> • Eligibility criteria for referrals across health service delivery areas (HSDA) <ul style="list-style-type: none"> - Residency restrictions • Lack of programs for women and children • Lack of child care • Lack of transitional programs for incarcerated or recently released populations • Lack of qualified Latino personnel (health educators, case managers, etc.) • Lack of social marketing to Latinos 	<ul style="list-style-type: none"> • Remove barriers/eligibility criteria for subspecialty referrals • Develop provisions for referrals outside of service areas under Title II • Funding should follow the client rather than be tied to an agency/or service area • Prioritize/allocate funding for women and children services • Increase Title IV funded programs • Provide child care on the premises where services are delivered • Provide funding for services • Increase links with universities • Train Latino outreach workers, peer educators, health educators, case managers and support group facilitators, etc.) • Provide salary differentials for bilingual/bicultural staff to attract and retain qualified Latinos • Provide staff training and support to avoid or reduce burnout • Funding for targeted social marketing campaigns in Spanish

Leadership and Advocacy

Barriers	Facilitators
<ul style="list-style-type: none"> • Lack of Latino Leadership • Poor advocacy due to apathy 	<ul style="list-style-type: none"> • Identify new leaders • Provide leadership training and support • Provide education, sensitivity, and advocacy training

Planning Processes

Barriers	Facilitators
<ul style="list-style-type: none"> • Latinos under-represented on RWCA Planning Councils and Consortia 	<ul style="list-style-type: none"> • Recruit, train, and support HIV+ Latinos • Address and prevent burn-out

Inter-Agency Collaboration

Barriers	Facilitators
<ul style="list-style-type: none"> • Lack of collaboration among service providers/organization 	<ul style="list-style-type: none"> • Form more partnerships with other CBOs of color • Enhance inter-agency collaborations

Funding

Barriers	Facilitators
<ul style="list-style-type: none"> • Competition for funding among service providers/organizations • Territoriality and divisions among E/R minority groups • Lack of support of faith-based communities/CBOs • Lack funding information on opportunities filtering down to community/CBOs <ul style="list-style-type: none"> - Misinformation - Lack of information about available resources - Information received late (resources, RFPs, PAs funding cycles) 	<ul style="list-style-type: none"> • Identify non-partisan mediators to address issues that stifle partnerships • Remove motive for competition by addressing funding and reimbursement process • Promote acceptance, diversity, and equality through education and training • Improve content of information and means of dissemination employed by funders to alert community

Funding (continued)

Barriers	Facilitators
<ul style="list-style-type: none"> Lack of/inadequate funding for services 	<ul style="list-style-type: none"> Inform all community providers, not just the largest, and most established Diversify funding base of CBOs and other public and private entities Form partnerships between health departments and CBOs to access private dollars

Discussion

The Latino Community Consultation Group did not have sufficient time to address community challenges separately. Instead, the discussion of community challenges was incorporated into the consideration of barriers to access to HIV/AIDS care. The participants identified a number of factors as barriers to, and facilitators of, access to HIV/AIDS care in their communities. As outlined above, the barriers to, and facilitators of care were organized into the following seven categories: socio-economic conditions, socio-cultural factors, care services systems, leadership and advocacy, planning processes, inter-agency collaborations, and funding.

Socio-economic Conditions

Participants identified a number of socio-economic issues including restrictive immigration policies due to Welfare reform and heightened Homeland security measures as significant barriers to access to care. Documentation requirements, particularly those related to citizenship and residency for applications for services present significant barriers to the large proportion of Latinos who are immigrants. Participants noted that more agencies are requiring documentation of this sort, and this is worrisome, because many agencies may begin to deny services to immigrants who cannot come up with the required documentation.

Others noted some government assisted medical programs are now requiring fees or co-pays, and this may create further barriers for poor immigrant families and individuals, who may not be able to afford the fees. The fear of deportation is pervasive among many legal immigrants, as well as undocumented immigrants, and may deter them from seeking services. Some legal immigrants applying for citizenship may not seek

services because they fear they may be considered a "Public Charge" by INS, and be ineligible for naturalization.

Participants noted that even when agencies will serve them, undocumented immigrants may not seek services, because they are unaware that they are available. Fear of deportation also leads people to seek poor healthcare services or buy drugs that may be dangerous (over-the-counter or in pharmacies across the border in Mexico).

In most areas, Latinos are absent or underrepresented on Title I planning councils, Title II consortia and other HIV related planning bodies.

Participants also noted various instances where INS/Border Patrol Officers intimidate immigrants by stationing their patrol cars in front of hospital emergency rooms or clinics, and thus deter them from seeking needed health care.

Other socio-economic factors such as extreme poverty, drug addiction and homelessness were mentioned as significant barriers to care. A common barrier to access identified by many participants is the lack of affordable housing, and a range of housing assistance options within their communities. Lack of flexible and readily available public transportation in many communities posed significant barriers to access. Among the facilitators identified to address these issues were more progressive immigration, housing, and social welfare policies, and a range of options for transportation, including boarding passes for people with HIV, and funding for agencies to purchase vans or pay for taxis to transport clients to appointments. Lack of life insurance, especially to cover burial expenses, was also mentioned.

Socio-cultural Factors

The participants identified a number of socio-cultural factors, including denial and fear of HIV, stigma, and sexual taboos as major impediments to access to care. They recommended such measures as increased funding to support stigma reduction education and interventions, and community education as facilitators. Language barriers were identified as serious obstacles to access. As noted earlier, the need for bilingual/bicultural staff is an important key to access. Participants recommended enhanced funding to allow organizations to hire trained translators and interpreters, and to recruit and retrain bilingual/bicultural staff and English as a second language (ESL) courses to address these obstacles. The participants also noted that in some communities, there is a paucity of good Spanish language materials available. They, therefore, recommended additional funding for materials development in Spanish. The low literacy or variations in literacy rates among Latino clients was also noted as a major obstacle in the delivery of services. Again, the participants recommended funding so that organizations

could develop and utilize communication and educational media that address low literacy (audio-visual aids, video tapes, audio cassettes, etc).

Care Services Systems

Participants identified a number of systems problems that are related to the socio-cultural issues previously discussed. For example, education and communication with Spanish-speaking clients is hampered by the lack of funds to hire good translators. Materials that have been poorly translated from English to Spanish are commonplace, and relatively useless, because the translations are so literal or culturally inappropriate that they become meaningless. The participants observed that many organizations do not understand the importance of good translations and often utilize computerized translation programs to produce materials in Spanish. The participants underscored the need for funding to hire translators, but also to have materials developed in Spanish that are culturally appropriate and tailored to reflect the language and cultural nuances, and variations of specific Latino sub-populations. These materials should also reflect, and be consistent with, the sub-groups' idiomatic expressions and regionalisms.

Another related issue raised is the lack of lack of culturally competent and linguistically appropriate services for Latinos, including prevention education and behavioral health (mental health, alcohol and drug treatment) services within the service referral networks in their communities. Participants noted that many behavioral health programs do not have trained bilingual and bicultural staff on board, and are therefore limited in their capacity to accept referrals of Latinos clients, especially Spanish-speaking ones. A paucity of bilingual/bicultural case managers, nurses, and pharmacists was also mentioned. The lack of bilingual pharmacists, in particular, presents major obstacles since most pharmacies in their communities can only give information to HIV positive patients on complicated drug regimens, indications, contraindications, and adverse medication interactions to clients in English. Bilingual/bicultural staff should receive pay differential that acknowledge and compensate them for these added skills.

Participant offered other facilitators to address and enhance cultural competence: train staff on client-centered services that acknowledge the humanity of clients, clarify values, dispel biases, and promote acceptance of diversity. They also recommended that Latino peers be recruited, trained, and hired to work with community members and serve as bridges to promote greater understanding and acceptance of people living with HIV. Development of provider skills in volunteer recruitment and retention to build a network of Latino volunteers in the community to fill these gaps was recommended.

Stigma, sexism, and machismo, as well as lack of trust of service providers, were other factors that participants noted as serious obstacles to HIV care within the care system. They explained that for many of the communities, "confianza" is a double-edged sword. For example, many stated they work in close-knit communities where HIV service providers are known and readily identified by the general community. This factor, which is also a facilitator to care, becomes a barrier when clients feel their confidentiality will be compromised if they are seen in known HIV service sites or with service providers. The fear of disclosure and associated HIV stigma leads many clients to seek services outside of their own communities.

Participants proposed the following measures to address some of these barriers to care: flexibility for clients to select a service provider of their choice and not be limited by residency or catchment area requirements, assure commitment to privacy and confidentiality protections through staff and volunteer training, and to provide staff and volunteers with gender sensitivity training to address sexism and "machismo".

Participants also noted that one of the major challenges to the delivery of accessible HIV services are the cultural differences in perceptions of what constitutes "professional behavior". They noted that often clients are turned away from services because they are late for their appointments, and that the demands for accountability by funders are driving providers to focus more on new cases, generating a high volume of client contacts rather than on providing comprehensive, quality care to existing clients. Participants agreed that such practices compromise the continuity and quality of care. These concerns resulted in an in-depth discussion of the benefits of cost reimbursement per capita client reimbursement mechanisms. To bridge the cultural divide, participants once again recommended staff training regarding cultural norms, values, beliefs, and health seeking behaviors.

Participants observed that the complexity of problems faced by most Latino clients, particularly immigrants with legal issues, demanded greater investment of time by case managers. However, high and increasing caseloads limit the amount of time most case managers can spend with clients. Undocumented immigrants require more case management services, due to legal issues and lack of eligibility for many publicly funded services. Flat funding for case management services and the impact of the CDC's Advancing HIV Prevention Initiative (to identify more HIV positive persons and link them to care) will continue to tax an already overburdened case management system, and further compromise access to care for Latinos with multiple needs. Among the

solutions participants offered to address these issues were increased funding for case management, lower caseloads, reimbursement based on the complexity and acuity of client illness and needs, and more funding for legal services for immigrants.

Additional resources were also identified as needed to fill the gaps in legal services for women and families, to address child custody and permanency planning issues. Participants noted that many Latinas are not comfortable dealing with death and dying issues, and will need added support to plan for their children's care in the event of their death.

Participants agreed that the rising cost of HIV related medications is a major obstacle to access to quality HIV care, especially for the poor and uninsured. They recommended community based strategies to establish collaborations with the pharmaceutical industry to assure drug access to these populations. They expressed concerns that the rising cost of medications, already creating a significant burden on the care system, will lead to further shortages, and possibly the inability to provide needed medications to all who need them. The lack of treatment education services for Latinos was also raised as a barrier to access. Participants recommended additional resources to train more Latino treatment educators and other health care providers on effective approaches to treatment education.

Participants noted the lack of specialty and sub-specialty services in many communities, particularly small and rural. In some communities, there is a lack of specialists, and patients need to be referred to specialists outside of service areas. However, such referrals are hampered by health service delivery area (Title II) residency requirements. Participants agreed that these barriers to access should be eliminated and that approaches should be devised to attach the funding for care to the client, rather than the agency/or service area.

Participants noted the lack of adequate services in their communities for underserved populations, including women and children, the incarcerated, the recently released persons, and the homeless. To address these service gaps, the participants recommended targeted funding for these populations, including an expansion of Title IV services. In the case of women, a growing population in need of services, they indicated the need for tailored, women-focused services. Some observed that women may not be that comfortable receiving services in traditionally gay-serving ASOs. They also identified a need for resources to support on-site child care services in the same locations where the women receive their HIV related services. Moreover, additional resources would

Participants stressed the importance of peer advocacy, particularly given the power imbalances that exist between HIV+ persons who receive services and care providers.

facilitate greater access to services for the incarcerated, the recently released persons, and the homeless. They note that support group services are important for many populations, and called for increased resources for expansion of support group services for HIV+ Latinos, MSM, women, and persons with co-infections. They also recommended collaborations with universities to have students serve as support group facilitators.

One major issue in most communities is the lack of qualified and trained Latino staff (outreach workers, peer educators, health educators, case managers and support group facilitators, etc). The participants recommended a number of strategies to address this issue, including training and support programs to reduce staff burnout, pay salary differentials to attract and retain bilingual/bicultural Latino staff. Participants noted that many agencies experience high staff turnover rates because qualified Latino staff can command higher salaries elsewhere. Training peers to assume staff positions is also a strategy, since many peer educators are motivated by other factors besides salary.

Participants agreed that there was a lack of social marketing campaigns in Spanish, targeted to different Latino sub-populations, in many of their communities. They recommended targeting funding to carry out such campaigns.

Leadership and Advocacy

Lack of leadership and apathy were a recurring theme. Participants identified burnout of leaders as a common problem and noted that resources are needed to carry out leadership training, mentoring, and support programs, to develop and support more grassroots Latino leaders. Poor advocacy due to apathy is hard to break through, particularly since involvement means exposure. This is a big step for many HIV+ Latinos who are struggling with the adverse consequences of stigma.

Under-representation of Latinos on HIV Planning Bodies

The participants agreed that in most areas, Latinos are absent or under-represented on Title I planning councils, Title II consortia and other HIV related planning bodies. They called for expansion of recruitment, training, mentorship, and support programs targeting HIV+ Latinos as one means of increasing representation. They also noted that many people serving on these planning bodies experience burnout and drop out.

Inter-agency Collaborations

While collaborations are a means of increasing access to services and maximizing resources, these are often wrought with inter-agency conflicts on the community level. Participants noted the need to enhance provider skills in collaborations and forming successful partnerships. They also noted that collaboration among CBOs of color should be encouraged and supported through training and technical assistance.

Funding

Participants repeatedly identified lack of funding or inadequate funding levels for most services needed by PLWH/A as a major barrier to access to services. They also identified competition among service providers for funding as a major obstacle to increasing access to care on the community level. Turf battles and divisions among E/R minority CBOs is common. Participants noted there is a lack of funding support for faith-based organizations and for CBOs. To address lack of collaboration and turf issues, participants suggested the use of non-partisan mediators. They also noted that the funding sources' funding and reimbursement processes inadvertently encourage competition, and discourage collaborations among agencies.

These funding difficulties are further complicated by the ineffective mechanisms funding sources use to disseminate information regarding funding opportunities. Participants noted that often the information does not filter down to CBOs. There is misinformation or untimely information provided, or the information is only provided to the larger and well known organizations. Participants recommended that funding sources improve their methods to disseminate information about grant opportunities to reach a broader array of community-based organizations in the Latino community.

Participants observed that small health departments encounter similar funding difficulties, but are not eligible to apply for private funding. Small CBOs, on the other hand, may not have the capacity to manage funds. Partnerships between CBOs and health department may maximize funding for certain services and such public/private ventures should be explored and supported.

Concluding Comments

Participants stressed the importance of peer advocacy, particularly given the power imbalances that exist between HIV+ persons who receive services and care providers. The advantage of having HIV+ persons who are providing services (as social workers or case managers) is that they can serve as role models for clients, to encourage them to become peer educators later on in the process.

Endnotes

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