

## CHAPTER 2: COMMUNITY SERVICES ASSESSMENT

A community services assessment is an essential component of the HIV prevention community planning process. A community services assessment is comprised of three steps:

- 1) *Needs assessment* — The process of obtaining and analyzing information to determine the current status and service needs of a defined population or geographic area.
- 2) *Resource inventory* — Current HIV prevention and related resources and activities in the project area, regardless of the funding source. A comprehensive resource inventory includes information regarding HIV prevention activities within the project area and other education and prevention activities that are likely to contribute to HIV risk reduction.
- 3) *Gap analysis* — A description of the unmet HIV prevention needs within the high-risk populations defined in the epidemiologic profile. The unmet needs are identified by a comparison of the needs assessment and resource inventory.

The goal of the community services assessment is to examine both the met and unmet needs of each priority population selected and identify barriers to reaching them and engaging them in prevention activities. A met need is a required service that is currently being addressed through existing HIV prevention resources that are available to, appropriate for, and accessible to that population as determined through the resource inventory. An unmet need is a required service that is not currently being addressed through existing HIV prevention services and activities, either because no services are currently available or because available services are either inappropriate for, or inaccessible to, the target populations.

Additionally, the assessment of prevention needs furnishes information about the extent to which specific target populations are aware of HIV transmission methods and high-risk behaviors, are engaging in specific high-risk behavior, have been reached by HIV prevention activities, and are likely to participate in HIV prevention activities. The assessment also identifies barriers that make it difficult to reach specific target populations and involve them in HIV prevention initiatives and suggests strategies that may be effective in overcoming these barriers.

### **Priority Populations**

After detailed review of the Epi Profile, the Prevention Committee put forward recommendations at the June 16, 2009 meeting of the SC HIV Planning Council for seven priority populations for the five-year HIV Prevention Plan (2010-2014). Only a slight modification was made from the previous Prevention Plan (2004-2009). The recommendations were ratified by the full Council. The seven priority populations, in rank order, are:

- 1) Persons living with HIV/AIDS
- 2) African American Men who have Sex with Men, Ages 15-44
- 3) African American Women who have Sex with Men, Ages 15-44
- 4) African American Men who have Sex with Women, Ages 15-44
- 5) White Men who have Sex with Men, Ages 15-44

- 6) Injection Drug Users, Ages 20-44
- 7) Hispanics/Latinos.

The populations are more fully discussed in Chapter 3: Prioritization of Target Populations.

## **1. Needs Assessments of Priority Populations**

On a yearly basis, the Prevention Committee reviews the literature and explores any new information on effective behavioral interventions and recommends to the full HIV Planning Council any necessary changes to the priority interventions table in Chapter 3. Since the last HIV Prevention Plan was submitted in 2004, a number of needs assessment activities have been completed or are underway. In 2005, focus groups were conducted across the state with HIV positive consumers, both in care and out of care. In 2007, a town hall forum with facilitated discussion was held one evening for African American MSM in conjunction with the state HIV/STD Conference and, from January 2008-April 2009, focus groups with this population were also held. In 2008, a town hall forum was similarly held at the HIV/STD Conference with People Living with HIV/AIDS. Also in 2008, a survey was conducted with consumers of Ryan White Part B programs. In 2009, additional focus groups and/or key informant interviews were conducted with White MSM and Hispanic/Latino MSM as part of the data collection efforts for the development of an MSM Strategic Plan. An 18-page survey of Transgender persons was also conducted in 2009 to gather information from this population, which had not been specifically addressed in previous data collection initiatives.

### **2005 Focus Groups with Persons Living with HIV/AIDS**

The purpose of this investigation was to identify the prevention and care needs of persons living with HIV/AIDS, to identify what influences HIV positive people to seek and/or continue HIV/AIDS medical care, and the perceived quality of HIV prevention and care services in South Carolina. The project was designed and executed in collaboration with the SC HIV Planning Council, the SC Ryan White Care Consortia, the National Alliance of State and Territorial AIDS Directors (NASTAD), DHEC's STD/HIV Division, and researchers from the Arnold School of Public Health at the University of South Carolina. Discussion guides addressed the following four areas as they impact (or affect) people living with AIDS: service utilization, barriers to care and unmet needs, prevention services and testing, and consumer involvement. A total of 20 focus groups were held, with a total of 113 participants across 12 sites. The majority of participants were African American (75.2%). Fifty-seven (57%) percent of the participants did not identify as belonging to any one ethnicity, but 40.7% reported they were not Hispanic. The focus group participants were almost evenly divided with males and females, with 49.6% being male and 48.7% being female. The average age of participants was 44 years old. The majority of the participants reported being heterosexual (60.2%), and 31% reported being homosexual. The vast majority of participants reported they were in care (96.5%) per the HRSA definition of "in care." Seventy-five percent (75.2%) of participants reported having received HIV medical care or a CD4 and/or viral load test in the past year (15.9% did not respond). Approximately 63% reported having received HIV Prevention Services (educational sessions, counseling and testing, and/or contact with an outreach worker) in the past year, while 18.6% reported not receiving HIV Prevention Services (15.9% did not respond).

When asked “What prevention services do you have in your area that help people from getting HIV,” the majority of the participants mentioned the agency that had recruited them to participate in the focus groups and the use of all types of media for HIV prevention messages. They also indicated that they had witnessed an increase in condom distribution in their communities but wondered if condoms were enough to address the risk among youth. The participants were asked, “What reasons have you heard for why people at risk for HIV have not had an HIV test?” The reasons included fear of a positive HIV status, of stigma related to being HIV positive, and denial that they are at risk for contracting HIV. The participants were then asked, “What can care or service providers do to help people with HIV tell their sex partners about their HIV status?” The responses were not conclusive. Many indicated that it was a personal matter that should not include professional health care providers, whereas others suggested educated personnel would help in the discussion process. The final area of discussion solicited suggestions about improving HIV care and/or prevention services. They were asked, “What would be the single most important change you would suggest to improve services to people living with HIV?” The respondents from every area had a plethora of ideas and suggestions focusing on HIV education, advocacy and policy change. The respondents felt as though the greatest need for prevention was among youth. They wanted to see more education in the schools and with parents. There was also recognition that the fundamentals of HIV prevention need to start at the individual level. Many of the participants also indicated that there needed to be a change in the HIV testing policy as well as advocacy for sexual minorities in South Carolina.

The **Report from the 2005 Focus Groups with Persons Living with HIV/AIDS** is included as Appendix B.

### **2007 Town Hall Meeting with African American MSM**

A Town Hall Meeting for African American Men who have Sex with Men was held on October 17, 2007, sponsored by the SC HIV Planning Council and the AAMSM Workgroup. The survey instrument was a one-page, 10-item, self-administered questionnaire developed by the AAMSM Workgroup. It included questions about demographics, HIV status and testing history, sexual identity, recognition of the “Many Men, Many Voices” HIV prevention intervention, and awareness of/participation in community HIV/AIDS services. There were also two qualitative questions about the services needed for AAMSM in respondents’ respective communities, and AAMSM issues in their communities. The survey was administered at the AAMSM Workgroup’s Information and Awareness Forum at the 2007 South Carolina STD/HIV Conference. Thirty-seven AAMSM responded to the survey. After respondents completed the survey, they participated in a moderated discussion, lasting approximately 45 minutes, in which they were asked additional questions about the perception of HIV in AAMSM communities, HIV/AIDS service delivery, barriers to AAMSM participation in HIV/AIDS programs, and strategies for overcoming those barriers. Respondents’ ages ranged from 18 to 57, with the average age 37. All reported having been tested for HIV. Most respondents reported getting their last HIV test in a doctor’s office or at the health department (37.9% each), followed by hospitals (10.3%), AIDS service organizations (6.9%), and community-based organizations (3.5%). Sixty-five percent (65%) of respondents reported being HIV-positive, while 32% reported testing negative, and 3% did not know their status.

When asked about the “Many Men, Many Voices” intervention, 73% of respondents reported that they had heard of the program. The majority of participants (94.6%) reported being aware of HIV/AIDS services being offered in their area and 87% reported participating in those. The services most widely participated in were: Community HIV/AIDS Activities, HIV/AIDS Education, and Care and Treatment. Respondents who indicated no participation in HIV/AIDS services were asked to identify reasons why they were not participating. Answers included a negative reputation of the local HIV/AIDS community-based organization; stigma; fear of confidentiality being breached through participation; and lack of caring.

Respondents were asked about programs or services that they felt were needed for African-American MSM in their communities. A need for more education and prevention programs in general was expressed by many respondents. In particular, “Many Men, Many Voices” was mentioned as a program that needed to be promoted and implemented more frequently. Also, many responses were related to young AAMSM in their communities. There were recommendations for youth programs targeting not only HIV/AIDS awareness and education, but also life skills training through internships and experiential learning. Another theme that was discussed was the need for affirmation and acceptance on the part of AIDS service organizations. Respondents were also asked about issues that they face as AAMSM in their respective communities. A major theme that emerged was the idea of fear and stigma. Respondents named fear and/or stigma as a major issue facing them in their communities. Several respondents mentioned internalized homophobia within the AAMSM community, as well as homophobia within the larger African-American community. Respondents were concerned about how to communicate with intimate partners about their HIV status, and the legal implications of not disclosing. Another theme that emerged was the need for an AAMSM community identity.

The moderated discussion following the survey reinforced themes that emerged in the survey. When asked about problems facing AAMSM in their communities, two main categories emerged: issues relating to sexual identity and issues relating to HIV. Issues relating to sexual identity included fear of losing family and friends after coming out, stereotypes, lack of safe spaces for AAMSM, division and lack of infrastructure among MSM, and lack of AAMSM leaders. Issues relating to HIV were more individual in nature and included fear of getting tested, fear of confidentiality breaches, insensitivity from medical professionals, and perceived economic costs of getting tested. When asked about the perception of HIV as a problem in our community, the idea of generational differences was raised. Younger people were perceived to be less worried about the spread of HIV than the older generation, who has witnessed many of its members die. Younger people were perceived to enjoy taking risks and not be concerned about their partners’ HIV/STD status. Also, the immediate threat of HIV/AIDS is not as visible as it once was. Reasons for lack of AAMSM participation in programs included fear of getting tested, fear of being “outed,” ignorance, fear of the ramifications of a positive result, religious norms, and division within AAMSM communities. Generational differences were noted again, citing that young AAMSM have not been properly engaged in the development and implementation of HIV prevention programs. Young AAMSM were also mentioned as the targets of “chicken hawks,” or older men who seek out younger men as sexual partners. This was seen as contributing to feelings of mistrust among AAMSM and lack of a cohesive community identity. Participants offered solutions to the challenges in engaging the AAMSM

community in prevention programs, which fell into two major categories: community factors and structural factors. Community factors included an increase in affirmation and support among AAMSM, with an emphasis on learning how to foster honesty, healthy relationships, and support. Several participants discussed the importance of valuing oneself and others, and the need for respect. Structural factors included a call for an AAMSM resource center and the development of a strong network among AAMSM.

The results of this study provide some direction for future assessment and activities. Young AAMSM were a population of concern to many who participated in the forum. Participants expressed concern about their their potential risk factors and challenges in recruiting them to participate in HIV prevention program, reinforced by the low participation of young AAMSM. It was noted that future programs should place special emphasis on determining the unique needs of young AAMSM as well as identify young AAMSM to serve as peer health educators and recruiters for prevention programs. Another area of focus is the concept of an AAMSM community in the state. The ability of AAMSM to form a cohesive community is linked to the concept of AAMSM identity. Participants reported a number of different identity labels, and such a diversity of labels can sometimes hinder group cohesion. Therefore, prevention programs should be cognizant of the ways in which AAMSM identify themselves and be as inclusive as possible in their program development and marketing. In addition to addressing the specific needs of AAMSM in their respective communities, prevention programs should also endeavor to address stigma and homophobia in the larger African-American community. The majority of participants indicated that stigma, fear, and homophobia were major issues that needed to be addressed both in prevention programs and in the community. Developing initiatives to impact stigma and homophobia, coupled with the development of “safe spaces” for AAMSM, may foster more trust and validation among AAMSM and consequently increase participation in HIV prevention programs.

The **Report from the 2007 AAMSM Town Hall Forum** is included as **Appendix C**.

### **2008 Consumer Town Hall Forum for People Living with HIV/AIDS**

In 2008, the SC HIV Planning Council (HPC), with guidance from its Consumer Advisory Committee and Needs Assessment Committee, elected to pursue the development and implementation of a Consumer Town Hall Forum to access direct input from persons living with HIV/AIDS across South Carolina. Working with the SC HIV/STD Conference Executive and Planning Committees, the HPC made plans to hold the Forum at the conference hotel and conference center one evening during the conference. The Conference’s Scholarship Committee worked closely with the HPC to enhance and support registration and lodging scholarship opportunities for consumers. Utilizing the Conference’s scholarship application process and with additional support from an anonymous donor, forty-five (45) registration scholarships were awarded, with twenty-five (25) of those recipients (who lived more than 50 miles outside of Columbia) also receiving lodging for the two nights of the conference. Additionally, HIV positive consumers not attending the conference were invited through area AIDS Service Organizations (ASOs) and encouraged to attend and participate. A total of sixty-two (62) consumers attended the event, which was held on October 15, 2008. Input from the Consumer

Town Hall Forum is utilized both in the development of the Ryan White Statewide Coordinated Statement of Need (SCSN) and Comprehensive Plan, as well as the HIV Prevention Plan for 2010-2014.

Participant profiles were distributed to all attendees participating in the Consumer Town Hall Forum discussion. Of the fifty-two participant profiles returned, fifty were used for the analysis and the following results section. Two profiles were rejected because respondents indicated that they did not reside in South Carolina. The term *participants* used in the Quantitative Results section indicates only those who completed the participant profile and does not necessarily represent all those who participated in the Consumer Town Hall Forum.

Forty-six (46%) of participants reported being female and twenty-seven (54%) reported being male. The age of participants ranged from 31 years to 62 years with an average age of 44.8 years. Twelve participants were in their thirties (24%), twenty-three in their forties (46%), eleven were in their fifties (22%), and four were in their sixties (8%). None of the participants were younger than 31 years of age. Forty participants reported their race as African American/Black (80%) and ten participants reported their race as Caucasian/White (20%). Of the thirty-one participants that responded to the question of ethnicity, none reported to be Hispanic/Latino(a).

Thirty-five participants reported residency in seventeen of the forty-six counties in the state. Almost all participants (n=49) responded to the question, “What is your sexual orientation?” with more than half of participants (n=26) identifying as *Heterosexual/Straight*, and one-third (n=17) identifying as *Gay/Lesbian*. Fewer participants identified as *Bisexual* (n=4) and *other* (n=2). Those that indicated *other* described themselves as “sexual” and “open-minded.” Other questions asked but not specifically noted in the summary below included: preferred language, living arrangement, educational level, employment status, annual income level, year of diagnosis, payment source for medications, and if they were registered and planning to vote in the 2008 general election.

Participants were also asked their current HIV/AIDS status. Slightly more than half (n=25) reported their current status as *HIV+ with no symptoms*; eleven reported *HIV+ with symptoms*; seven reported an *AIDS Diagnosis with no symptoms*; five reported an *AIDS Diagnosis with symptoms*; and one reported *don't know*. Nearly all (n=49) responded that they had received HIV medical care or had a CD4 and/or viral load test. One responded *no* to the question. Forty-one reported *yes* to the question, “In the past year, have you received any HIV prevention services (such as educational sessions, counseling/testing, contact with an outreach worker)?” Seven participants responded *no* to this question. When asked to identify how they felt they were infected with HIV, 40 indicated they were infected through *unprotected sex with someone HIV positive*; seven indicated through *needle sharing with someone HIV positive*; three reported *blood transfusion*; and two reported *don't know*. Four reported *other* and wrote in the following responses, “protected sex – condom broke – with HIV+ partner,” “was doing...for AIDS patient,” and “boyfriend.” All but one participant (n=49) responded yes to the question, “Have you told anyone that you are HIV positive?” When asked “Who have you told that you are HIV positive?” and to “check all that apply,” 49 participants noted the most frequently selected responses: *Physician/other healthcare provider* (n=38), *case manager(s)* (n=36), *parent(s)* (n=33), *friend(s)* (n=30), *sibling(s)* (30), and *others in my support group* (n=29). Those responses were followed closely by *my significant other* (n=26), and *other family* (n=25).

Additionally, twenty participants told *people at church, synagogue, or other faith home*; seventeen told a *co-worker(s)*; sixteen selected the response *I speak publicly about being HIV positive*; and fourteen told *my spouse* of their HIV+ status. One additional respondent reported *other* and wrote in *television/newspaper*. All but one participant (49) responded to the question, “Do you currently take medications that are prescribed for treating HIV?” Forty-seven responded yes and two responded no. Thirty-five (35) of 48 participants responded they were involved with local HIV-related community events (World AIDS Day, National Testing Day, task force, advisory committee, speaker’s bureau, etc.). Twelve participants responded *no* and one participant responded *don’t know*.

Approximately 62 consumers attended the Forum discussion. Participant responses were recorded both via tape recorder and via three note-takers in the room – one at the front and two at the back. Main points from participant responses, along with specific participant quotes, were summarized in three parts: HIV care services, HIV prevention services and consumer involvement. When asked “What HIV care services are most important to you,” the consumers identified medical care, medications, “other” non-HIV specific medications and care, and health insurance as their most important HIV care services. Throughout the Forum discussion, consumers indicated the value of each of these services while also expressing difficulties in obtaining them in various circumstances. Of the “other” non-HIV specific medication and care, mental health care was stressed as an area of great need. Consumers spent a great deal of time discussing problems they had encountered seeking HIV-related care services in South Carolina. In particular, consumers discussed challenges with their care providers, including being treated or seen by their provider only as a person with HIV, not being treated by the same providers, not trusting their providers, and/or not feeling that their providers were fully knowledgeable about, or forthcoming with them, regarding the side effects of HIV medications. Additionally, consumers expressed frustration with the lack of coverage for “other” medications, access limitations for persons living in rural areas, children aging out of care, and long term community care. In order to improve HIV care services in South Carolina, consumers recommended that persons living with HIV, especially in rural areas, have access to the same services as those living in larger cities in the state. In addition, consumers strongly recommended that education/training opportunities regarding HIV meds, how to talk to doctors/health care providers, and how to be “educated consumers” when it comes to their overall health care be provided to persons living with HIV. Consumers also recommended that educational materials that physicians/health care providers use, regarding HIV disease and HIV medications, not include a lot of medical jargon and take into consideration the lower reading/literacy levels of some consumers. Similarly, consumers recommended that providers be trained in how to communicate with their HIV positive patients using less medical jargon, how to be better listeners, and how to “meet consumers where they are.”

Consumers identified HIV testing, prevention programs, support groups, and partner notification as the most important prevention services to them. Prevention programs for MSM of color and support groups for persons living with HIV were noted as particularly important, as each provides a safe place for stigmatized groups /persons to discuss issues important to their sexual health. Consumers were quite concerned about the lack of information young people were receiving in the schools regarding HIV/AIDS and their sexual health. Thus, consumers encouraged DHEC and ASOs to do more to educate young people and their parents through a

variety of venues (e.g., youth groups, community organizations, churches) about HIV/STI prevention and their sexual health. In addition, consumers wanted to see more education and prevention opportunities for persons infected with HIV and more testing opportunities, particularly for newly released prisoners. Consumers made several recommendations for improving HIV prevention services in South Carolina. Notably, the first two recommendations directly involved consumers themselves in providing outreach and education about HIV in their communities. Other recommendations pertained to the creation of support groups for children infected with or affected by HIV and the provision of syringe exchange programs in the state.

Consumers made three recommendations to encourage involvement in the SC HIV Planning Council. First, they recommended that the Planning Council and/or Consumer Advisory Committee host meetings in outlying areas (beyond Columbia) to encourage participation among individuals unable to travel. Second, consumers recommended that Planning Council representatives either travel to other states or have representatives from other states come to South Carolina to share their “lessons learned” in providing HIV care and prevention services with the Planning Council. Thirdly, the participants encouraged more consumer forums similar to the one being conducted. Along with consumers in attendance at these forums, participants suggested that health care providers be present.

The recommendations from the Consumer Town Hall Forum include:

- Train/empower consumers to be “educated consumers” regarding their own health care, navigating the health care system and in how to communicate with providers.
- Train providers in how to better meet the needs of consumers, by listening to and effectively communicating (using less medical jargon) with consumers.
- Work with service providers to develop and/or revise educational materials for consumers (re: HIV disease, medications, and other health care concerns), paying particular attention to reading level and cultural appropriateness of such materials. Further, train providers in how to review materials with consumers.
- Explore and inform consumers of funding opportunities to cover “other” non-HIV-related care and medications.
- Work with service providers and consumers to differentiate between medication side effects and natural physiological and physical changes that take place as we age. Further, work with service providers to understand the potential interactions of HIV medications and other medications that our aging population may likely be prescribed.
- Expand testing opportunities through medical mandates for individuals recently released from incarceration and those hospitalized for medical procedures.
- Continue to provide prevention education programs for target populations, especially MSM of color.
- Expand the provision of prevention education programs to persons who are HIV positive (e.g., prevention for positives).
- Continue to provide and expand availability of support groups for persons living with HIV.

- Expand provision of support groups/services to children/youth infected with and/or affected by HIV.
- Continue to provide and expand efforts to educate youth/young adults about HIV/STI prevention and sexual health issues through the schools, community-based organizations, youth groups, and churches.
- Increase involvement of consumers through organized outreach and education efforts within schools and communities; provide consumers with appropriate training to conduct such efforts.
- Host SC HIV Planning Council and/or Consumer Advisory Committee meetings in outlying areas (other than Columbia) to allow for participation of consumers who are unable to travel.
- Share “lessons learned” from other states regarding the provision of HIV care and prevention services during SC HIV Planning Council and/or Consumer Advisory Committee meetings.
- Conduct more consumer-focused forums and involve health care providers in those discussions.

### **January 2008 - April 2009 Focus Groups with African American MSM**

Based on the results of an African-American Men who have Sex with Men (AAMSM) Town Hall Forum held at the 2007 South Carolina STD/HIV Conference, a plan was developed to hold a series of focus groups throughout the state. These focus groups and the data analysis were made possible through a collaborative effort between the AAMSM Workgroup, the South Carolina HIV/AIDS Council, Lowcountry AIDS Services, AID Upstate, HopeHealth, and the South Carolina HIV Planning Council. The focus groups were designed to expand upon the findings of the Town Hall Forum, eliciting participants’ responses to questions about general AAMSM health issues, HIV risk factors, awareness of and participation in HIV prevention programs, barriers to mobile HIV testing, and strategies for overcoming those barriers.

Initially, six focus groups were held in the first quarter of 2008 at community-based organizations who had received funding to implement the “Many Men, Many Voices” curriculum: the South Carolina HIV/AIDS Council in Columbia; Lowcountry AIDS Services in Charleston; and AID Upstate in Greenville. In the first quarter of 2009, the focus group plan was amended to allow for groups to be conducted with HopeHealth in Florence and Orangeburg. Each community-based organization was responsible for recruiting participants for two groups—one consisting of AAMSM in the community who were ages 18-25 (referred to as “younger”), and one consisting of older AAMSM ages 26 and above (referred to as “older”). In the case of the HopeHealth expansion groups, the 18-25 group was conducted in Florence, and the 26+ group was conducted in Orangeburg. Additional groups of mixed ages were held at the three initial focus group sites, for a total of twelve focus groups. Focus groups were facilitated by trained professionals from the AAMSM Workgroup. A note taker took detailed notes for analysis. Each focus group lasted 60-90 minutes. Prior to participating in the focus groups, participants completed informed consent and confidentiality forms, followed by a survey. The

survey instrument was a one-page, eight-item, self-administered questionnaire developed by the People of Color Initiative's AAMSM Workgroup. It included questions about demographics, HIV status and testing history, sexual identity, recognition of the "Many Men, Many Voices" HIV prevention intervention, and awareness of/participation in community HIV/AIDS services.

A total of 88 AAMSM took part in the twelve focus groups. Forty participants were between the ages of 18 and 25, and 48 participants were age 26 or older. There were some participants who came to groups that did not match their age group, due to scheduling conflicts with their age-appropriate group or being recruited to participate in the wrong group. Because their experiences and input were still considered valuable, they were not turned away in those situations.

Almost all of respondents (90% of younger, 97.3% of older) reported having been tested for HIV. Most of the younger participants reported being tested either in a hospital or AIDS service organization (25% each), followed by doctor's offices (10%) and health departments (7.5%). Conversely, older participants reported being tested in hospitals (31.7%), followed by health departments (22%). Respondents were asked to report their HIV status. One-eighth (12.5%) of participants in the younger group reported being HIV-positive, while 82.5% reported testing negative. In the older group, more than two-thirds (67.4%) reported testing positive for HIV, with 28.3% identifying as HIV-negative. Of those who reported being HIV-positive from both groups, 61.1% of them reported receiving care and treatment. When asked about the "Many Men, Many Voices" intervention, 36.8% of younger respondents and 37.5% of older respondents reported that they had heard of the intervention. Respondents were asked to choose the statement that best described how they thought of themselves. Most of the younger participants identified themselves as a "Black gay man" (43.2%) or a "Man" (21.6%), followed by "Black man" and "Gay Black man" (16.2% each). Older participants, on the other hand, identified themselves as a "Gay Black man" (31.8%), followed by "Black gay man" (22.7%), "Black man" (20.5%), and "Man" (15.9%).

The majority of participants reported being aware of HIV/AIDS services being offered in their area (77.5% of younger participants, 85.4% of older participants). Younger participants were most aware of HIV testing (65%), educational activities (60%), and community activities (42.5%). Older participants were most aware of testing as well (62.5%), followed by case management (56.2%), care and treatment (52.1%), and educational activities (41.7%). A little over half (52.5%) of younger participants and about two-thirds (66.7%) of older participants reported participating in local HIV/AIDS services. When asked which services they had participated in, younger participants reported taking part most in HIV testing (40%), educational activities (32.5%), and community activities (10%). Older participants reported taking part most in case management (33.3%), care and treatment (31.2%), educational activities (29.2%), and testing (27.1%). Respondents who did not answer "yes" to participation in HIV/AIDS services (37.5% of older participants, 60% of younger participants) were asked to identify reasons why they were not participating. Several respondents indicated that they were not aware of the HIV/AIDS services being offered. Other responses referred to logistical conflicts, including school and employment conflicting with the times services are held, and transportation challenges. One respondent reported being turned away from participation because he was not HIV-positive.

The focus group discussion began with a general question about issues and problems that AAMSM face in their communities. Both the younger and older groups were concerned about homophobia and discrimination based on their sexual orientation, including discriminatory hiring and employment practices. The younger group reported being more concerned about issues of identity and acceptance—for example, the challenges of harassment and being able to “blend in” to the majority culture. One participant referred to the process of recognizing and accepting their sexuality as an “identity crisis.” The older group, on the other hand, reported more concerns about concrete issues, such as access to health care services, including health insurance for themselves and their partners, and building relationships. The older group was also concerned about legal issues, particularly issues of HIV status disclosure to potential sexual partners. Both groups agreed that there was a lack of safe spaces where they felt secure enough to disclose their sexual identities and the issues that were associated with those identities. They felt that agencies did not have the adequate resources to meet their needs as AAMSM. Both groups also mentioned the Black church as an issue of concern, but in different capacities. Younger participants talked about the church as a place where family members took them after disclosure of their sexuality, which led to negative experiences. Older participants, however, talked about the church in dual terms—on one hand, it was called “the root of most Black people,” but on the other hand, was identified as a source of homophobia and stigma.

The second focus group question pertained to “hangout spots” in their respective communities. Participants identified similar locations in each area: nightclubs, malls, parks, and high-traffic streets were the main areas named. They also mentioned alternatives to public locations, such as friends’ houses, Internet sites, and travel to other cities. Overall, participants in both age groups expressed frustration about the lack of public spaces where AAMSM could come together, regardless of whether they were in more urban or rural areas. Many older participants reported staying to themselves because of this lack. Younger participants cited ball culture (e.g., homes of house mothers or house fathers, ball competitions) as an additional venue in which they interact with other AAMSM.

Participants were asked for their perceptions of concern about the HIV epidemic among AAMSM in their communities. In both groups, there were differences of opinion on the level of perceived threat of HIV. The younger groups believed that it was a big problem, but that AAMSM tended to make light of it. They mentioned that, while it was a concern, many had no personal experience with the disease to heighten or reinforce a sense of concern. In regards to the way that it affects the body and the ways in which it is transmitted, one participant called it “a magnificent disease,” while another called it a “weapon of mass destruction.” Participants echoed the idea that their peers did not worry about HIV infection until they were personally affected. Questions were also raised about the ways in which HIV funding was used and distributed by the government. The older groups felt that there was not enough education and communication taking place about HIV; people still believe old myths and misconceptions. One participant said, “*I am very selective about who I sleep with and I can tell who got it by looking at them.*’ We still have that mentality.” They stated that they didn’t think it was as popular a subject as in the past, now that medications are helping HIV-positive people to live longer. There was concern that HIV-negative individuals did not take the disease as seriously as before. Disclosure of HIV status was another area of concern among the older groups. Both groups agreed that many AAMSM were afraid of learning about their serostatus.

Participants were asked, “What are some of the things you think are putting AAMSM at risk for HIV?” Both groups mentioned ignorance, lack of knowing their HIV status, and a lack of education about HIV as major risk factors for infection. Both groups also identified multiple sex partners, denial of the threat of HIV, lack of honesty in sexual relationships, and lack of visibility of faithful relationships in the gay community. Members of the younger groups stated the feelings of invulnerability that are associated with being young, as well as media images of AAMSM. They thought that the media portrayed AAMSM in a very negative light, with stereotypes of effeminacy and promiscuity. They also mentioned that many younger AAMSM equate unprotected sex with love and acceptance, so although HIV-related knowledge may be high, there are other competing factors. Low self-esteem, a need for validation by others, and boredom were also mentioned as risk factors. Participants in the older groups talked extensively about drug use. Crack cocaine, crystal methamphetamine, ecstasy, cocaine, and marijuana were specifically named. One participant stated that when individuals are under the influence of drugs, they “just want to feel flesh.” Older participants also talked about situational sex encounters, such as in prison or sex for money/drug encounters. These groups also talked about lack of adherence to medication among HIV-positive individuals as a potential risk factor.

Older and younger groups in each city were aware of similar HIV-related programs and services. Participants named specific community-based organizations in each city, most frequently the organization in which the focus groups took place. They also identified general HIV outreach, counseling, and testing initiatives in each city sponsored by CBOs or by local health departments. Some participants were also able to name evidence-based interventions, such as Many Men, Many Voices; d-up; VOICES/VOCES; and EMPACT. When asked how they became aware of these programs or services, participants in both groups identified friends and marketing products (i.e. billboards, pamphlets) as their primary communication vehicles. Older participants expressed concern about the exclusivity of certain programs. For example, one participant expressed concern that some programs would not admit those who were actively using drugs or alcohol. Another pointed out that service providers were “selective” in whom they recommended to take part in HIV/AIDS programs or services, often excluding individuals who may have conditions or characteristics that were considered undesirable. When asked for reasons why AAMSM do not participate in HIV prevention programs, both groups identified fear and stigma as major barriers to participation. They said that HIV-related signage on a building was enough to prevent people from entering. More specifically, they associated this fear with sexual identity and “coming out” issues as well as HIV-related service delivery. Many participants shared the perception that those who work in HIV prevention are either gay, HIV-positive, or both, and that was a deterrent to many AAMSM. Once again, participants identified trust issues as a barrier to participation; because many HIV prevention professionals come from their communities and share social networks, they were not assured that their information would remain confidential. They were concerned that accessing HIV-related services may be “too public.” Many participants also indicated a lack of awareness of services. One participant in an older group who had recently moved to South Carolina stated, “I had no clue where to go.” A younger participant associated participation in HIV prevention programs with confirmation of same-sex attractions and/or behavior, and that could be a barrier for those who did not want to identify as gay or bisexual. One older participant stated that Black men in general have a problem with talking about emotional issues.

Participants were asked to offer potential solutions or strategies to address barriers to participation in HIV prevention programs. Both groups thought that organizations should do a better job of marketing and advertising their programs. Word of mouth was a strategy named by both groups as being effective in AAMSM populations; older groups also suggested marketing through churches, peer educators, and the Internet. They stated that programs should not always be marketed as LGBT programs. One younger participant stated, “You can’t make it a gay thing.” Groups also mentioned the importance of diversity in marketing images. They wanted to see more diverse images of Black men in marketing materials—not just the “stereotypical” Black gay men, but also men that might be considered “DL” or whose sexuality cannot be readily determined. Both groups also stressed the importance of having trained, client-sensitive staff to administer the programs. In terms of logistics, both groups suggested holding programs during non-traditional hours at locations other than AIDS service organizations, because of the stigma associated with them. They also suggested holding a variety of events, such as parties, fashion shows, dinners, and out-of-town trips to pique the interest of potential participants. Participants indicated that HIV does not always have to be the focus of these events—that HIV/AIDS-related programming should have a designated time span within the event so as not to overwhelm attendees. Older and younger groups agreed that incentives should be offered to those who take part in these activities. They also stressed the importance of utilizing AAMSM role models. Both groups also mentioned interest in developing Black gay community centers. These centers could not only provide HIV/STD information, but also discussion groups, holistic health programs (e.g., fitness programs, relationship counseling), job placement programs, opportunities for networking, and venues to educate the larger Black community about Black LGBT populations. One younger participant stated, “People fear what they don’t understand.” Participants felt that an increase in dialogue and opportunities to learn about Black gay culture would facilitate greater understanding and acceptance. Younger groups, in particular, requested to see positive role models in the gay community and/or members of professional Black gay organizations. In many of the groups, “Many Men, Many Voices” was mentioned as a successful program that should be offered more frequently. Some participants suggested that people should be allowed to attend more than once, because of the possibility of learning more about themselves and the topics offered.

The last set of focus group questions was related to mobile HIV testing. First, participants were asked about barriers to taking part in mobile HIV testing. Both groups expressed similar views in this regard. Privacy and confidentiality were major concerns for both groups. They felt that too many people would be able to see those who chose to get tested and make assumptions about their HIV status, which would lead to an “embarrassing” experience. One participant remarked, “The smaller the town, the bigger the gossip.” Sanitary concerns were also raised about mobile testing. Fear of getting a positive result was mentioned by both groups as a deterrent to mobile testing. Participants also felt that nightclubs might be an inappropriate place and time to approach individuals about testing. One participant stated, “I came to dink and party, not test.” In that same vein, concerns were also raised that club attendees may be intoxicated before arriving at the mobile testing venue, and so may not be in a rational frame of mind to get tested. Fears about receiving a positive result were also expressed. When asked for suggestions on how to overcome barriers to mobile HIV testing, several suggestions were offered by both groups. Both groups suggested the use of incentives to increase participation, including free club admission, food and drink coupons, and promotional item giveaways (i.e. CDs and movie

tickets). Both groups also said that having attractive staff could be an effective way to encourage AAMSM to take part in mobile testing. Other suggestions included active promotion by DJs and club staff, providing HIV prevention literature inside clubs, testing for other STDs besides HIV, sufficient mobile testing staff, and inconspicuous signage.

The results of this study provide some direction for future assessment and initiatives. Despite differences in age, there were many similarities between the views of younger and older AAMSM. Both groups were concerned about being discriminated against due to expressions of sexual orientation and sexual identity. Both older and younger groups had a shared recognition of areas for AAMSM to meet and interact in their areas, including clubs, malls, parks, and high-traffic streets. Both groups were aware of similar HIV prevention services in their respective areas, and had similar views on strategies to increase participation in HIV prevention programs and mobile HIV testing. A major issue that emerged from both groups was the issue of trust. Participants of all ages reported concerns about being able to trust other AAMSM, family, community members, and service providers. Participants from both groups observed that many HIV prevention professionals come from the same communities that they are a part of, which gives them concerns about the confidentiality of their personal information if they visit an AIDS service organization or community-based organization. One younger participant stated, "Punks are not to be trusted." Another older participant shared, "I don't trust nobody." This was especially apparent in discussions about health professionals. One older participant related an anecdote about a nurse at a local health department whom he felt judged him unfairly. Because this nurse made him feel defensive about expressing his sexual orientation, he developed a mistrust of health professionals in general as a result. To combat this, efforts must be made by health professionals to regain the trust of the AAMSM community and reassure them of their confidentiality standards.

There is also a need for programming that will facilitate the development of local AAMSM communities and encourage provisions of confidentiality. This is particularly true in smaller, rural communities, where smaller social networks can lead to greater confidentiality concerns. The results of these focus groups also illustrate the need for diverse programming for AAMSM in this state. While there were many similarities in the observations and needs of South Carolinian AAMSM across age groups, there were also unique differences that should be addressed specifically with each group. Younger AAMSM participants spoke extensively about the need for more AAMSM visibility in the state. They expressed interest in seeing Black gay professionals, role models, and mentors who could give them an image of the men they could become. They were very concerned about the way society portrays AAMSM, and were passionate about defying those stereotypes. Older AAMSM participants, on the other hand, spoke more about the provision of specified services, mostly HIV-related services. They identified concerns about access to care for newly-released incarcerated men and substance abuse programs. Because of these differences in perspective and need, AAMSM programming should be cast broadly to cover a variety of topics and offer a menu of services. Some of the topics that should be addressed include employment/life skills, AAMSM role models, and networking across regional and state lines. To meet these diverse programming needs, the development of an AAMSM resource center may be beneficial. This AAMSM resource center could provide holistic health information as well as a venue for the larger African-American community to learn more and engage in dialogue about AAMSM issues. In addition to

addressing the specific needs of AAMSM in their respective communities, prevention programs should also endeavor to address stigma and homophobia in the larger African-American community. The majority of participants indicated that stigma, fear, and homophobia were major issues that needed to be addressed both in prevention programs and in the community. Developing initiatives to impact stigma and homophobia, coupled with the development of “safe spaces” for AAMSM, may foster more trust and validation among AAMSM and consequently increase participation in HIV prevention programs.

There were several limitations to this study. First, there were some sampling challenges that impeded the generalizability of the focus group results. The community-based organizations that recruited participants for the focus groups had a tendency to recruit from their existing client bases, which may have skewed the results. For example, one-eighth of younger participants reported testing positive for HIV, and more than two-thirds of older participants reported being HIV-positive—well above the established seropositivity rates for the population. Additionally, there were some participants who were in focus groups that did not match their age categories. While this could have affected some of the discussion that took place, it is unlikely because of those participants’ proximity to the age cutoff. Despite the limitations, however, this study has yielded insightful information into the HIV prevention needs of AAMSM living in South Carolina. In fact, the study itself seems to have had positive effects on participants and, by extension, the AAMSM communities they represent. After many of the groups, participants remarked that having a forum to discuss these issues was valuable, and something they would like to do more often. Some remarked that it was the first time they felt like their opinions were heard.

The recommendations developed from the AAMSM Focus Groups include:

**1) Develop comprehensive sexual health programming that addresses HIV, STIs, and other sexual health trends that may be of interest to AAMSM (e.g., "sexting").**

Focus group participants indicated that they had a wide range of health interests beyond HIV, and that recruiting AAMSM into activities labeled explicitly as HIV prevention can be difficult. Because of the fact that infection with an STI can greatly increase a person's risk of becoming infected with HIV, it is important to address an array of sexual health issues.

**2) Increase HIV prevention web outreach and programming.**

Many participants indicated that, for various reasons, they and/or their peers use the Internet as a primary mode of meeting social and sexual partners. This is especially true in more rural areas, because there are no physical spaces (e.g., clubs, bars) dedicated to the AAMSM community. Because so many AAMSM are accessing social and sexual networking websites, it is important to provide HIV prevention messages and opportunities to interact with trained professionals in these venues. Some 3MV providers have developed profiles on certain sites in order to engage AAMSM in conversation and recruit participants for 3MV cycles. In addition to these, HIV prevention organizations may wish to consider developing and updating websites to provide HIV/STI prevention information with attractive images and links to holistic health information as well.

**3) Explore the development of accessible "safe spaces."**

Many participants stated that they enjoyed the focus group experience because it provided them with an opportunity to talk with other AAMSM in a non-threatening environment. Also, most physical areas in South Carolina that are "gay-friendly" are bars or clubs, which do not appeal to all AAMSM. HIV prevention organizations should consider the development of neutral, safe locations for AAMSM to meet and interact. These venues can be used for discussion groups, dinners, or other activities. Due to the stigma associated with many AIDS service and HIV prevention organizations, providers should consider identifying alternative spaces in the community that are nondescript and accessible, since transportation is also an issue.

**4) Develop a statewide AAMSM Resource Network.**

Many of the younger focus group participants stated that they desired to see other professional Black gay and bisexual men who could demonstrate positive images and provide resources and support to them as they mature. Providers can facilitate this by identifying these men in their communities and requesting their participation in the Resource Network. Resource Network participants can be approached to serve as mentors, guest speakers for group activities, and in other capacities as identified by providers in their respective communities.

The results of the study, combined with the favorable responses to the focus group process, should provide a solid foundation for the development of AAMSM programming in South Carolina.

**2008-2009 Hispanic/Latino Community Needs Assessment Activities**

On June 4, 2008, a Statewide Hispanic/Latino HIV/AIDS Strategy Roundtable Summit was held in Columbia. One of a series of summits held in the Southeast, the event provided information that was used to develop a set of recommendations identifying needs of the Hispanic/Latino community. Co-sponsored by the Latino Commission on AIDS, the Deep South Project, Palmetto AIDS Life Support Services (PALSS), Catawba Care Coalition, the SC Hispanic/Latino Health Coalition, and the SC DHEC STD/HIV Division, the meeting included introductory remarks, presentation of Hispanic/Latino epidemiologic data, a panel discussion, and smaller workgroup discussions. Recommendations from the event fell into six broad categories: Data and Research, Outreach and Recruitment, Culturally and Linguistically Appropriate Services, Networking, Intervention, and Policy. These recommendations were accepted by the HPC at its August 19, 2008 meeting:

Cultural and Linguistic Competency Recommendations:

- Help agencies recruit and retain bilingual staff.
- Find out where to get Spanish-language materials.
- Increase consumers' understanding of how U.S. medical system works.
- Get all dialects available on the language line (e.g. Mixteco).
- Produce culturally and educationally appropriate materials (no higher than 4<sup>th</sup>-grade literacy level).
- Encourage services to expand hours to accommodate Latino clients.

#### Data/Research Recommendations:

- Compile data on what happens when clients come to facilities, i.e. DHEC, RW clinics? What is the reality of service provision?

#### Intervention Recommendations:

- Learn about the interventions already developed for this population.

#### Outreach recommendations:

- Forge links with Spanish-language media in the area.
- Identify key people in the community as potential intermediaries (e.g. business owners, trailer parks, apartment complexes).
- Identify and map community resources.
- Build trust in available services.
- Publicize policy that RW is available to undocumented; create a resource directory?

#### Networking recommendations:

- Create a subcommittee within the state Planning Council.
- Use the PC outreach and training group to build capacity throughout the state.
- Liaison with other communicable diseases' staff.

#### Policy recommendations:

- Collect data disaggregated by ethnicity (not just white, black, other).
- Increase Latino representation on Planning Council.
- Open Planning Council to ER representatives.
- Formulate recommendations to DHEC on how to improve access.
- Encourage students in the health professions to learn Spanish.

As a direct result of the recommendations from the Roundtable Summit Recommendations, a Hispanic/Latino Workgroup was created. The workgroup, cross-cutting the HPC committees, has met several times and is working to implement the recommendations. A direct result of this work has been the implementation of in-state regional roundtable meetings, linking local ASOs, Hispanic/Latino organizations, and other service providers.

#### **October 2008 – February 2009 Survey of People Living with HIV/AIDS**

The South Carolina Department of Health and Environmental Control (DHEC) contracted with Public Consulting Group, Inc. to conduct a Needs Assessment of People Living with HIV/AIDS (PLWHA) in order to identify the HIV care and treatment needs of the clients in care throughout the eleven (11) Ryan White Part B HIV/AIDS Service Providers in South Carolina.

PCG conducted surveys on site at all eleven providers in South Carolina which include: ACCESS Network, Inc.; AID Upstate; CARETEAM; Catawba Care Coalition, Inc.; Hope Health Edisto; Hope Health Lower Savannah; Hope Health Pee Dee; Medical University of South Carolina; USC Department of Medicine; Upper Savannah Care Services; and Piedmont Care, Inc. throughout the months of October through December, 2008 and follow up surveys in

January and February, 2009. The 11 service providers provide medical care and supportive services to people living with HIV/AIDS, with a focus on the following core services: outpatient/ambulatory medical care, ADAP (local), oral health care, health Insurance premium and cost sharing assistance, home health care, home and community-based health services, hospice services, mental health services, medical nutritional therapy, medical case management, and outpatient substance abuse services.

Additionally, limited support services including case management (nonmedical), emergency financial assistance, food bank/home delivered meals, health education/risk reduction, housing services, legal services, linguistics services, medical transportation services, outreach services, psychosocial support services, referral for health care/supportive services, and treatment adherence counseling are offered to patients in order to allow patients access to care and retention in care. All of the 46 counties in South Carolina are served by one of the 11 service providers depending on geographic proximity to the service provider. ADAP services are available through a direct dispensing model for all eligible patients and insurance assistance for persons with low income HIV/AIDS population throughout the state of South Carolina. PCG's objective was to identify gaps, barriers, and needs in the Ryan White Services that the eleven providers offer to HIV/AIDS clients. The survey was administered to clients who currently receive care or had received care at that specific provider within the past two years. DHEC and PCG determined the number of samples needed for the surveys for each provider.

PCG's final report of the Ryan White Part B Consumer Surveys is data in table format. A summary analysis of the findings indicates that 560 randomly selected clients, served by a Ryan White Part B service provider in the past two years, were surveyed. The purpose of the survey was to gain insight into the client's knowledge of available services and whether clients are accessing needed services. This assessment will also identify service gaps and those service needs not currently being met for the clients.

#### Testing and Linkage

Thirty-four percent of clients found out they were positive by requesting a test. The majority of clients were diagnosed through passive methods: 48% found out when receiving care for something else, 4% found out when donating blood, and 5% found out in prison. 84% report being referred to HIV medical care when they became aware of their HIV status. 70% report going to medical care immediately, 17% went within one year, and 13% waited 1 year or more.

#### Medical Care

Ninety-eight percent of survey respondents were HIV positive clients receiving medical care. 2% were HIV positive and not receiving care. 91% claim to not often miss their medical appointments. Of those 9% missing medical appointments, transportation was the most commonly sighted reason. Other reasons included: worried someone will find out status, no way to pay for it, work schedule, and forgetting. 94.4% of respondents with AIDS report that they take their medications daily, on a regular schedule as prescribed. If clients were to miss doses the top reasons include: forgetting, side effects, difficult schedule, and not wanting to take the medications. 76.9% have received HIV/AIDS education and/or counseling.

## Satisfaction with Medical Services

Table 1.

	<b>Satisfaction</b>	<b>Dissatisfaction</b>
Contacting Medical Doctor	74% very satisfied	2% very dissatisfied
Doctor's Medical Advice	95% satisfied	5% dissatisfied
Nurse's Medical Advice	87% satisfied	13% dissatisfied
CM Medical Advice	84% satisfied	16% dissatisfied

## Knowledge and Use of Available Services

The most commonly accessed services are: Medical Care (85% accessed), Medical Case Management (66%), AIDS Drug Assistance (60%), Oral Health Care (48%), Health Education/Risk Reduction (46%), and Medical Transportation (30%). These most commonly used services are also those that most clients knew were available to them. Clients were most aware of available Medical Care (95% known), AIDS Drug Assistance (90%), Psychosocial Support (88%), Medical Case Management (87%), Medical Transportation (86%) and Health Education/Risk Reduction (85%).

The most unknown services to clients are: Health Insurance Assistance (59% unknown), Housing Services (55%), and Legal Services (46%). All three of these rate high on Table 1, which shows the gap analysis of need for services with the usage of services.

Table 2. Comparing need with usage

	% of those needing a service that did not get it in the past 12 months
Hospice Services – Core	94%
Legal Services – Support	94%
Housing Services – Support	93%
Linguistic Services – Support	86%
Health Insurance Assistance – Core	72%
Home Health Care – Core	67%
Emergency Financial Assistance – Support	65%
Substance Abuse Services – Core	61%
Psychosocial Support – Support	45%
Food Bank – Support	43%
Treatment Adherence – Support	40%
Transportation – Support	39%
Oral Health Care – Core	38%
Mental Health – Core	36%
Medical Nutrition Therapy – Core	35%
Medical Case Management – Core	19%
AIDS Drug Assistance – Core	13%
Health Ed./Risk Reduction – Support	10%
Medical Care – Core	3%

As noted in Table 2, there are varied gaps between the need and usage of every eligible Ryan White service. Noticeably, providers are meeting the needs best with Medical Care, Health Education/Risk Reduction, AIDS Drug Assistance, and Medical Case Management. These programs have been the HRSA-mandated focus of the RW Part B program.

There is probably misunderstanding on the part of the clients about some definitions for the less known and less used services. Obvious examples include Hospice Services and Linguistic Services. It is doubtful that Hospice Services are medically indicated for the 103 clients in this sample population that claimed Hospice as a need. Ninety-nine percent of survey respondents indicated that English was the language they were most comfortable speaking yet there is a large gap in meeting the need for Linguistic Services.

Housing Services, Legal Services, Health Insurance Assistance and Emergency Financial Assistance represent of the greatest client needs not being met by Ryan White service providers.

Clients claim ease with obtaining most services that they have tried to access. Oral Health Care, Emergency Financial Assistance, and Medical Transportation were identified as the most difficult to obtain. The reasons stated for these being difficult are service delivery and no access/availability.

#### Other Services of Importance Identified by Clients

Besides, HIV Medical Care, other services identified as important to the clients in order of most responses: financial assistance (32), housing (22), dental services (22), other health care needs (20), support groups (16), insurance, including Medicaid and Medicare (14), and education (6).

#### Suggested Changes from Clients

The most commonly stated suggestion for change was for more community awareness, education and testing (25). Other common suggestions were: support groups (16), dental services (15), transportation services (15), and confidentiality (8).

There were also multiple suggestions related to providers (21): these ranged from having more doctors, more clinic hours, better communication with providers, provider choice, less wait time, seeing the same doctor for all health issues, seeing the same doctor each time, and ensuring doctors are knowledgeable HIV specialists.

In conclusion, the majority of clients are satisfied with and thankful for the services they receive from the Ryan White Part B providers. Most are self-reported as consistent with their medical care and adherent to their prescribed medication regimen.

#### Knowledge of Services and Ease of Use

The self-reported adherence to medical treatment is consistent with the findings on client's use of services. Client's needs are most met for: Medical Care, AIDS Drug Assistance, Health Education/Risk Reduction, and Medical Case Management. Clients had greatest knowledge of these services and indicated ease with obtaining them. Knowledge of these services and ease of obtaining services appear to be contributing factors to reducing unmet need of services and, in this case, adherence to medical treatment.

The less commonly known services seem to correlate with those services that are less often used and are some of the clients' greatest gaps in service needs. Knowledge of service and ease of access are two variables to consider when reducing service gaps. Client eligibility for specific services, resource limitations, and HRSA priorities may also be factors in these service gaps.

One recommendation suggested by several survey respondents for increasing knowledge of services is to create a service listing by provider. This may increase user knowledge and increase requests for services. The eligibility for services, resources limitations, and HRSA's priorities and resource limitation should also need to be included.

### Recommended Priority Services

As noted in Table 2, all eligible Ryan White services have an identified unmet need. Based on the commonality and consistency of needs identified throughout the survey, needs identified in the gap analysis, and needs stated directly by the client, the following list of services has been identified as priorities for reducing the unmet need. HRSA's priorities have also been taken into consideration in the development of this list.

- (1) Medical Transportation – Medical Transportation is the only service that was stated by clients to directly interfere with adherence to medical care. Medical Care is one of HRSA's priority services. Transportation was stated as a need by many clients and was considered a difficult service to obtain.
- (2) Oral Health – Oral Health Care is a HRSA priority service. It was consistently mentioned by clients as a need and was difficult to obtain. Although Oral Health Care is relatively well-used service, it can be assumed that the client's dental issues are more involved than the dental services offered.
- (3) Housing Services and Emergency Financial Assistance – With 78% of clients living below 200% of the FPL and 68% of clients not working, housing and emergency financial assistance were widely stated throughout the questionnaire as important needs. Housing was relatively unknown service and is one of the greatest demonstrated gaps. EFA was indicated difficult to obtain.
- (4) Psychosocial Support – Although the gap in Psychosocial Support was not as large as other services, these appear to be of much value to the clients. Clients clearly indicated a need for support groups and commented on the need for confidentiality and community education. Confidentiality was also a factor in medical care treatment adherence. An assumption could be made that the need for support groups comes from feeling of discrimination and stigma from the community.
- (5) Health Insurance Assistance – Health Insurance Assistance is a HRSA priority service and cost saving to the Ryan White program. Although many clients will not qualify, clients and service providers would benefit if all eligible clients were enrolled.

### 2009 Transgender Survey

In 2006, during a review of SC Ryan White Care programs data by the HIV Planning Council's Needs Assessment Committee, it was noted that eight transgender (TG) persons were receiving Ryan White care and support services in the AID Upstate service area. The entire remainder of the state did not reflect serving as many (8) transgender people. Concerned that this was a data

anomaly and not truly reflective of the number of TG persons served in the state, the Committee informally began inquiring as to if and how service providers noted TG clients in their consumer population. As a result of anecdotal reports, the Committee elected to seek a trainer for and begin development of a Transgender 101 course. Upon recommendations of community contacts, a male-to-female transgender person from the upstate was contacted and a successful and informative one-day training was held in late 2006. Following completion of that course, a Capacity Building Assistance request was filed in early 2007 with the CDC for a workshop to be provided by The Transitions Project (UCSF) on HIV Prevention with Transgender Persons. Following that successful skills-building training, the Committee recognized that SC had no needs assessment data on the TG population, and efforts were begun to develop and implement a comprehensive survey of transgender persons. Over the course of 2008, an 18-page survey was developed, DHEC IRB-approved, and pilot tested. In April of 2009, the survey was distributed through social networks of TG persons and via HIV prevention and care contractors, with a deadline for receipt of completed surveys by June 15, 2009. Individuals completing the survey and also returning a coded participant incentive form would each receive a \$20 Wal-Mart gift card. Due to minimal response, the survey deadline was extended to July 13. As of July 31, 2009, a total of 17 completed surveys were received. The analysis of this survey is currently in process and will be released in a separate document upon its completion. The final document will be included as an appendix to the annual update of the HIV Prevention Plan.

### **Other MSM data collection efforts**

In addition to the focus groups with AAMSM, focus groups and key informant interviews are planned for later in 2009 with White MSM and Latino MSM. The results of those data collection efforts will be summarized and, when they are finalized, included as appendices to the annual update of the HIV Prevention Plan.

### **Other data collection efforts in South Carolina are more fully discussed in Chapter 6: Surveillance and Data Collection Initiatives**

## **2. Resource Inventory**

This comprehensive resource inventory includes information regarding HIV prevention activities in South Carolina and other education and prevention activities that are likely to contribute to HIV risk reduction. The resource inventory information described in this Chapter helps to describe the ‘met’ prevention needs by geographic area in the state.

South Carolina’s public health system is divided into eight regions representing anywhere from four to ten county health departments. The state office, the STD/HIV Division, is located in the Bureau of Disease Control along with the TB Control Division, Division of Acute Disease Epidemiology, Division of STD/HIV Surveillance, and Immunization Division, all within the Health Services Deputy area of the SC Department of Health and Environmental Control. The STD/HIV Division and Division of STD/HIV Surveillance are physically located on the same floor, enhancing opportunities for data sharing and reporting. The STD/HIV Division also includes and houses Ryan White program staff, increasing communication for linkage to care and joint planning and training efforts.

# DHEC Regions



All public health regions offer STD and HIV prevention services including STD screening and treatment, HIV counseling and testing, partner services (formerly know as partner notification and partner counseling and referral services or PCRS), and HIV prevention comprehensive risk counseling and services. Most offer Health Education/Risk Reduction and Public Information services. Central office staff provides quality assurance, contracts management, training and capacity building, public information/health communication, evaluation, and planning. In 2009, a Resource Inventory of HIV prevention activities was compiled into two sets of tables. The first set of tables, a checklist of services provided by county, provides an at-a-glance look at a spectrum of prevention services. The second set of tables includes prevention contractors and health department providers, the interventions provided, and target populations served.

The format of the Resource Checklist was presented to the HPC during the April 2009 meeting for review and to offer any additions or changes. From that meeting, the checklist was updated and by-county information collected and entered. Services provided in each county were contrasted with services available to county residents but provided outside the county. The revised Resource Checklist was presented at the August 2009 HPC meeting. The **2009 Resource Checklist** is included as **Appendix D**.

The primary funding for direct HIV prevention services in South Carolina is the Centers for Disease Control (CDC). This funding includes the HIV prevention cooperative agreement to S.C. DHEC and the CDC grants that have been awarded directly to community-based organizations (PALSS, S.C. HIV/AIDS Council and HopeHealth). These CDC funds total more than \$1.2 million in 2009. Additionally, DHEC receives some state funds for specific HIV/STD prevention activities (approximately \$4.4 million annually) which support staff to conduct counseling and testing and partner services and for a faith-based initiative of the SC HIV/AIDS Council. State funds also include a portion to pay for labs and STD treatment drugs. Additional funds for HIV counseling and testing services are provided in the HRSA Part C Early Intervention Services grants and the SAMHSA Alcohol and Drug Abuse Block Grant – HIV Early Intervention Services.

### **Limitations**

The information in the Resource Inventory on target populations, interventions, and funding is specific for the DHEC-funded providers. For other providers included in the checklist, however, information was not always available according to the HPC's priority population definitions. Therefore, the summary analysis – while county-specific – does not include population types by race/gender categories and may not reflect risk characteristics. In addition, the types of interventions for these other providers could not always be specifically defined. On the checklist, services are noted with an “X” if they are provided in that county. Additionally, services that are available to residents of a specific county, but are not provided in that county, are noted with an “A.” Residents accessing services noted with an “A” may have to drive to a regional hub or center for service provision.

While this information attempts to portray the *availability* of prevention services in South Carolina, it does not relay other key components of unmet need such as *acceptability* and *accessibility* of services. For example, services may not be offered during times of day or days of the week that are convenient. The physical environment of an agency may not be user-friendly or culturally acceptable to the target populations. For example, a community-delivered HIV counseling and testing event on a college campus may not reach those at greatest risk (such as African American MSM on an HBCU campus) because that population likely will not participate in a testing event where other students/faculty are present, regardless of how ‘confidential’ the staff attempt to make the environment. Also, while some services may be available in each county, the data do not specifically reflect staff burdens compared to HIV incidence and prevalence, particularly important for staff- or time-intensive interventions.

Finally, there may be other providers delivering services not reflected in the Resource Inventory. In 2009, staff focused the inventory on those organizations and activities most involved with HIV prevention or sexual/drug risk reduction. There may be other organizations conducting these activities or other efforts such as clinical trials or research projects at medical schools or universities which are not reflected.

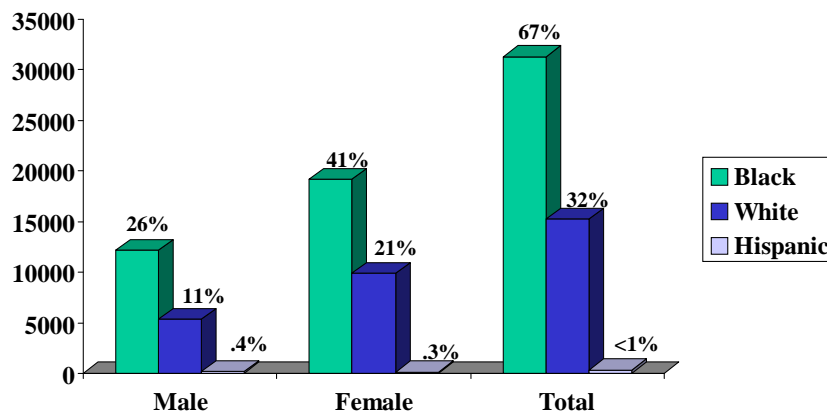
## Summary Analysis

### a. *Populations Served*

Figures 1 – 4 below portray the populations reached for DHEC HIV counseling and testing sites, community counseling and testing providers, PCRS services, and Health Education/Risk Reduction providers. These data come from DHEC program and contractor reports. Consistently across all prevention services, the majority of populations reached are African Americans.

Figure 1 shows counseling and testing services by local health department by race/gender. In 2008, DHEC served primarily African American women (about 41% of total persons served), followed by African American men (26% of total).

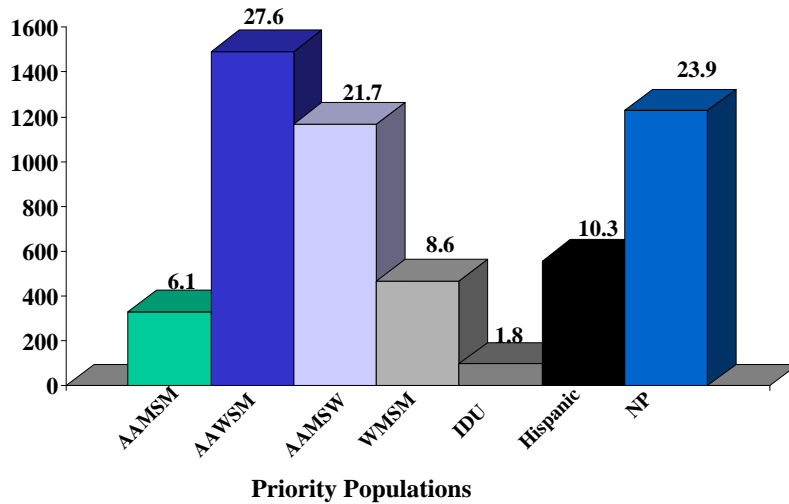
**Figure 1: Number and percent of persons receiving HIV counseling and testing services in local health departments CY2008, by Race/Gender**



In 2008, 48,499 persons were tested in the local health departments. Race percents for males and females are based on total number of persons identifying as Black, White or Hispanic (N=46,824). Data excludes persons with other/unknown race.

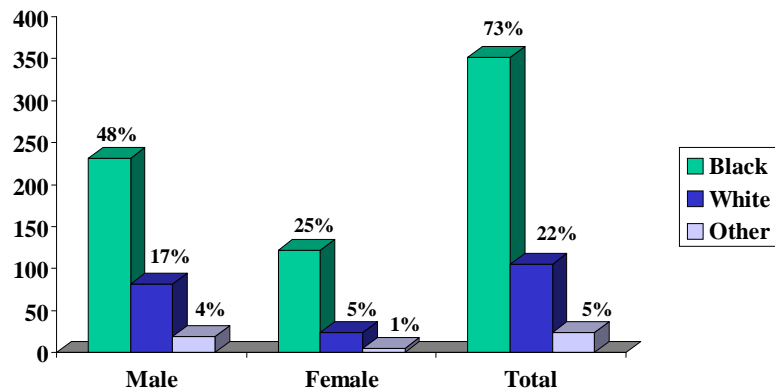
Data collected from community-based organizations (Figure 2) also shows that among SC priority populations, 27.6% of counseling and testing services served primarily African American women who have sex with men (AAWSM) followed by African American men who have sex with women (21.7% of total).

**Figure 2: Number and percent of persons receiving HIV counseling and testing services by DHEC-supported community organizations CY2008, by Priority Population**



PCRS services (Figure 3) represent the number of HIV infected persons interviewed for partner follow up (contacts reached are not reflected in this data). These data essentially equal the portion of newly diagnosed and reported persons, with 73% of total persons interviewed being African Americans; 48% were men, and 25% were women.

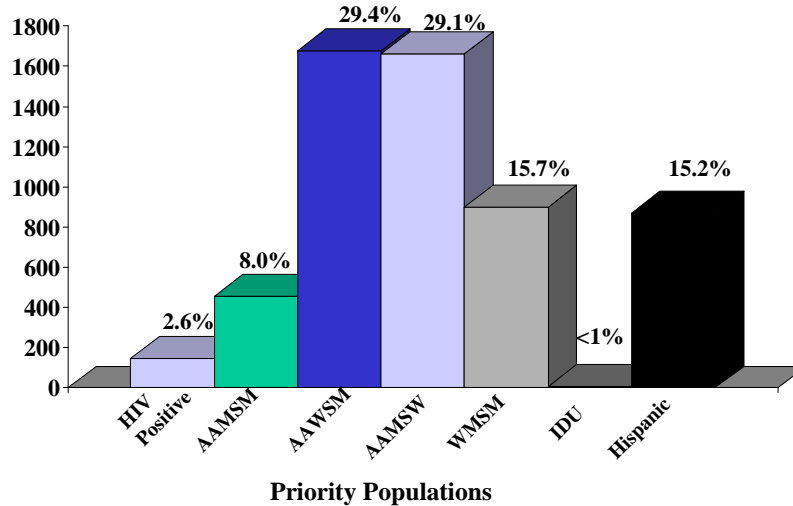
**Figure 3: Number and percent of HIV infected persons receiving partner counseling services in CY2008, by Race/Gender**



779 cases were diagnosed in 2008. Race percents for males and females are based on total number of persons receiving services (N=482). Data excludes persons with unknown race.

Among SC priority populations, health education/risk reduction providers (HE/RR) served mostly African American women who have sex with men (29.4%) and African American men who have sex with women (29.1%). About 3% of the total persons receiving HE/RR services were HIV infected persons (Figure 4).

**Figure 4: Number and percent of persons receiving HE/RR programs by DHEC-funded providers in CY2008, by Priority Population**



Includes ILI, GLI, and Outreach. Percents based on total number of persons within priority populations receiving services (N=5,717).

*b. Prevention Interventions Provided*

To summarize the types of interventions available across the state for all populations, the table in the appendix (HIV/STD/Hepatitis Prevention, Care and Support, and Other Services) was prepared for the HPC. Also in the appendices are prevention program models delivered by health departments and prevention contractors.

*c. Prevention Funding in South Carolina*

In order to assist the HPC in priority setting and assessing gaps in services, a following summary of HIV prevention-specific funding in South Carolina was reviewed for **FY/CY 2008**.

<b>DHEC FEDERAL HIV PREVENTION FUNDING FROM CDC – FY/CY 2008</b>	
1. Counseling/Testing/Referral Services (CTRS)	\$ 1,622,171
2. Partner Services (PS)	\$ 899,508
3. Health education/risk reduction (HE/RR)	\$ 1,299,764
4. Public Information (PI)	\$ 26,586
5. Evaluation	\$ 75,559
6. Capacity Building	\$ 32,830
7. Community Planning	\$ 118,316
8. Other (includes agency fringe benefits, indirect, general overhead, office supplies, etc)	\$ 271,374
<b>SUBTOTAL</b>	<b>\$ 4,346,108</b>

<b>DHEC STATE GENERAL REVENUE STD/HIV FUNDS – FY 2009</b>	
1. County Health Departments (Nurses, DIS, Health Educators, Social Workers) providing HIV CTRS, STD diagnosis and treatment; PS; HE/RR, PI; CRCS and ILIs	\$ 3,404,484
2. State Office (HIV/STD Lab test, STD treatments)	\$ 1,146,820
3. Project FAITH	\$ 1,000,000
SUBTOTAL	\$ 5,551,304
<b>CDC DIRECT FUNDING TO CBOs</b>	
Directly Funded Prevention Projects (3)	\$ 1,218,235
<b>OTHER DHEC PREVENTION-RELATED FUNDING – FY 2009</b>	
1. DAODAS Contract for HIV CTRS and Hepatitis C Services	\$ 374,630
2. CDC HIV Expanded Testing	\$ 938,316
3. CDC Infertility Prevention	\$ 406,733
4. CDC STD Services	\$ 1,345,605
5. CDC HIV Surveillance	\$ 1,530,631
SUBTOTAL	\$ 4,595,915
<b>GRAND TOTAL</b>	<b>\$15,711,562</b>
<b>Note: funding amounts based on FY (CY) 2008 or FY2008/2009 depending on type of fund</b>	

### 3. Gap Analysis

Based on a review of the community services assessment data (needs assessment and resource inventory) and the epidemiologic profile data, the HPC confirmed the populations at highest risk for HIV and the greatest need for services. The descriptions of Priority Populations in Chapter 4 summarize the specific barriers and needs for prevention services for each population.

#### *Summary: What are the Primary Met Comprehensive Prevention Needs in South Carolina?*

Based on the community services assessment, the following indicate ‘met’ prevention needs:

- Resources for HE/RR interventions reflect a greater amount of effort being targeted to the top priority populations (African American MSM and MSW and African American WSM).
- Interventions such as counseling, testing and referral; partner services, and STD services are available in each county for all priority populations. It is acknowledged that these interventions are only partially “met” needs as they may not be consistently accessible; be delivered in convenient, community settings, or fully meet all the prevention needs of clients served.
- A significant amount of resources are allocated to reach HIV-infected persons through counseling and testing, partner services, and referrals to care. The wide network of existing HIV care providers in the state provide varying levels of HIV risk reduction counseling at least upon initial entry to care. Additionally, secondary prevention services such as early intervention services, medical treatment and case management, the AIDS Drug Assistance Program, and HOPWA services are available to all residents of all counties in South Carolina.

#### *Summary: What are the Primary Unmet Comprehensive Prevention Needs in South Carolina?*

Funding for prevention efforts in South Carolina is not sufficient to address all of the populations at risk or fully address all prevention needs of any priority population. Enhanced case

management activities are needed to improve the successful linkage of newly diagnosed persons to care services in a more timely manner (see description of Linkages in the Coordination and Linkages Chapter).

Both STD/HIV prevention and HIV care services target in particular African Americans, who are disproportionately impacted by these diseases. Many challenges exist, however, that must be addressed to eliminate this health disparity. The overall impact of poverty, substance use, and insurance status contributes both to increase African Americans' risk for acquiring STD and HIV and to create challenges in providing prevention and care services. The impact is particularly significant in rural areas of the state where there are fewer prevention and care providers, longer distances to travel for services, and fears of stigma and discrimination.

Issues of confidentiality remain constant barriers, especially for persons in rural areas. Fear of alienation and rejection if someone in their small town finds out their HIV status is so great that many clients are reluctant to get tested and, if infected with HIV, often live in denial. The fear of being found out prevents clients from seeking services, from following up on symptoms, and from asking questions of health care providers. These fears can also be a barrier for drug adherence, providing the additional challenge of having to keep medications secret from others in their home or work settings.

Primary barriers and unmet HIV needs that have been identified by both prevention and care providers include the following:

- Scarce human and financial resources challenge the delivery of HIV/STI services. Many STD clinics must turn clients away for same day treatment. Ryan White-funded care providers do not have sufficient resources to meet the core and support service needs of clients.
- Access to the targeted populations is challenged by stigma, distrust, and concern for confidentiality;
- Preventive health services targeting African American MSM, including outreach and education, are challenged by a lack of defined open "community." This problem is further exacerbated by the lack of family acknowledgement/support of sexuality issues;
- Preventive health services targeting Hispanic/Latino MSM, including outreach and education, are challenged by a lack of defined open "community." This problem is further exacerbated by the lack of family acknowledgement/support of sexuality issues and by complicated immigration issues;
- Time constraints due to large client/patient caseloads limit access to providers and create inequities in availability (and quality) of clinic and risk reduction interventions;
- Testing barriers include the stigma being tested, fear of service providers not maintaining confidentiality, fear of being seen at an HIV/STD service provider location, and fear of knowing one's HIV status;
- Missed opportunities for HIV testing due to a lack of immediate accessibility of testing services (i.e., person is ready to be tested today and may not be "ready" next week);
- Lack of a referral system for STI testing for clients being referred from CBOs to DHEC
- Lack of statewide opportunities for community delivered STD/HIV screening and outreach services for populations not being reached by "traditional" services;

- Loss of funding for mobile van testing and screening programs restrict access to these services for rural or transient populations;
- Need for easier access to drug treatment and prevention services for persons using alcohol and other drugs;
- Lack of trained staff for all interventions;
- Lack of trained staff to provide effective interventions particularly to MSM and persons living with HIV/AIDS;
- Providers unable to speak or understand a client's language;
- Lack of members of the affected communities advocating for HIV prevention and ownership of HIV;
- Need for all school districts in South Carolina to provide age-appropriate evidence-based Comprehensive Sex Education programs for all youth in kindergarten through grade 12;
- Need to provide information to high risk groups who do not access community services (the unemployed, out of school youth, etc.);
- Need for expanded, targeted peer education programs for youth and young adults, especially those who are gay, lesbian, bisexual, transgender or questioning;
- Need for increased peer education and skill building for persons living with HIV/AIDS; and
- Need for better and earlier linkage to care for persons living with HIV and to retain them in care;
- Need for increased consumer and provider knowledge about housing programs, emergency financial assistance services, and assistance with maintaining housing; and
- Lack of knowledge about employment opportunities and/or job linkage programs and services for persons living with HIV/AIDS;

Finally, for each of its priority populations, the HIV Planning Council also identified a need for more behavioral risk data, social network information, and needs assessment information involving members of the priority populations to better guide decisions for planning, designing and/or implementing interventions and targeting resources.

Key recommendations for addressing these unmet needs are:

- Reach uninfected people at risk at the community level and engage them in risk reduction activities.
- Involve African American community representatives in planning, implementing and delivering local prevention initiatives.
- Conduct needs assessment activities with African American men who identify as having sex with women.
- Conduct needs assessment activities with African American women who identify as having sex with men.
- Reach HIV-infected people with HIV testing, referrals to care and support services, and on-going secondary prevention services (including linking persons with substance abuse treatment programs, family planning, STD, mental health, housing, etc.).
- Provide information to high-risk groups who do not access community/agency services (i.e., the unemployed, out of school).
- Increase programs targeting men who have sex with men.
- Expand targeted peer education programs for youth and young adults.

- Increase the provision of age-appropriate evidence-based Comprehensive Sex Education for all youth in kindergarten through grade 12 in all school districts in the state.
- Improve access to drug treatment and prevention services for alcohol and other drug-using persons.
- Increase the number of trained staff to provide a range of effective interventions, particularly for men who have sex with men and for persons living with HIV/AIDS.
- Build capacity among community organizations, including the faith community, to address community prevention needs while recognizing differences in abilities to deliver these services.
- Engage other key leaders to address underlying issues causing HIV stigma and health disparities for African Americans.