

# Report

## *African American Community Consultation:*

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Access to HIV/AIDS Care Issues

January 29, 2004  
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.<sup>1</sup> 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 in 2002.<sup>2</sup> 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.<sup>3</sup>

The Ryan White Comprehensive AIDS Resources Emergency (CARE) Act, originally enacted by Congress in 1990, and subsequently amended and reauthorized in 1996 and 2000, is due for reauthorization again in 2005.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, reduce the use of more costly inpatient care, increase access to care for underserved populations, and improve the quality of life for those affected by the HIV/AIDS epidemic.<sup>4</sup> CARE Act funding is distributed through grants to states, local governments and 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.<sup>5</sup>

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 underserved areas and communities of color.

On an annual basis, the 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.<sup>6</sup>

During 2003, in preparation for the upcoming 2005 reauthorization of the CARE Act, the HIV/AIDS Bureau engaged in extensive consultation with constituents, the CDC/HRSA Advisory Committee on HIV and STD Prevention and Treatment, national partners, frontline service providers, community members and people living with HIV/AIDS. This consultative process was designed to solicit broad feedback on current HIV/AIDS treatment and care issues and the future directions needed to improve and strengthen the CARE Act. This process also included an examination of how well the CARE Act is fulfilling its purpose of providing quality health care, treatment and crucial support services to low-income, uninsured, underinsured and underserved people living with HIV and AIDS.

## **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 29, 2004, with a group of African American 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 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 African American 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 formulation of recommendations for reauthorization

## Participants

The participants of the African American Community Consultation Group meeting were diverse, representing community-based service providers, consumers of CARE Act services, and members of CARE Act Title I Planning Councils. A total of seventeen individuals participated from a cross section of cities and states including Los Angeles, CA, Miami, FL, Albany and Savannah, GA, Chicago, IL, Shreveport, LA, Jackson, MS, Las Vegas, NV, Ambridge, PA, Columbia, SC, Nashville, TN, and Dallas and Houston, TX.

The service providers included executive directors, program directors, and frontline staff of AIDS service organizations, faith and community-based organizations, and primary health care centers. The organizations represented provide services to a broad range of vulnerable, underserved and at-risk populations and persons living with HIV/AIDS. Clients served include women, children, heterosexual men and men who have sex with men, as well as homeless, incarcerated and recently released populations, and persons with substance abuse and mental health issues. These organizations provide a mix of services including outreach, anonymous and confidential HIV-antibody testing, pre- and post-test counseling, health and risk reduction education, condom distribution, substance abuse counseling, prevention case management, referrals and linkages to other services, emotional support, support groups for persons living with HIV/AIDS, counseling services, personal care services, housing assistance, and comprehensive primary health care.

*Disparities in access to HIV care and health outcomes persist for minorities living with HIV disease, despite advances in HIV clinical care and drug therapies, and the decline in the number of deaths among persons with AIDS.*



# *Trends of HIV/AIDS among African Americans*

African Americans in the US have been disproportionately impacted by the HIV/AIDS epidemic. While African Americans make up 12.3% of the total population of the US, they account for 39% (347,491 of 886,575) of the estimated cumulative AIDS cases reported through 2002 and 50% of the AIDS cases reported in 2002.<sup>7</sup> In 2002, the AIDS diagnosis rate among African Americans was more than 10 times the rate among whites (58.7 compared to 5.9 per 100,000). Among women, the rate of AIDS diagnoses per 100,000 was 23 times greater for African-American women when compared with the rate for white women (48.6 compared to 2.1). Among African American men, the rate of AIDS diagnoses was nearly 9 times greater than the rate for white men (108.4 compared to 12.3).<sup>8</sup>

Moreover, African Americans account for 37% of the cumulative estimated deaths of persons with AIDS reported through 2002 and more than half (52.3%) of estimated AIDS deaths reported in 2002.<sup>9</sup> African Americans accounted for 42% (162,412 of 384,906) of the estimated number of persons living with AIDS in the US by 2002. By year end 2002, more than half of the estimated number of persons living with HIV/AIDS reported from the 30 areas with confidential name-based HIV infection reporting, were African American.<sup>10</sup> In terms of survival after an AIDS diagnosis, African Americans had the poorest rates of all racial and ethnic groups for people diagnosed with AIDS since 1994, with 55% surviving after 9 years compared to 61% of Hispanics, 64% of whites, and 69% of Asian/ Pacific Islanders.<sup>11</sup>

Nearly half (48.5%) of the new cases of HIV (not AIDS) reported in 2002 from 39 areas with confidential named-based HIV infection reporting, were among African Americans.<sup>12</sup> Early diagnosis of HIV infection is important for both HIV prevention and care. Early diagnosis and entry into care is associated with delays in progression from HIV to AIDS and increased survival rates. Unfortunately, a significant proportion of African Americans learn their HIV diagnosis late (within one year of their AIDS diagnosis). A study conducted by CDC of people diagnosed with HIV found that 56% of those that were diagnosed with AIDS within one year of their HIV diagnosis were African American.<sup>13</sup>

Different subgroups of African Americans have been more highly impacted by the HIV/AIDS epidemic. Males account for the 66% of the new AIDS cases and 57% of the new HIV cases reported among African American adults/adolescents in 2002. Moreover, among African American males, the leading exposure category is men who have sex with other men (MSM). MSM accounted for 32% of the AIDS cases and 30% of the HIV cases reported among African American males in 2002, followed by injection drug use which accounted for 19% of the new AIDS cases and 11% of the new HIV cases in the same year. Women account for an increasing proportion of the AIDS cases among African Americans. For example, in 1991, African American women represented 22% of new AIDS cases reported among all African Americans. This proportion increased to 34% by 2002. In 2002, of the new cases reported among African American women, the leading exposure category, for AIDS was heterosexual contact, and for HIV, it was risk not reported or identified (57%).<sup>14</sup>

## **Geographic Distribution**

According to the US Census Bureau, more than half of the 36 million African Americans in the US live in the South (55%). The Northeast (18%) and Midwest (18%) region account for nearly one-fifth each of the African American population. About 9% of the African American population lives in the West. More than one-half (52 percent) of all African Americans live in a central city within a metropolitan area, and 13 percent live in non-metropolitan areas.<sup>15</sup>

At the end of 2001, there were 151,530 African Americans living with AIDS in the US. While African American persons living with AIDS have been reported in virtually all states, there are geographic variations in the impact of the HIV/AIDS epidemic among African Americans across the country. The two regions of the country accounting for the largest proportions of African Americans living with AIDS are the Northeast (38%) and the South (37%).<sup>16</sup> Nearly three-quarters (72%) of the African Americans living with AIDS in the US reside in ten states and nearly half (48%) reside in ten metropolitan statistical areas, as detailed in the table below:

<b>Ten States/Jurisdictions with the Highest Number of African Americans Living with AIDS 2001</b>			
<b>Jurisdiction State/Territory</b>	<b># of African Americans Living with AIDS at the end of 2001<sup>17</sup></b>	<b>MSA of Residence</b>	<b># of African Americans Living with AIDS at the end of 2001<sup>18</sup></b>
New York	27,080	New York, NY	22,888
Florida	19,543	Washington, DC	9,337
California	9,597	Philadelphia, PA	6,343
Maryland	8,915	Baltimore, MD	5,963
New Jersey	8,716	Miami, FL	5,724
Texas	8,520	Atlanta, GA	5,540
Georgia	8,308	Chicago, IL	5,191
Pennsylvania	7,281	Newark, NJ	4,473
District of Columbia	5,989	Los Angeles, CA	3,588
Illinois	5,937	Houston, TX	3,254

## **HIV/AIDS Among African Americans**

African Americans living with HIV/AIDS face significant barriers to access to HIV care, including poverty, lack of health insurance and competing subsistence needs.

- An estimated 32.9 million people in the US lived below the poverty level in 2001, including 8.1 million African Americans. The poverty rate, which was 12 percent for the total population, was 23 percent for African Americans. The poverty rate for African American men (20 percent) was nearly three times that for white men (7 percent). The rate for African American women (25 percent) was more than twice that for white women (9 percent).<sup>19</sup>
- African Americans with HIV/AIDS were more likely to be publicly insured or uninsured than their white counterparts, with over half (59%) relying on Medicaid compared to 32% of whites. About one-fifth of African Americans with HIV/AIDS (22%) were uninsured compared to 17% of whites. African Americans were much less likely to be privately insured than whites (14% compared to 44%).<sup>20</sup>

- Studies have documented that when compared to whites on key indicators of access and quality of HIV care, African Americans experience significant disparities. For example, Shapiro, et al. found that African Americans with HIV that were in care were less likely to receive antiretroviral therapy, less likely to receive prophylaxis for *Pneumocystis carinii* pneumonia (PCP), and less likely to receive the more effective combination therapies (protease inhibitor or non-nucleoside reverse transcriptase inhibitor drugs) than whites. While these differences in access and quality of care decreased over time, they were not completely eliminated.<sup>21</sup>
- African Americans were more likely to report postponing medical care because they lacked transportation, were too sick to go to the doctor or had one or more other competing needs (housing, clothing, food).<sup>22</sup>

*The level and quality of HIV/AIDS care in communities is influenced by the extent to which African American consumers, community based organizations, and service providers have relationships with their political leaders and can garner their support.*

## CARE Act Funded Services

CARE Act funded programs provide an important source of care for uninsured and underinsured African Americans living with HIV/AIDS. In 2001, based on data from Annual Administrative Report, the percentage of African Americans served by CARE Act programs ranged from a low of 20% to a high of 64%. The percentage distribution of African Americans served by CARE Act programs in 2001 was:

- **Title I** - 47 percent of the duplicated clients; 49 percent of the duplicated clients seen for medical care were African American.
- **Title II** - 48 percent of the duplicated clients; 47 percent of the clients receiving medical care services
  - 37 percent of the clients served by ADAP
  - 20 percent of the clients served by HIPs.
- **Title III EIS Program** - 47 percent of all patients for whom demographic information was reported
- **Title IV** - 64 percent of all clients for whom demographic information was reported.<sup>23</sup>

The diversity of the African American population in the US and the differential impact of HIV/AIDS by age, gender, sexual orientation, mode of exposure and geographic region pose significant challenges for program planners and service providers. An effective response to the needs of this population requires the design and implementation of culturally competent HIV/AIDS-related services. This requires program planners and service providers to understand and address the complex cultural, social, and economic factors affecting the delivery of HIV/AIDS services to African Americans and how these vary by region,

and sub-populations. In addition, it will be beneficial for program planners and service providers to better understand how such factors as sexual orientation, religious beliefs and educational attainment further modulate sub-group variations.



# *Meeting Proceedings*

On January 29, 2004, HRSA's HIV/AIDS Bureau convened the African American Community Consultation Group meeting. The National Minority AIDS Council (NMAC), in partnership with HAB identified participants for the meeting and arranged the meeting, travel and lodging logistics. The meeting was held at the Doubletree Hotel and Executive Meeting Center, in Rockville, Maryland, from 9:00 AM to 4:00 PM.

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. Steve Kilkelly, a consultant who facilitated the meeting, introduced and distributed 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.



# *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.

## **Community Strengths**

The participants identified the following community strengths:

### **Community Support**

- Connections to political leadership
  - Increases ability to garner support
  - Openness of local, state and federal elected officials
- Churches more involved
  - Black Churches address social, economic and civil rights issues
  - Increased involvement of pastors and other faith-based leaders
  - Church leaders need to spearhead response to HIV/AIDS
- Public Awareness
  - Greater public awareness of HIV and related issues leads to greater public support
  - More people understand HIV is not a "gay" disease
- National Black AIDS Awareness Day
  - This activity is a start but every day must be an awareness day
  - Broad cross-section of community leadership needs to become more involved

### **Socio-Economic Conditions**

- Broader economic and community development
  - Response is stronger when economic, social, political and educational opportunities and systems are in place
  - Some people think CBO stands for "constantly broke organization."
- Need community development to support CBOs
- Need capacity development to get organizations to levels of effectiveness
- How to plan with other health care providers, churches and businesses to create influence that supports the provision of effective services

## **Advocacy**

- Advocacy and education leading to policy change
  - Caring individuals and aggressive advocates play key role
  - Advocates involved in many local issues who won't take no for an answer
  - Need to view health care as a civil rights issue
- HIV-infected or affected advocates

## **Care Delivery System**

- Consumer involvement
  - Makes services more responsive to the needs of PLWH/As
  - Include in service organizations as employees, peer educators and on client advisory boards
- Strong CBOs serving PLWH/A
  - Committed CBOs with a history of service in the community
  - CBOs' increased ability to compete for funding
- Accessibility of services
  - Located in areas near public transportation
  - Located near other services and resources
- Availability, scope and quality of services
  - Broad range of services available for different sub-populations
  - Services available at times to fit working clients' schedules
- More HIV testing centers available
  - New testing technologies enable delivery of same day HIV test results
  - Linked to services for HIV+ persons
  - Provide counseling, education and incentives such as meals.
- Experienced medical providers
  - Experience in HIV care
- AIDS Drug Assistance Program
  - Provides prescription drugs for uninsured
  - Increased enrollment
- Good networking and referral systems
  - Good communication among service providers
  - Information sharing
  - Providers' awareness of community resources
- Collaborations
  - Good inter-agency collaborations
  - In smaller communities/ rural areas
  - To maximize resources, avoid duplication

## **HIV Planning Processes**

- Participation in planning processes helps to connect social services and medical care
- Level playing fields ("don't get mad, get even")
  - Process is not where it should be
  - But progress is being made
- Having a planning body in the community
  - Efforts to include all
  - Open meetings
- Consortia
  - Oversight by the lead agency
  - Advocacy of the lead agency for partnership with the state
- Diversity in representation at planning table and in organizations
  - Need to include community data in the planning process
  - Need for network to address prevention and treatment issues

## **Discussion**

The participants identified a number of important community strengths that were organized into five categories: community support, socioeconomic conditions, advocacy, care service delivery system and HIV planning processes.

### **Community Support**

Community support was demonstrated through the level of involvement of political leadership, faith based leaders and churches in HIV issues and in the degree of public awareness regarding HIV and its specific impact on the community.

Participants indicated that having connections to political leaders is a key factor in building a strong community response to HIV. The level and quality of HIV/AIDS care in communities is influenced by the extent to which African American consumers, community based organizations, and service providers have relationships with their political leaders and can garner their support. Some participants for example, noted the openness and strong support of their Mayor's Office, or their U.S. Senator.

Faith communities and churches play key leadership roles in responding to social, economic and civil rights issues in African American communities. Participants repeatedly identified the involvement of faith community leaders and churches as an important component of African American communities' response to HIV/AIDS. Some participants

noted that in their communities, more black pastors are getting involved. Others stated that the importance of the involvement of faith communities varied depending on the geographic area. However, most stressed the importance of enhancing the involvement of black pastors and churches.

Participants noted that public awareness of HIV/AIDS and other related issues such as substance abuse, leads to greater public support of HIV/AIDS related services. Some participants, for example, stated that in their communities, more people understand this is not a gay disease, more Magic Johnson posters are being put up, or more anti-drug commercials come on during primetime. Other participants noted that a broad cross section of community leadership needs to get involved in raising awareness of the devastating impact of HIV /AIDS in African American communities. A number of participants observed that activities such as the annual National Black AIDS Awareness Day held in February, are important vehicles to coalesce different sectors of the community, raise awareness around HIV/AIDS and plan community-led responses.

### **Socio-Economic Conditions**

Existing socio-economic conditions within communities are important factors that affect access to HIV/AIDS care. Participants identified broad economic and community development as an important element in responding to HIV/AIDS. The response will be stronger to the extent that communities have economic, social, political and educational opportunities and systems in place to address community needs. They noted that community development also involves strengthening community-based organizations (CBOs).

### **Advocacy**

Participants agreed that strong advocacy is an important component of building effective HIV care delivery systems in their communities. They highlighted the key roles of individual, caring and aggressive advocates who are involved in many local issues and who won't take no for an answer. Some participants indicated that health care is a civil right and that taking the civil rights activists' approach to solving problems in the HIV/AIDS arena may promote greater community involvement in advocacy. Participants also emphasized the key role that HIV-infected and affected advocates play in advocacy.

### **Care Service Delivery Systems**

A number of strengths were identified within the existing care service delivery systems in their communities. Participants observed that

consumer involvement in the delivery of HIV care was critically important in making services more responsive to the needs of people living with HIV disease. Having consumers involved as employees in care service organizations, as peer educators, on client advisory boards and as advocates contributes to access to and delivery of quality HIV/AIDS care. They noted that many persons living with HIV are faced with the dilemma that they may lose their health care coverage if they return to work. Others who are working may have to quit their jobs if they become really sick and need care. One participant stated that, "Unless the health insurance problem is resolved, there may be fewer people with HIV working in the service delivery system and CBOs because they can only get health care if they are unemployed. "

Participants agreed that having committed community-based organizations (CBOs) with a history of service provision in the African American community is a major strength. They also mentioned the advantage of CBOs' increased ability to compete for funding in sustaining services.

Service location is an important factor in assuring access. Participants noted the advantage of having services located in areas that are accessible to clients via public transportation (agencies located on/near bus routes and providing carfare). They also noted the importance of having providers located in areas accessible to a variety of other resources.

Participants identified the existence of a broad range of services that are confidential and available to meet the specific needs of different subpopulations as a major strength. They noted improvements in the availability, scope, quality and confidentiality of services in many communities. Some indicated that they now have services in African American communities within their city that were previously underserved. The types of services mentioned include: services for men who have sex with men (MSM); women over 50 who are married; HIV testing; counseling for HIV infected people; counseling services offered at flexible times; good referral services; condom distribution; housing for the homeless; support groups; and programs for recently released prisoners.

Participants stressed the importance of greater availability of HIV counseling and testing services, particularly those utilizing new testing technologies (OraSure and OraQuick). These testing services enable providers to deliver HIV test results within shorter periods of time and link HIV+ persons to care services. They also stressed the importance of

*Unless the health insurance problem is resolved, there may be fewer people with HIV working in the service delivery system and CBOs because they can only get health care if they are unemployed.*

having these services complemented by counseling, education and incentives such as meals.

Participants noted that having medical providers that are experienced in providing HIV care facilitates delivery of quality care services. They also agreed that access to medications is very important, particularly for clients who are low income and uninsured or underinsured. The availability of medications through the AIDS Drug Assistance Program (ADAP) program fills this need.

*Many people with HIV are afraid of the consequences of disclosure of their status in their communities, and therefore, forego needed services. Stigma also fuels denial that results in lack of community recognition and involvement in HIV/AIDS.*

Strong connections and good communication among service providers in highly impacted communities was viewed as important to the delivery of a continuum of quality HIV care and support services to persons living with HIV disease, especially those experiencing co-morbidities, and multiple psycho-socio-economic problems. Participants identified network strengths, such as the level of communication with partnership members, information sharing, providers' awareness of community resources, HIV handbooks, network meetings and good training networks.

Participants noted that they can improve their sphere of influence through collaborations. They stressed the importance of effective collaborations among social service and faith-based organizations, medical providers, and with state and local health departments, in order to maximize resources, avoid duplication and deliver needed services.

The size of the community, service area and client population are factors that can facilitate collaborations. Participants noted that in urban or rural communities, where the service area and population is smaller, collaboration may be easier because service providers know each other.

## **HIV Planning Processes**

HIV planning at the local level is the cornerstone of assuring access to a continuum of prevention and care services for affected populations. The participants considered involvement of representatives of African American communities (service providers, HIV+ and affected persons and community leaders) in local HIV planning processes crucial to assure that services are responsive to the needs of African Americans affected by HIV disease. Strong participation in planning processes was also considered an essential mechanism to connect social services and medical care. In communities where there is a level playing field, and there are efforts to include representatives of all affected communities in the process, planning is more responsive. Participants noted that in some communities, the degree of openness to participation of African

Americans in these planning processes is not where it should be. However, there was general agreement that progress is being made.

Participants noted the importance of having planning bodies in their communities, such as CARE Act Title I planning councils and prevention community planning groups (CPGs). They identified factors that contribute to effective planning, such as inclusiveness, open meetings, transparency of the evaluation, transparencies of grant making and allocation processes, site visits and project review by program officers.

Participation in HIV consortia was also noted as important. Participants identified the following as factors that facilitated participation in consortia and good planning by consortia: oversight by the lead agency, advocacy of the lead agency for partnership with the state, the needs assessment process, and accessibility of state officials, particularly for data.

## **Community Challenges**

The participants identified the following factors as key community challenges:

### **Socio-Economic Conditions**

- Extreme poverty and economic disparities
- High unemployment rates
- Lack of affordable housing
- Lack of health insurance (related to joblessness)
- Lack of transportation, especially mass transit
- Poor public schools and education
- Immigration and migration
- Co-morbidities and co-infections

### **Racism and Discrimination**

- Lack of trust
- Backlash - feeling that all services are for people of color
- Lack of unity
  - Divisiveness along racial lines persists
  - Divisiveness based on gender and race

### **Stigma**

- Fear of the consequences of disclosure of HIV status
- Lack of participation of community due to HIV/AIDS stigma
- Increased stigma in communities
- Rural Southern Bible Belt ideology contributes to stigma

## **Community Support and Leadership**

- Lack of support and leadership from key sectors
  - Limited church and faith-based community involvement
  - Limited business community involvement
  - Lack of involvement of caring legislators

## **Care Service System**

- Lack of collaboration among organizations
  - Territoriality and competition for funding and clients
  - Lack of unity among service organizations
  - Public health departments not supportive of faith-based organizations
- Inadequate health care and prescription drugs
  - Not enough medications
  - Limited participation from ADAP
- Limitations of medical providers
  - Shortages, especially in rural areas
  - Limited HIV experience
  - Lack of understanding of prevention issues
  - Lack of cultural competence
- Limitations in responsiveness of services to client needs
  - Service hours and locations
  - Lack of after work hours
  - Need to integrate more spirituality in services
  - Lack of support for non-medical services

## **Consumer Involvement**

- Lack of consumer involvement
  - Limited number of consumer advocates participating in the process
- Lack of consumer education and empowerment
  - Peers feel intimidated by professionals
  - Women do not speak up like men

## **HIV Planning Processes**

- Lack of participation of African American consumers and community representatives
- Lack of participation of key groups at the planning table (voices are not heard and issues are not presented)
- Participants do not feel empowered to be at the table

## **Funding**

- Inadequate funding targeted to African American community-based organizations
  - Minority funds go to non-minority organizations
  - Competition for funding
  - Inadequate levels of funding to staff programs
- Difficulties serving minority populations due to inequities in the distribution of funds (especially MAI)
- Inappropriate use of funding by recipient organizations
  - AIDS treated as a business
  - Focus on income rather than on provision of client centered services
  - Focus on numbers (cases) rather than people

## **Organizational Capacity**

- Lack of organizational infrastructure and capacity
  - CBOs need help transitioning from storefront operations to savvy business
  - Fundraising fiscal, program management and organizational development
  - Data collection, evaluation and quality assurance
- Lack of economies of scale
  - Too many small organizations funded
  - Merge small organizations to pool resources to serve people with HIV

## **Discussion**

The participants identified a number of significant challenges faced by their communities that affect access to HIV/AIDS care. The challenges were organized into five categories: socio-economic conditions, racism and discrimination, stigma, community support and leadership, and care service systems.

### **Socio-economic Conditions**

A number of existing socio-economic conditions present significant challenges to communities and negatively affect access to HIV care. Participants noted high rates of poverty and extreme poverty, particularly in rural areas among African Americans as a major challenge. Another related factor is the high rate of unemployment and lack of jobs that pay a livable wage in their communities. Some participants noted that the lack of jobs, particularly for individuals being released from the correctional system, means that their basic needs are not being met. One participant

*Some participants noted a backlash in the service delivery arena related to the increased focus on, and targeting of funding for, services for people of color.*

observed that in his community, more people are getting involved in alternative means to income such as gambling and sex work. Such income generating activities may ultimately result in greater involvement of community members with the criminal justice system. Moreover, lack of income and meaningful employment may impact an individual's self-esteem and lead to unhealthy or risk taking behaviors.

Participants also identified widespread homelessness and lack of affordable housing as a major challenge in many communities. Some noted that many people are living in shelters and others who own their own homes are at risk of losing them because of limited income. Participants identified lack of funding to address homelessness and to provide housing assistance to allow their clients to stay in their homes as a major obstacle to access to care.

In addition, participants noted the high rates of people living in their communities that have no health care insurance. This is in part related to the high rates of unemployment. Many people who were previously covered through their employers have lost their coverage due to unemployment. Others may not qualify for public health care benefits for a number of reasons. Moreover, participants noted that many people living with HIV (not AIDS) lack health insurance.

Another factor that negatively influences access to care in many communities is the lack of public transportation. This problem is most acute in rural areas where clients have to travel long distances to reach service sites. Participants noted that in areas where public transportation is available, it is often limited in scope, frequency and hours of operation. Some participants noted that transportation problems impede the ability of many people in their communities to access HIV counseling and testing sites.

Low educational attainment was also noted as a major challenge for many community members. Many participants identified the poor quality of public education in their communities as a contributing factor that led to high drop out rates and low high school graduation rates. Lower educational attainment and low literacy affects clients' ability to access and navigate complicated service systems, apply for benefits, utilize printed educational materials and follow instructions on medication labels.

Participants noted increases in the Hispanic/Mexican populations in their communities due to immigration and migration. Some observed that access to care and services for this population is limited due to

undocumented status, language barriers, lack of health coverage, and low literacy. In addition, in some communities, the Hispanic/Mexican population is transient due to employment in migrant farm work, and this leads to greater difficulties in continuity of care. Moreover, barriers related to language and cultural differences between service providers and these populations limits their ability to provide needed services.

Participants noted that they are seeing more and more clients who have a combination of co-morbid conditions and co-infections that further complicate their HIV care. In addition to HIV infection, many clients have such co-morbid conditions as alcohol and drug abuse, mental illness, hypertension, cardiovascular disease and diabetes. Others have co-infections such as Hepatitis C and tuberculosis.

### **Racism and Discrimination**

Participants identified factors such as lack of trust and unity as major challenges to improving access to HIV care in their communities. They noted that deep divisions still exist in many of their communities along racial lines. There is also significant divisiveness related to gender and sexual orientation. Some participants noted a backlash in the service delivery arena related to the increased focus on, and targeting of funding for, services for people of color.

### **Stigma**

HIV/AIDS related stigma was repeatedly identified as a major community challenge by the participants. Some participants noted that many people with HIV are afraid of the consequences of disclosure of their status in their communities and therefore forego needed services. Stigma also fuels denial that results in lack of community recognition and involvement in HIV/AIDS. Some participants noted an increase in HIV/AIDS related stigma in their communities, and others stated that stigma is entrenched in rural, southern, Bible Belt communities where religious beliefs reinforce and justify stigmatizing attitudes.

### **Community Support and Leadership**

Participants identified lack of support and leadership from key sectors of their communities including religious, business and political sectors as a major challenge. Some participants noted that there was limited leadership on HIV/AIDS and involvement in community education by churches and faith based leaders. Others stated that the business sectors in their communities were minimally involved in addressing HIV/AIDS. Still other stated that legislators and appointed officials in their communities show little interest and are not involved in this issue.

## Care Service Systems

Participants agreed that there were a number of challenges to access to care inherent within the care service systems in their communities. These include lack of collaboration among organizations and public health departments, inadequate care and prescription drugs, limitations of medical providers, and limited responsiveness of services to client needs.

Participants noted lack of collaboration among organizations as a major challenge. Impediments to collaboration include territoriality, competition for funding and clients, and lack of trust and unity among providers. Moreover, participants stated that in some of their communities, public health departments are not supportive of faith-based organizations.

Participants agreed that inadequate health care and limitations in the availability of prescription drugs through private and public health coverage and programs, including ADAP, presented significant obstacles to access to care for the people with HIV in their communities.

The short supply of medical providers in many communities (especially small or rural ones) and the limited number of providers with HIV care experience makes access to care a major problem. Other challenges to access include lack of provider cultural competence, and lack of understanding of prevention issues and of social support services by medical providers.

Participants agreed that the organization and scope of services provided in many of their communities do not respond effectively to the needs of the clients receiving the services. The sheer complexity of the health care delivery system presents major challenges to access by clients. Moreover, many services are organized around the providers' rather than the clients' needs in terms of schedules, hours of operation and location. Participants noted that in general there was a lack of availability of services after work hours for employed clients. They also expressed concern that many services are being moved out of the CBOs in their communities and that there is greater emphasis on case-management rather than client advocacy.

Participants pointed out that the people living with HIV/AIDS in their communities have myriad social and psychological problems and needs, yet they experience lack of support for services other than medical ones.

Participants also noted lack of support for certain types of services such as education for older persons (over 50), treatment education and

prevention, and counseling and support services for persons who test positive for HIV infection. They also agreed organizations need to address and integrate spirituality within their organizations and service delivery approaches.

## **Consumer Involvement**

Participants indicated that limited or lack of consumer involvement in the planning, design and delivery of services presents major obstacles to access to care. While consumers can play a major role in assuring that services are responsive to client needs, a number of factors preclude their involvement. These include intimidation of consumers by professionals, lack of empowerment of HIV+ persons, lack of organizations designed for women and lack of support, mentoring and encouragement of women with HIV to participate in planning and advocacy activities.

## **HIV Planning Processes**

Although participants recognize that participation of African American consumers and community representatives in HIV planning bodies is important, they noted a significant absence of African American representation at planning tables in their communities. This absence then means that their voices are not heard and that key issues regarding care and prevention needs and services are not brought up for consideration by these planning bodies. One of the major obstacles to participation mentioned is a lack of empowerment.

## **Funding**

Participants acknowledged lack of funding targeted to African American community based organizations as a major factor affecting access to care in their communities. A number of participants identified key challenges to serving the ever growing numbers of African Americans with HIV in their communities because funding through the Minority AIDS Initiative (MAI) is often going to non-minority organizations. African American community-based organizations experience difficulties getting funded by federal, state and local entities or receive inadequate levels of funding. These organizations are therefore unable to expand their staffing to meet the growing client need.

The limited resources available for care services also leads to fierce competition for funding among service providers. In addition, participants noted that many organizations are treating AIDS service delivery as a "business" rather than a client centered human service. Such organizations are focusing on generating numbers to justify their funding and are losing sight of the clients' needs. What some participants

*People living with HIV/AIDS in their communities have a myriad of social and psychological problems and needs - yet they experience lack of support for services other than medical ones.*

characterized as "provider greed" therefore appears to be driving the approach to service delivery in many organizations.

### **Organizational Capacity**

Participants identified lack of organizational infrastructure and capacity as a major impediment to the delivery of quality HIV services. They discussed a number of training, technical assistance and capacity building needs including fiscal capability and management, transitioning from storefront operations to well run and fiscally sound organizations, fundraising, board development, data collection, analysis and use in planning, monitoring, and evaluating services, and development and implementation of quality assurance systems.

Participants agreed that there are many small community based organizations struggling to survive and deliver services in their communities. These organizations lack economies of scale and need technical and capacity building assistance to maximize resources through collaborations and resource pooling with other organizations to better serve people living with HIV in their communities.

## **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:

## Stigma

Barriers	Facilitators
<ul style="list-style-type: none"> <li>• Shame</li> <li>• Fear of disclosure and discrimination                             <ul style="list-style-type: none"> <li>- Do not seek services</li> <li>- Avoid services in "gay" organizations</li> </ul> </li> </ul>	<ul style="list-style-type: none"> <li>• Stigma reduction efforts</li> <li>• Education of community members (AIDS 101)</li> <li>• Support groups to expand education to treatment/care</li> <li>• Support groups with guest speakers to expand the education of persons with HIV/AIDS</li> <li>• Developing organizations within cities that stand for diversity and equality</li> <li>• Education on compassionate, non-judgmental counseling</li> </ul>

## Family and Community Support

Barriers	Facilitators
<ul style="list-style-type: none"> <li>• Lack support from family</li> <li>• Lack of community support</li> <li>• Lack of political support (legislators)</li> </ul>	<ul style="list-style-type: none"> <li>• Community support groups</li> <li>• Increase number of HIV+ persons in legislature</li> </ul>

## Socio-Political

Barriers	Facilitators
<ul style="list-style-type: none"> <li>• Inequality and inequity                             <ul style="list-style-type: none"> <li>- Classism</li> <li>- Racism</li> <li>- Sexism</li> </ul> </li> <li>• Political controversy</li> <li>• Conservative moral and religious values on the local level                             <ul style="list-style-type: none"> <li>- Increasing pressure for conformity</li> </ul> </li> </ul>	<ul style="list-style-type: none"> <li>• Community outreach and peer models</li> <li>• Involve and educate community and people living with HIV/AIDS</li> <li>• Focus on HIV as a public health crisis rather than a moral issue.</li> </ul>

## Socio-Economic Conditions

### Barriers

- Poverty
- Lack of health insurance or inadequate coverage
  - Clients have to make choices (rent vs. medications)
  - Inadequate prescription drug benefits
- Restrictive income and asset eligibility criteria for benefits or services
  - Disadvantages for homeowners
  - Types of services/benefits clients can qualify for depends on whether they have an HIV or AIDS diagnosis
- Homelessness
  - Lack of affordable housing
  - Senior citizens with limited income may often choose between housing and medications.
- Lack of child care
- Lack of transportation
- Limited public transportation
- Co-morbidities
  - Substance abuse (drug and alcohol)
  - Mental health issues
  - Co-occurring substance abuse and mental illness
  - Other psycho-social issues
  - Weak linkages to mental health services
  - Location of services

### Facilitators

- Provide incentives to clients (food vouchers)
- Develop collaborations with pharmaceuticals to obtain free or low cost medications
- Drop in groups
- Provide permanent housing or supplemental housing assistance (housing assistance may free up resources to enable them to pay for their medications).
- Make resources available to organizations to provide child care where client receives the services
- Allocate funding just for transportation
- Provide more realistic transportation options
- Develop connections with transportation providers
- Collaborate at the federal level with Department of Transportation (DOT) to facilitate new approaches to provide to transportation for people suffering from health challenges
- Establish effective linkages to substance abuse treatment
- Assure that primary care facilities also address substance abuse and mental health needs
- Utilize case conferencing to assure coordination
- Provide HIV services in drug treatment facilities
- Provide school based services
- Behavioral health services based in care facilities

## Care Service System

### Barriers

- Lack of knowledge of HIV serostatus
- Difficulties reaching and retaining targeted population in services
- Poor access to health care
  - Lack of caring for persons with HIV/AIDS
  - Lack of peer driven approaches
- Clients' negative perceptions of health care system
  - Clients' previous negative encounters with health care system
  - Provider biases towards clients
- Lack of Cultural Competence
- Social/cultural distance between clients and providers social/cultural distance
  - Providers lack of understanding of consumers' culture
  - This impacts consumers willingness to access services
  - Services not located in community
  - Disrespectful communication style of providers
  - Providers' lack of understanding of impacted communities
  - Lack of diversity of providers
  - Providers' background not reflective of community's culture (language, behaviors)

### Facilitators

- Education seminars
- Outreach, counseling and testing
- Expand definitions of outreach to include one-to-one peer counseling
- Street outreach
- Provide incentives
- Services need to be more community based
- Provide one stop shopping.
- Culturally competent and relevant programs
- Offer incentives for testing and health care
- Use peer models to assist clients to gain necessary navigational skills
- Community outreach and peer-based service models and programs
- Provider education about the needs of different populations
- Include consumers in process
- Partnerships between minority/majority organizations to mentor minority organizations
- Develop better communication skills
- Provider education
- Use of technology for case conferencing for social service providers and medical providers to eliminate social and cultural barriers and bridge gaps.
- Culturally competent and relevant services
- Need to treat the whole person, not just the body

## Care Service System (continued)

Barriers	Facilitators
<ul style="list-style-type: none"> <li>- Lack of integration of spirituality in holistic service delivery models</li> <li>• We are not just body parts; we are mind, body and spirit.</li> <li>• Overloaded and untrained case managers</li> <li>• Inadequate number of HIV medical providers (physicians)</li> <li>• Lack of HIV knowledgeable primary care providers                             <ul style="list-style-type: none"> <li>- Lack of knowledge of all HIV medications</li> <li>- Lack of knowledge of treatment protocols</li> </ul> </li> <li>• Lack of effective treatment adherence education                             <ul style="list-style-type: none"> <li>- Medication side effects</li> </ul> </li> <li>• Inadequate understanding of differences of HIV disease in people of color compared to white gay men</li> <li>• Lack of caring, client centered approaches to service delivery</li> <li>• Financial gain drives service delivery ("provider greed")</li> <li>• Provider focus on generating high client counts to get grants/increase revenues rather than meeting client needs</li> <li>• Funding allocated to the wrong groups</li> <li>• Lack of services for HIV+ women                             <ul style="list-style-type: none"> <li>- Existing ASOs originally established to serve gay men and MSM tailor programs to meet their needs but may not necessarily be culturally appropriate to serve women</li> </ul> </li> </ul>	<ul style="list-style-type: none"> <li>• Need to address the wellness of the person as a whole.</li> <li>• Shouldn't just keep pushing the pills on the people.</li> <li>• Increase effectiveness of case managers through knowledge and skills building training</li> <li>• Provider education</li> <li>• Collaborations between doctors and pharmaceutical companies to increase knowledge of HIV medications and drug regimens</li> <li>• Use peers to help to educate clients at their level and to bridge social distance and social status differences</li> <li>• Conduct clinical trials that include members of racial and ethnic minorities</li> <li>• Develop caring approaches to delivery of services</li> <li>• Organizations should employ HIV+ people</li> <li>• Provider organizations should develop mechanisms to obtain more input from people living with HIV</li> <li>• Develop better accountability and monitoring processes for organizations receiving funding</li> <li>• Fund the groups committed to serving African Americans living with HIV</li> <li>• Educate organization's Boards about the need for services tailored to meet women's needs</li> <li>• Develop women focused services</li> <li>• Provide case management services</li> </ul>

## Care Service System (continued)

<b>Barriers</b>	<b>Facilitators</b>
<ul style="list-style-type: none"> <li>- Women often do not feel comfortable in such organizations</li> <li>• Inadequate services for incarcerated and recently released populations</li> <li>• Lack of medical care and medications for HIV+ persons</li> <li>• Lack of HIV related services for senior citizens</li> <li>• Breaches in confidentiality and privacy protections</li> <li>• Breaches in confidentiality and privacy protections</li> <li>• Lack of adequate consumer grievance mechanisms</li> </ul>	<ul style="list-style-type: none"> <li>• Periodic testing in prisons (once DOC knows inmates HIV diagnosis they must provide medical services)</li> <li>• Pre and post release services to connect to community resources and services</li> <li>• Recognize their vulnerability to HIV infection and need for culturally appropriate HIV care services</li> <li>• Develop programs/services to address their needs</li> <li>• Establish open dialogues between clients and staff to increase understanding of the impact of breaches in confidentiality on clients, identify potential for breaches</li> <li>• Improve through policies and procedures</li> <li>• Examine ways to effectively use facilities and information systems to protect privacy and assure confidentiality</li> <li>• Provide on-going staff and volunteer training</li> <li>• Patients' Bill of Rights</li> <li>• Develop grievance mechanisms</li> <li>• Assign someone to listen to clients and handle complaints effectively to address their needs (client advocate, patient representative, ombudsperson)</li> <li>• Establish or enhance accountability/monitoring of process</li> </ul>

## Organizational Capacity and Sustainability

Barriers	Facilitators
<ul style="list-style-type: none"> <li>• Agencies' capacity/longevity                             <ul style="list-style-type: none"> <li>- One year funding cycles</li> <li>- Low administrative cost rate (10%)</li> </ul> </li> </ul>	<ul style="list-style-type: none"> <li>• Multi-year funding cycles</li> <li>• Increase administrative cost rates</li> <li>• Provide planning and capacity building resources (Title III)</li> <li>• Enhance inter-agency collaborations</li> </ul>

## Discussion

Participants identified a number of factors related to the barriers to, and facilitators of, access to HIV /AIDS care in their communities. These factors are categorized above into six categories: stigma, family and community support, socio-political issues, socio-economic conditions, care service systems, and organizational capacity and sustainability. Many of the issues discussed in this section were also identified by participants in the section on community challenges.

### Stigma

HIV/AIDS related stigma and homophobia fueled by ignorance, leads to shame and fear of rejection and discrimination. These factors as well as the negative attitudes of service providers towards clients because of their life style choices, create barriers to access to HIV/AIDS care services. Many people living with HIV are afraid their sero-status will be disclosed if they are seen in HIV related service organizations. Others do not want to receive services in AIDS service organizations that have traditionally served gay men. Many women with HIV do not seek services because they are ashamed and are afraid of how others in the community will view them if their sero-status is known.

African American communities face stigma not only related to HIV but also to race. The participants identified the need to work in communities to reduce stigma through on-going community education carried out by people living with HIV and faith and community leaders. They also identified the need for funding to provide support group and counseling services to people living with HIV to mitigate the negative effects of stigma on their self esteem and to deal with their fear of disclosure. The participants also stressed the need for provider training to expand their understanding of the impact of stigma and to enhance their skills in the delivery of compassionate, non-judgmental counseling and services.

## Family and Community Support

Participants identified the lack of family and community support as a major barrier to access to care. They came up with several measures to address this issue on the service delivery and political levels. For example, they recommended providing support groups for people living with HIV and increasing the participation of persons living with HIV in legislative bodies.

## Socio-political Issues

Participants identified the persistent inequalities, experienced by many marginalized groups in their communities, based on race, gender and class, as a major barrier to access. Another key barrier is the growing political and social conservatism. They identified community outreach and education, and on-going advocacy involving people living with HIV as one strategy to address these barriers. They also recommended development of strategies at a community and national level to raise public awareness of HIV as a public health rather than moral issue.

## Socio-economic Conditions

Participants identified a number of barriers related to socio-economic conditions in their communities that are similar to those discussed in the section on community challenges. Poverty, lack of health insurance or inadequate health coverage, restrictive income and asset eligibility criteria for benefits or services, homelessness, lack of affordable housing, lack of child care, transportation and co-morbidities were all identified as issues that affect access to HIV/AIDS care.

The participants offered a number of measures that can be employed at the community and service provider levels to address these barriers and facilitate access to care. These include providing incentives to clients such as food vouchers; forming collaborations with doctors who are not HIV specialists to help uninsured persons in their communities and collaborations between doctors and pharmaceuticals; providing resources for housing assistance, child care and for the purchase of vans to transport clients; co-locating HIV primary care, substance abuse and mental health services in drug treatment centers or schools. They also suggested some measures that require action at the federal state and local levels. These include revisions of restrictive income and asset eligibility requirements for benefits and services; expansion of public transportation systems; providing permanent housing; expanding publicly funded health care coverage to people with HIV, and expanding prescription drug benefits for people with HIV.

*(The group) ...suggested formation of partnerships between minority and mainstream organizations to bridge social distance and mentor minority agencies. To do this, they suggested case conferencing between medical and social services providers utilizing technology, and funding community based organizations to deliver culturally competent and relevant care services in their own communities.*

## Care Service Systems

Participants identified numerous barriers to access within the care services delivery systems in their communities. These included individuals' lack of knowledge of their HIV serostatus, difficulties reaching and retaining targeted populations in services, poor access to health care, lack of peer driven approaches, clients' negative perceptions of the healthcare system, provider biases and lack of cultural competence. The participants suggested a number of ways to address these issues including education and street outreach that includes one-to-one peer counseling, and provision of incentives to get HIV+ persons into and to retain them in care. They also underscored the importance of using peer approaches to provide services and assist HIV+ persons with enhancing their skills in navigating complex service systems.

Participants suggested a number of strategies to address the problems related to lack of cultural competence and provider biases. They emphasized the need to improve provider-client communications, and provider understanding of the cultural beliefs, values and social realities that influence clients' health-seeking behaviors through provider training and education. They also suggested formation of partnerships between minority and mainstream organizations to bridge social distance and mentor minority agencies. To do this, they suggested case conferencing between medical and social services providers utilizing technology, and funding community-based organizations to deliver culturally competent and relevant care services in their own communities.

Other barriers identified include overloaded and untrained case-managers, inadequate numbers of HIV knowledgeable medical providers, lack of effective treatment adherence education, lack of client centered approaches to service delivery, and organizations driven by profit rather than service motivations. To address these barriers, participants suggested provider training and education, use of peers to provide treatment education and deliver other services, and enhanced efforts by funding agencies to monitor funded programs and assure the delivery of quality HIV care services to clients.

The participants also raised numerous concerns about the lack of services tailored to meet the needs of HIV+ women, incarcerated and recently released individuals, and older persons (over 50). They identified several strategies to facilitate the expansion of services for these underserved populations such as: education of organizations' boards of directors and staff on the needs of these underserved populations, provision of tailored case-management, and collaborations with other systems (prison health services).

Participants repeatedly identified breaches in confidentiality and inadequate privacy protections and mechanisms to resolve consumer grievances as major issues that impact clients' access to and utilization of services. Participants mentioned the need for training for organizations, their staff and volunteers on confidentiality and privacy protections. They also identified the need for a patients' bill of rights, and assistance for organizations to set up, manage and monitor, grievance procedures and mechanisms to handle consumer complaints.

### **Organizational Capacity and Sustainability**

Finally, participants identified organizational capacity and sustainability issues as impediments to continuity of service delivery in their communities. They noted that many funding entities provide grants on a one-year basis, and organizations must therefore constantly focus their energies on resource development. In addition, they mentioned that administrative costs are not adequately covered in many grants. For example, a 10% administrative cost rate is too low. They identified multi-year funding cycles, higher administrative cost rates in grants, planning and capacity building resources, such as those provided under Title III and enhanced inter-agency collaborations as measures that would facilitate organizational capacity and sustainability.



# Endnotes

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<http://books.nap.edu/books/030908265X/html/R1.html#pagetop> p. 61.

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<sup>5</sup> Summers T, Alagiri P, Kates J, *Federal HIV/AIDS Spending: A Budget Chartbook Fiscal Year 2002*, the Henry J. Kaiser Family Foundation, Fifth Edition, September 2003, p. 5.

<sup>6</sup> U.S. Department of Health and Human Services, Health Resources and Services Administration's HIV/AIDS Bureau (HRSA/HAB), *Ryan White CARE Act 2001 Data Report for Title I, Title II*, <http://hab.hrsa.gov/reports/saar2001/saar2001report.htm>; *Ryan White CARE Act Title III 2001 Data Report* <http://hab.hrsa.gov/reports/titleiii2001/2001t3report.htm>; *2001 Ryan White CARE Act Title IV* <http://hab.hrsa.gov/reports/TitleIV2001/>.

<sup>7</sup> CDC, *HIV/AIDS Surveillance Report* 2002:14: [p. 12].

<sup>8</sup> Ibid, p. 14.

<sup>9</sup> Ibid; p. 16.

<sup>10</sup> Ibid; pp. 17 & 19.

<sup>11</sup> Ibid; p. 26.

<sup>12</sup> Ibid, pp. 32, A3 & A5

<sup>13</sup> CDC, *Late Versus Early Testing of HIV --- 16 Sites, United States, 2000-2003*, *MMWR Weekly* June 27, 2003 / 52(25);581-586

<sup>14</sup> CDC, *HIV/AIDS Surveillance Report* 2002:14: [pp. A4 & A5].

<sup>15</sup> McKinnon, *ibid*, pp. 1-2.

<sup>16</sup> CDC. Characteristics of persons living with AIDS and HIV, 2001. *HIV/AIDS Surveillance Supplemental Report*, 2003; 9(No. 2): Table 3 <http://www.cdc.gov/hiv/stats/hasrsupp92/table3.htm>.

<sup>17</sup> CDC, *Ibid*.

<sup>18</sup> CDC, Characteristics of persons living with AIDS and HIV, 2001. *HIV/AIDS Surveillance Supplemental Report*, 2003; 9(No. 2): Table 7 <http://www.cdc.gov/hiv/stats/hasrsupp92/table7.htm>.

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<sup>20</sup> The Henry J. Kaiser Family Foundation, *African Americans and HIV/AIDS*, HIV/AIDS Policy Fact Sheet, September 2003.

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