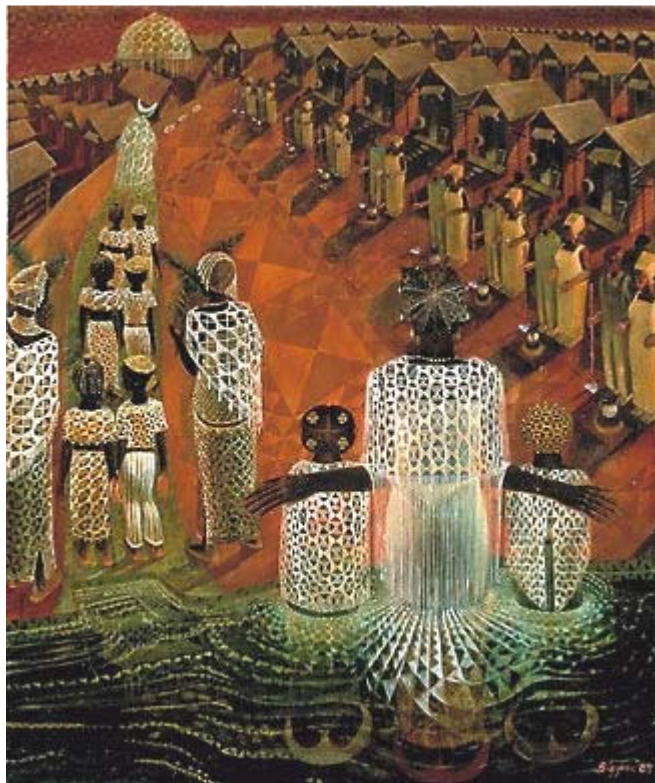


“A KNOCK AT MIDNIGHT: RE-EVALUATING HIV/AIDS IN THE BLACK COMMUNITY”

Black HIV Summit Report
Los Angeles Region



John Biggers
Baptism
1989

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EXECUTIVE SUMMARY

The Los Angeles Regional Summit occurred on June 27, 2003 and is part of a statewide effort to develop a blueprint and achievable action plan that will be used toward substantially reducing the impact of HIV/AIDS in the Black¹ community in California. The Los Angeles summit ('the Summit') was entitled "A Knock at Midnight: Reevaluating HIV/AIDS in the Black Community" and took place at the King Drew Medical Magnet High School.

Based upon discussions both at the State and local levels, the Black HIV Providers Network decided to take responsibility for conducting the regional summit in Los Angeles and use this as an event to help move forward the goals of the Network. The goal of the Summit was to elicit information and opinions from key stakeholders, leaders and decision makers in the Black community. The Summit hosted individuals from prominent Black organizations (such as the NAACP), youth organizations, gang diversion programs, religious and spiritual organizations, and Black fraternities and sororities along with those intimately involved with HIV/AIDS services in the Black community.

The Los Angeles summit was designed based upon the model developed by the statewide planning committee, which included six essential questions that served as the framework for discussion groups. The summit consisted of morning plenary sessions and afternoon strategy sessions. The plenaries examined the current state of affairs for four primary focal areas- treatment, prevention, policy and research – as they relate to the HIV epidemic in the Black community of Los Angeles. The strategy sessions provided the context for the summit, allowing participants to provide expert feedback on one of the four focal areas.

There were five recurring overarching themes found in all four of the afternoon strategy sessions. Most notably, key stakeholders, leaders and decision makers expressed concern about the need for culturally competent and appropriate programming, the ability to provide appropriate systems of delivery, the lack of adequate resources, the lack of community-wide collaboration and coordination, and the lack of an established research agenda. While these were recognized as the most consistent and all-encompassing themes, several other common issues were identified throughout the day and are presented in the Common Themes section of this report.

Throughout the entire Summit, participants exhibited optimism that the Los Angeles region possessed the expertise and determination needed to achieve its long-term goals and tackle the common issues documented. Throughout the day, there was a sense of recognition that this was a first step in a community capacity building process to provide culturally competent and relevant research, prevention, treatment, and policy for the Black community in Los Angeles.

¹ For the purposes of this report, the term "Black" and "African American" have been used interchangeably

As with any large event, there were some challenges and successes. However, with persistence and a lot of commitment from a truly wonderful group of individuals who provided valuable assistance in the planning and implementing the summit, the event was an overall success. The summit had 80 participants who reflected the diverse disciplines and communities that are affected by HIV/AIDS. One of the great successes of this regional summit was that it was a truly grassroots undertaking with virtually no financial support elicited from outside sources.

Los Angeles Black HIV Summit Description

On June 27, 2003, the Black HIV Providers Network conducted the Los Angeles Regional Summit entitled “A Knock at Midnight,” at the King Drew Medical Magnet High School in Los Angeles, California. There were approximately 80 participants representing community based organizations (CBOs), HIV-infected and affected individuals, local government personnel, public and private funding institutions, faith-based organizations and individuals, community activists, and educators. While efforts were made to ensure participation by all levels within organizations (front-line, middle and higher management), the majority of attendees were those with the power to implement the recommendations and strategies that resulted from the Summit.

The goal of the Summit was to elicit information and opinions from key stakeholders, leaders and decision makers in the Black community; as a result invitations to attend the Los Angeles summit were non-transferable. The Summit hosted individuals from prominent Black organizations (such as the NAACP), youth organizations, gang diversion programs, religious and spiritual organizations, and Black fraternities and sororities along with those intimately involved with HIV/AIDS services in the Black community.

Background

In 2002, as a result of a number of meetings and discussions, a group of concerned individuals from AIDS organizations throughout Los Angeles met to discuss their concerns regarding the state of HIV/AIDS in the Black community. This group, called the Black HIV Providers Network, planned a two-day retreat in August 2002 to discuss how organizations could work together collaboratively to impact AIDS in our communities. Though quite a challenging undertaking, the retreat created a core group of people interested in continuing to improve services and strategies to combat the epidemic.

A similar discussion was taking place between concerned individuals and the State Office of AIDS in Sacramento. It was decided that a statewide movement was needed to examine the factors and issues related to the high prevalence and incidence of HIV/AIDS in Black communities throughout California. Planning committees were established comprising of active individuals in five (5) of the most impacted regions of California. These regional summits were designed to facilitate the integration of the community perspective with the epidemiological, treatment and care, research, policy, and funding efforts currently in place in each of the identified areas. The Black HIV Providers Network agreed to take responsibility for conducting the regional summit in Los Angeles and to use this event to help move the Network’s goals of building stronger collaboration among local organizations that serve HIV-infected and affected communities.

Summit Design

The Summit in Los Angeles began with an opening prayer and welcoming remarks (see “Summit Agenda”). The plenaries examining the question, “Where are We Now?” in relation to our four focal areas, set the tone for the day. The Opening Plenary Session also included a presentation on epidemiological data with information specific to the Black community in the Los Angeles region. The plenary was designed to provide all participants with background information that would be utilized as a foundation for the facilitated strategy sessions. The morning plenary also provided a context for the keynote discussion during lunch, which focused on the importance of culture in examining risk-reduction, HIV/AIDS, and behavior in the Black community.

Following the morning plenary, participants were asked to move into their smaller facilitated strategy groups. The strategy groups provided an opportunity to engage in more directed discussion on the focus areas: Research, Prevention, Policy, and Treatment. Participants were pre-assigned to one of these four groups based on their expertise and experience in hopes of offering current and accurate information of what is in place and what is needed in each of those areas. In addition, two facilitators were assigned to each group. These facilitators were knowledgeable on the topic and were trained prior to the Summit. To ensure that responses and discussions were accurately and adequately reported, each group was also assigned one note-taker. Each of the four focus groups was given the task of responding to the following six questions/statements:

Question 1: Where are we now with respect to addressing HIV in the African American community in the Los Angeles region?

Question 2: Where do we want to be with respect to the impact of HIV on the African American community in the Los Angeles region by the year 2010?

Question 3: We plan to reach those goals in the following manner:

Question 4: We face the following challenges in addressing and/or reaching the goals that we have set for our region:

Question 5: We have the following opportunities to significantly address the impact of HIV on the African American community in our region:

Question 6: The following recommendations and/or responses are currently in place to reach our goals of significantly reducing the impact of HIV on the African American community in the Los Angeles region:

There were a number of success and challenges in conducting this Summit. The most prominent challenge was pulling together a large enough planning group to successfully conduct the Summit. The small numbers of people involved in the beginning stages of planning for the Summit seemed insurmountable. As a result, the original date for the summit in April had to be changed to June 2003. Despite this

challenge, with persistence and a lot of commitment from a truly wonderful group of individuals, the numbers that provided valuable assistance in the planning for the summit grew. With this expanded planning group, a list was developed that reflected the diverse disciplines and communities that are affected by HIV/AIDS. Lastly, one of the greatest successes of the Summit was that it was conducted as a truly grassroots effort, where all members contributed something to the effort of producing a successful event. Agouron Pharmaceuticals, Inc. provided catering for the Summit. Funding received from the California Endowment primarily went toward the development and reproduction of a report that could adequately inform organizations in the Los Angeles Black community about some common themes in the challenges and possibilities for collaborative work on strategies.

Common Themes

Each of the four facilitated strategy groups was designed to elicit expert feedback and identify gaps and barriers as well as to highlight effective approaches in the Los Angeles region. The strategy sessions provided participants with opportunities to respond to each of the six designated questions and discuss the needs, challenges, and successes related to efforts in the Black community. Five overarching themes were identified that transcended the four impact areas and those are provided, in detail, in the Conclusion section. Below are the common themes and issues identified by participants in the four focal areas in response to the six specific questions. In many cases, the responses were not stated in a manner to address the question, so we have summarized the statements to answer the question.

Where are we now with respect to addressing HIV in the African American community in the Los Angeles region?

- 1) We still lack adequate outreach strategies and efforts to educe increased participation of African Americans in clinical trials
- 2) We are lacking evidence-based research on differences/similarities within the African American community and its subpopulations. In addition, we need to have research that compares the African American community with other populations in hopes of designing effective prevention
- 3) We are lacking a coordinated multidisciplinary effort amongst established service providers
- 4) Not enough has been published on best practices around prevention, treatment models, retention, and medicine adherence in the African American community
- 5) Both knowledge and access to research and treatment is low in the Black
- 6) community
- 7) Behavioral risk group (BRG) categories are confining and many individuals are not identifying with particular categories. This also plays an enormous role in solidifying resources as funding is primarily designed to serve specific BRGs
- 8) A very large disconnect exists within the Black community between those who self-identify as heterosexual vs. homosexual. This disconnect has unfortunately undermined many prevention efforts in the community.
- 9) Continued oppression and stigma associated with HIV/AIDS that preclude many Blacks from fully acknowledging their risk
- 10) Fragmented medical services (in particular those in the managed care system) that significantly impacts prevention and treatment services.
- 11) Current case management and treatment models are crisis-based and not based on true prevention

Where do we want to be with respect to the impact of HIV on the African American community in the Los Angeles region by the year 2010?

- 1) More effective, efficient, and culturally competent strategies to addressing AIDS in the broader Black community (not just to high risk groups)
- 2) Better models of education in the community
- 3) Reduced negative myths and stigmas attached to HIV/AIDS
- 4) Greater collaboration between community and the private sector
- 5) Community ownership—Black community thinks of HIV/AIDS as a community problem and not a problem of a particular group
- 6) Empowerment of community residents to advocate for better and more responsive services
- 7) More evidence-based research in the community
- 8) More comprehensive approach to research and systems delivery
- 9) Closer links between policy, prevention, and treatment
- 10) Better and more timely dissemination of research findings to community
- 11) Increased education and training of non-HIV/AIDS service providers in hopes of offering a full circle of multidisciplinary services to those in need

We plan to reach those goals in the following manner:

- 1) Implementing more focused and coordinated outreach services to the Black community
- 2) Designing more culturally tailored HIV/AIDS services to meet the needs of the Black community
- 3) Increasing funding for primary prevention, research, and treatment services
- 4) Providing more support for Black researchers (including education and training) and Black research institutions that do important work in the community
- 5) Increasing programs that empower the community
- 6) Increasing African American involvement in evidence-based research and clinical trials
- 7) Promoting active participation and lobbying for more funds for community-based research and services
- 8) Increasing collaboration amongst HIV/AIDS service providers and between traditional and nontraditional service providers

We face the following challenges in addressing and/or reaching the goals that we have set for our region:

- 1) Lack of men (especially, non-gay-identified men) involved in HIV/AIDS research and prevention efforts
- 2) Insufficient resources to execute effective outreach and prevention programs; in addition, lack of resources to contribute to training and support collaborative efforts

- 3) Many nonprofit organizations are totally reliant on government funding which means they must following guidelines that are not always culturally appropriate or empowering
- 4) Persistent stigma and phobia in the Black community attached to HIV
- 5) Lack of an established coordinated effort between providers
- 6) Lack of holistic health perspective amongst providers
- 7) Research is seen as unappealing and difficult to understand by much of the community, hence, it lacks support
- 8) Continued suspicion and unwillingness to participate in research and treatment
- 9) Low self-perceived risk amongst many in the community
- 10) Fragmented medical services and culturally inappropriate care
- 11) Low self-esteem and self-efficacy in the community around prevention

We have the following opportunities to significantly address the impact of HIV on the African American community in our region:

- 1) Support/increase Black researchers within our community
- 2) Develop culturally appropriate language and models specific to Black culture to enhance critical thinking abilities
- 3) Expand Black HIV providers group by working in partnership with non-HIV centered organizations
- 4) Examine best practices for promotion of healthier lifestyles
- 5) Utilize the media to create more awareness
- 6) Incorporate spirituality into all phases of service delivery
- 7) Tap into the power of Black celebrities, because of our proximity and relationship with the entertainment industry, this is a prime opportunity
- 8) Develop greater social networks

The following recommendations and/or responses are currently in place to reach our goal of significantly reducing the impact of HIV on the African American community in the Los Angeles region:

- 1) Although not as strong as we would like, there is some advocacy for more Black participation in research and clinical trials
- 2) Develop policy that creates a system of universal prevention measures to replace BRG model
- 3) Address other underlying vector influences that prevent risk reduction activities
- 4) Address underlying social issues/behavioral issues that put the community at such high risk for infection
- 5) Look at individuals who are successfully managing the disease and identify their resiliency and incorporate these treatment and prevention activities/services
- 6) Examine the role of spirituality in prevention, testing, adherence, and treatment outcomes
- 7) Design prevention education programs that are holistic in nature
- 8) Develop and disseminate best practices to the community
- 9) Earmark more resources for primary prevention activities

- 10) Develop more peer-to-peer programs
- 11) Culturally tailor programs---the Black community is not monolithic
- 12) Develop an HIV prevention and treatment methodology that is culturally relevant and consistent with Black culture and social norms

Conclusion

As participants in the strategy sessions discussed the HIV/AIDS epidemic throughout the day, the interdependence of five overarching themes became more apparent. The most persistent themes centered on culture, system delivery, resources, collaboration and coordination among organizations, and research.

There was consensus among all groups that it is vital to have access to culturally competent, comprehensive and preventive care to help facilitate the development of strategies to address the Black community. These strategies must take into account how cultural and social norms impact risk-taking and risk-reduction behavior. The pervasive and historical discrimination as manifested in disparities in health, economics, technology, education, stigma as well as the need for a solution based in cultural competency have perpetuated the growth of the HIV/AIDS epidemic in the Black community. It was agreed upon that the effort to create culturally competent programs would require the understanding that the utilization of the beliefs, history and traditions of the Black community is necessary to increase communication around preventative behaviors. In addition, many of the groups emphasized the importance of understanding that culture includes more than just race and ethnicity, but other “cultural” groups such as youth, elderly, and substance users. With that understanding, better models of service delivery could be developed.

Current service delivery systems in Los Angeles were thought to be fragmented and inconsistent. Participants argued that perhaps one of the biggest challenges was providing services based upon behavioral risk groups (BRGs), which many funders require as a mechanism for categorizing clients. These BRGs were thought to severely limit community access and were too restrictive. It was noted that advocating for the creation of a system of universal prevention could replace the BRG model and provide a better understanding of risks regardless of sexual orientation or practices. Unfortunately, most of the community organizations rely heavily, if not entirely, on governmental funding and are mandated to serve specific risk categories and groups. The wide-ranging sentiment was that new public, private, entrepreneurial, and nontraditional avenues of funding would be sought out for new and efficacious programs to be developed.

The lack of adequate funding continues to be one of the major challenges faced by organizations and individuals in HIV/AIDS research, prevention, policy, and treatment. There was a general feeling that the lack of funding allocation for primary prevention efforts and community-based research significantly limited the number of new, innovative strategies and programs available to the Black community. With that as a springboard, participants spent time discussing alternative ways in which they could maximize community resources and secure funds to use for training and promotion of services to the greater community. Several of the strategy groups discussed the geographic advantage Los Angeles has in creating lasting partnerships with entertainment media. The ability of the media to reach large, diverse groups of people presents the opportunity to net more exposure of the realities of the Black community

around HIV infection, which in turn could possibly bring about diverse, funding sources. It was acknowledged that to undertake such a daunting task as to diversify the funding streams within the Black community, there must be a coordinated, concerted effort from multiple agencies throughout the Los Angeles area.

Collaboration between and amongst AIDS Service Organizations (ASO) and other prevention/care providers was noted to be significantly challenging. Current collaborative efforts are proving to be fruitful, yet many were noted to not necessarily focus specifically on the Black community. In the past, prevention and treatment multiparty efforts in the Black community lacked cohesiveness and did not necessarily demonstrate sensitivity to the needs and concerns of many of the subpopulations within the community. Organizations that served populations such as heterosexual women and men, youth, transients, and incarcerated individuals were often times neglected in favor of those that served MSM and IDUs. The need to develop ongoing multidisciplinary collaborations focused specifically on the Black community and its numerous subpopulations was echoed in each of the strategy sessions. The idea of a multi-agency, community-based think tank was proposed to develop culturally appropriate strategies that would be effective in the community. While participants differed in their ideas of the types of agencies involved, it was agreed that this was a step in the right direction. The think tank could provide the opportunity to invite public and private agencies that traditionally have not been at the table, such as managed care organizations, law enforcement, and school officials to set the prevention, treatment, policy, and research agendas for the Black community.

Establishing a research agenda in the Black community was noted by all strategy groups as an important and urgently needed next step. Some community based research efforts taking place in the Los Angeles area were noted, but a multidisciplinary, culturally competent and relevant research agenda was missing. Groups differed on where they felt the immediate need for a research agenda should focus. Some participants felt more research and clinical trials on effects of medication, and treatment and care for HIV infected individuals (including prevention activities for HIV positives) should be the first priority. Others felt that primary prevention efforts for HIV negative individuals were the starting point for this effort. As one participant noted, "Research is as valuable for those not infected as those who are." While there was not universal agreement on where the agenda should begin, the goal of the research agenda was clear: design and implement an agenda developed by the Black community for the Black community. The groups determined this research would examine the cultural complexity of the community, ascertain a better understanding of risk behaviors and the psychosocial factors that determine this behavior, and will incorporate constructs of importance in the Black community such as spirituality and faith.

While the list of "needs" and "lack of" appears to be discouraging, the participants were optimistic that the Los Angeles region possesses the expertise and determination to achieve the goals it set for 2010. Although the focus of each group elicited different

responses, the common and overarching themes across all four groups offered a glimpse into the larger issues surrounding HIV/AIDS services for Black communities.

An experienced and diverse group of agencies, united in advocacy, education, volunteering and experience, welcomed the opportunity to unite and collaborate with each other to develop strategies to combat further rising rates of HIV/AIDS infections. In spite of the challenges presented, the key stakeholders, leaders, and decision makers identified several strategies and programs that have been effective in targeting individuals thought to be at greatest risk. It is through this knowledge and experience that Summit participants were able to provide recommendations on approaches and strategies that may perhaps be effective in the Black community. The group left the Summit feeling excited and energized with this first step in a community capacity building process to provide culturally competent and relevant research, prevention, treatment, and policy for the Black community in Los Angeles.

Summit Agenda

Time	TOPIC	Location	PRESENTER
8-9:00	Registration	Magnet School Lobby	
9 -9:15	Welcome	Lecture hall	Eric Bing, M.D., Ph.D., M.P.H.,
	Plenary Session: “Where are We Now?” <ul style="list-style-type: none"> • State of AIDS in Los Angeles Black Communities: • Overview of Prevention Efforts in LA County • Overview of Treatment and Care in LA County • Research in Black Communities: • HIV Policy efforts in LA County 		Dr. Nina Harawa Ms. Alicia Dixon Dr. William King Dr. Jean Davis, Ms. Carrie Broadus
11 - 11:15	Break		
11:15-12:30	Strategy Session I Prevention Treatment/Care Research	Magnet School Classrooms	Facilitators & Note-Takers
12:30–1:00	Lunch	Cafeteria	
1:00-1:30	African Americans and Health: A Cultural Context	Cafeteria	Dr. Erylene Piper-Mandy
2:00-3:45	Strategy Session II Prevention Treatment/Care Research Policy	Classrooms	Facilitators & Note-Takers
4-5:00	Report back and Closing	Lecture Hall	

Summit Focus Group Findings

Research Focus Group

Question 1: Where are we now with respect to addressing HIV in the African American community in the Los Angeles region?

- * In a state of complacency on clinical trials: 1) Researchers say more African Americans need to be involved in research, yet they don't do what's needed to recruit them; and 2) The community says those medications don't work for us yet they aren't involved in clinical trials or research
- * In need of more evidence-based research/information on how African Americans are similar/different than other populations with regard to HIV/AIDS
- * A lack of multidisciplinary coordinated effort including mental health, medical, and support services
- * Gaps in the dissemination process of research findings In need of information on what research is currently being conducted and what has been done already
- * In need of best practices around treatment models, retention, and medication adherence for African American
- * A disparity between classic medical model and psychiatric model for those at highest risk for infection and those already infected In need of a complete health hazard appraisal on each at-risk person
- * In need of best practices on how African Americans are different medically, psychologically, and environmentally, and how to use this in program planning and implementation
- * We need to better understand HIV in people not in medical care

Question 2: Where do we want to be with respect to the impact of HIV on the African American community in the Los Angeles region by the year 2010?

- * Better understanding of how and why African Americans engage or don't engage in the clinical trials process
- * More comprehensive (multidisciplinary) approach to research and systems delivery
- * Better coordination between psychosocial, environmental, medical, and system delivery
- * A better understanding of how African American's engage in the research process and help them understand the reality of participating in research
- * Better dissemination of research findings to the community
- * Better understanding of the psychiatric realm of HIV/AIDS
- * More culturally competent efforts to address Black community as a whole, not just segments of the community
- * Examining intrinsic thought patterns in low risk populations and see how that applies to them not contracting disease and apply that to high-risk populations.
- * Taking a holistic approach by treating the whole person, not body parts

- * Massive HIV and health education campaign specifically targeted to the Black community
- * Closer link between prevention and policy--all different disciplines coming together to do research together

Question 3: We plan to reach those goals in the following manner:

- * Increase African American involvement in the research and clinical trials process
- * More sharing of resources between traditional white institutions with resources and Black institutions that have the African American populations the researchers are interested in
- * Increased links between research in different disciplines and researchers (goes back to holistic approach)
- * Evaluate current research funding structures/networks to see if they are doing what we want them to do and if not, how to accomplish what needs to be done
- * Move toward more collaborations with non-medical providers (e.g. mental, physical, nutrition)
- * Tap into non-traditional funding sources
- * Support affirmative action and educational training of African American researchers so they can be the “face” of research and meet our needs
- * More capacity building with CBOs
- * Increased participation between RO1/top research institutes and Black institutions
- * Look at work in other communities and evaluate/examine how to adapt and what can be adapted to African Americans successfully
- * Active participation and lobbying for more funds for community-based research
- * Identify the cultural norms that continue to put African Americans at high risk for infection
- * Institute better research techniques and procedures
- * Looking at similarities and differences in HIV and Hepatitis C populations
- * Best practices for African American patient retention/recruitment and medication compliance
- * Work with the Office of Minority Health in conjunction with Office of AIDS Research to bring more funds into the African American community Better communication between funding source and CBOs
- * CBO’s contract with researchers to ensure that the data come back to them in a form they can use; and only contract with researchers who are doing relevant research
- * Understand the intersecting role of side effects/toxicity/adherence on treatment success
- * Streamlined data collection procedures

Question 4: We face the following challenges in addressing and/or reaching the goals that we have set for our region:

- * People feel like guinea pigs in research
- * Continued suspicion and unwillingness to participate in clinical trials
- * Substance abuse and other competing issues
- * Many African Americans don't think HIV/AIDS is a big deal for them
- * Some religious institutions look at HIV as the product of sin
- * Youth don't think it can happen to them if they aren't gay
- * Stigma associated with disease
- * Lack of funding for implementation and dissemination (specifically in relation to Black health issues)
- * Lack of education in regards to informing clients that doing this research is important regardless of whether or not they get paid
- * Not having a clear understanding of what really happens in research
- * Many times white institutions only collaborate with Black institutions to have access to their client population and the Black institutions often feel used and discarded
- * Managed care has fragmented and impersonal medical services
- * Medical reimbursements difficult to obtain, affecting Black MDs
- * Participants and CBOs don't receive study findings of projects for which they participate in
- * Too much time between gathering data and actually reporting results — specifically in cases where clients are followed for years

Question 5: We have the following opportunities to significantly address the impact of HIV on the African American community in our region:

- * Expanding the group by bringing in the non-HIV centered organizations such as the Urban League, NAACP, Schools, Professional Orgs, Fraternities/Sororities, and Churches
- * A significant amount of Black researchers in Los Angeles compared to other regions
- * Look at best practices
- * Create more awareness via ads, media, campaigns—use media to encourage research (BET, Viacom, UPN, CA HIV/AIDS hotline)
- * Evaluate social marketing campaigns throughout county (to include CBOs)—is it worth the expenditure?
- * Pharmaceutical companies can come and talk about benefits of medications and de-mystify stereotypes/myths surrounding medication.
- * Talk to less traditional collaborative institutions like correctional facilities, foster care, and the media
- * The use of spirituality

Question 6: The following recommendations and/or responses are currently in place to reach our goals of significantly reducing the impact of HIV on the African American community in the Los Angeles region:

- * Address other underlying vector influences (i.e. rape, abuse, transfusion)
- * Address underlying social issues/behavioral issues in order to positively affect those that are HIV positive
- * Effective early education to break the cycle that invites alcohol/drug use
- * Effective early intervention with youth/adolescent populations and their families with research studies
- * Look at individuals who have successfully managed disease as well as those with resiliency factors and bring that to treatment and prevention programs— what are those factors?
- * Look at effects of antidepressants on lowering risk and treatment adherence
- * Look at spirituality and its role in prevention, testing, adherence, and treatment outcomes
- * Conduct quality of life research on person taking standard medications vs. those taking a holistic approach (alternative therapy)
- * Examine other transmission vectors (co-morbidities)
- * Review effective work in HIV research with sex workers in Haiti and Kenya
- * Develop a RFP that evaluates other RFPs in place
- * Evaluate faith-based initiatives

Prevention Focus Group

Question 1: Where are we now with respect to addressing HIV in the African American community in the Los Angeles region?

- * We have lots of agencies addressing problem, the challenge is turning summit into action plan—believes capacity is there but could use coordination
- * Lack of prevention and attention in the transgender community
- * Awareness level has been raised of “mid-life women” are now more aware but seniors and youth could use some attention
- * Youth still “reckless with sexuality”
- * Lack of coordination between support organizations
- * Self-esteem and communication about sex is really needed!
- * Do we have an accepted definition of prevention? How do you determine underlying issues?
- * Disconnect of HIV/AIDS in Black community [Gay vs. Heterosexual]
- * Media isolation of HIV/AIDS
- * Marketing is too general and causes disconnect
- * Continued oppression and stigma associated with HIV/AIDS
- * Folks do not identify with BRG categories and the identification of groups causes community to opt out by not realizing it is a community problem, not a particular “group”
- * Data indicates many people testing positive do not fall into categories
- * Prevention Planning Committee meets w/o consulting community—community leaders not informed of decision-making committees
- * Strong social influences of music
- * Gaps in services to straight Black men
- * Economic dependence of women
- * Environmental factors
- *

Question 2: Where do we want to be with respect to the impact of HIV on the African American community in the Los Angeles region by the year 2010?

- * 100% Access, 0% Disparity
- * Thinking outside of the box
- * Understanding the incarcerated population and their increased risk of HIV
- * Creating a holistic approach to expanding and coordinating services
- * Setting realistic goals
- * Correcting services that aren’t working
- * Better outreach workers that are valued in the community
- * More evidence based research
- * More comprehensive case management to address needs of high risk negatives
- * Creating a full circle of services—a place to go when you are negative and need services

- * More accessible services located in community
- * Mechanism of empowerment at policy level
- * Education and training of non HIV/AIDS service providers—cross training
- * Institute routine HIV testing
- * Involvement of Los Angeles Unified School District (LAUSD) in network of information
- * Doing a better job targeting youth (combating negative lyrics in music)
- * Greater networking access
- * Better training of health care providers

Question 3: We plan to reach those goals in the following manner:

- * Initiate actual prevention strategies
- * Better marketing, PSAs, billboards, and publicity
- * Focus on money coming into HIV/AIDS arena and conducting a very public, and culturally appropriate, marketing and media approach
- * Focus group health education material and leadership
- * Use knowledge and expertise already in community, don't wait for "sanctioned" knowledge
- * Conduct door-to-door surveys
- * Collect missing info from diverse sectors of Los Angeles
- * Develop Black think tanks
- * Community empowerment and a series of community forums
- * Aggressive political advocacy—especially on federal level (2004 election)
- * Collaboration between CBOs and Sheriff and State Office of AIDS to council prisoners released
- * Conduct and support evidence based research to support what "community" knows works
- * Support community education and Black researchers in the community
- * Increase work with churches and other faith-based organizations
- * Support Black youth friendly environments
- * Develop a marriage between research and community to impact faster solutions and problem solving
- * Include loved ones who lost someone to HIV/AIDS to bring the experience and reality check
- * Think Black!

Question 4: We face the following challenges in addressing and/or reaching the goals that we have set for our region:

- * How do we address the men not being involved in HIV prevention?
- * Lack of funds effects all phases of prevention
- * Dearth of specials programs that do research on African American women
- * Lack of aggressive lobbying like gay White men did in Hollywood

- * Total reliance on government funds
- * Lack of engagement of small business, chamber of business, recycling Black dollars
- * HIV stigma and phobia with Black entertainment and community as a whole
- * No real coordinated effort to raise money
- * Changing perspective of “other” people
- * Health promotion vs. risk prevention strategies
- * Package and Marketing
- * Incentives for radio stations, TV programs, and artists who provide more positive message and include prevention and HIV messages
- * Distrust between agencies Lack of holistic health perspective
- * Lack of community participation in making the plan
- * Funding makes organizations label people

Question 5: We have the following opportunities to significantly address the impact of HIV on the African American community in our region:

- * Holistic health promotion--using existing social structure and events to integrate health promotion messages
- * Using television—seeking rising stars, contests that showcase Black talent, and shows with Black programming
- * We can try to replicate an awareness campaign like the one Destiny’s Child did in Africa
- * Slip messages into existing events (1st Lady Tea, jazz concerts, Black professional organization events, Movie theatre previews, church)

Question 6: The following recommendations and/or responses are currently in place to reach our goal of significantly reducing the impact of HIV on the African American community in the Los Angeles region:

- * In-depth study of infrastructures in Africa that have created significant change in HIV prevalence, like in Uganda
- * Create prevention education programs that are holistic in approach and include self esteem in the context
- * Develop and disseminate best practices
- * HIV speakers bureau that helps to build leadership, personal behavior and value clarification—HIV positive speakers make the best impact because it puts a face on HIV
- * World AIDS Day—HIV positive folks can help put a face on HIV
- * More money for primary prevention
- * Peer-to-peer messages and programs
- * Gender, age, and cultural specific programs—we are not a monolithic community

Treatment Focus Group

Question 1: Where are we now with respect to addressing HIV in the African American community in the Los Angeles region?

- * Although treatment exists, access is limited
- * Knowledge about treatment is low in the community
- * Cultural viewpoints transfers to clients (providers should address personal concerns and issues in order to effectively serve clients)
- * In need of being “real and true” about treatment; don’t lighten, but enlighten
- * Focus on prevention to positive persons
- * Need to increase and promote clinical trial studies
- * Treatment is crisis focused

Question 2: Where do we want to be with respect to the impact of HIV on the African American community in the Los Angeles region by the year 2010?

- * Steady infection decline
- * 100% testing with follow up
- * Universal prevention without labels, i.e. BRGs
- * Realistic approach to prevention
- * HIV Vaccine
- * Universal (medical expansion) health coverage
- * Short term treatment
- * Approved microbicide
- * More acceptance of disease in broader community
- * Knowledgeable providers
- * Enhanced incentives with trials
- * Youth focused education
- * Family focused education
- * More outreach for HIV positive individuals
- * Updating HIV 101 curriculum
- * Increased education in elderly community
- * HIV testing of incarcerated individuals

Question 3: We plan to reach those goals in the following manner:

- * Microbicide advocacy and education
- * Increased funding
- * More training
- * Advocate for HIV testing as standard part of health screenings
- * Update HIV 101 curriculum
- * Marketing/media campaigns

- * Educate African American entertainers and encourage them to promote safer sex
- * Challenge faith based organizations
- * Challenge men to become more active in the HIV and safer sex arena
- * Safer sex promotion with elderly
- * Pre/post counseling stays intact
- * Show results of research
- * Knowledge, education, patience

Question 4: We face the following challenges in addressing and/or reaching the goals that we have set for our region:

- * Funding
- * Stigma
- * Competition (class, rank, socialization)
- * Low self-perceived risk
- * Working in isolation (non-collaborative environment)
- * Burnout
- * Racism, sexism, classism
- * Cultural barriers
- * Service Planning Area (SPA) configuration
- * Grant education
- * Paperwork
- * Lack of tech savvy individuals
- * "Free is cheap" myth
- * Resistance to medical services
- * Low self-esteem and self-efficacy
- * Literacy level
- * Lack of critical thinking
- * Judgments
- * Cultural competency
- * Transportation

Question 5: We have the following opportunities to significantly address the impact of HIV on the African American community in our region:

- * Utilization of the media
- * Access to the entertainment Industry
- * More outreach at public functions and community events
- * Marketing
- * Partnering resources/collaborations
- * Education
- * Developing stronger volunteer base
- * Developing greater social networks

Question 6: The following recommendations and/or responses are currently in place to reach our goal of significantly reducing the impact of HIV on the African American community in the Los Angeles region:

- * Committed CBOs
- * AIDS Ministry in churches
- * Experience in the community
- * Diversity
- * Clinical Trials
- * Domestic Violence Programs
- * Substance Abuse Programs
- * Elected officials concerned
- * Case Studies
- * Pre/post test counseling
- * Recovery programs
- * Fundraising
- * Legal protection and policy
- * Literacy programs
- * Technology

Policy Focus Group

Question 1: Where are we now with respect to addressing HIV in the African American community in the Los Angeles region?

- * Fragmented
- * No consistent outreach plan to the African American community
- * Not addressing broader issues in the African American community that has nothing to do with HIV
- * BRG—creates a false safety barrier that all our community don't always fit
- * Agency collaborate working together but current collaboration not culturally/community focused
- * Case management current model is crisis based

Question 2: Where do we want to be with respect to the impact of HIV on the African American community in the Los Angeles region by the year 2010?

- * 1st goal—reach out to the large community (outreach/testing/condoms available)
- * Preventative case management redesigned to be less crisis oriented
- * Decrease the rate of morbidity of people infected with HIV as well as decrease the disproportion of those infected
- * Stigma—dispel the negative stigma about HIV disease and those infected
- * Education—more outreach and programs for the youth
- * Better models of education for the community
- * Greater collaboration with community and private sector and entities involving grass root organizations
- * Resources of public and private involvement
- * Community ownership—people getting involved
- * Social justice issues and HIV/AIDS (drugs, violence, nonaffordable housing)—issues that tie the community and economic development together
- * Address the hopelessness (to empower people infected/affected, get private sector/legislative involved/churches get involved)
- * Messages/actions/deeds—issues around homophobia
- * Empowerment—how I see myself and how I relate
- * Gender bias/gender consciousness—how men are perceived, how women are perceived, able to tackle/address the social/religious, put down on men/women
- * Empirical data on prevention/MSMs
- * Local policy based on issues that affect black people
- * Replenish people's thinking/create programs—symptoms of being black, look at conscience and subconscious, define terms for black people

Question 3: We plan to reach those goals in the following manner:

- * Broad community response to local, state, federal legislation as it relates to social justice/issues (health) Outreach to broader local communities—media, tools, education, etc.
- * Find and use resources outside of and including HIV/AIDS to increase broad community empowerment (messages—actions—deeds--gender bias—perspective)
- * Culture and gender awareness
- * Exam current PCM model and deconstruct and rebuild based on community feedback
- * Community policy to help shape legislation
- * Incorporation of fundamental spiritual benefit(s)
- * Strengthen the message to increase self esteem
- * Categorized empirical data that speaks to the community empowering and seeking models that deal with individual value vs. “set in stone” methods not working.
- * Redefining “what does it mean to be a Black man/woman in America?”—and shift thinking to we define ourselves

Question 4: We face the following challenges in addressing and/or reaching the goals that we have set for our region:

- * Is there any PRIDE in being a black man/woman in America?
- * How do we make the shift of defining who we are
- * Instill HOPE—that has direction and critical thinking component
- * Re-language inherited terminology
- * Resources to address training and cultural shift to critical thinking
- * No standard of the “Black experience”
- * Use current PCM data to show need for focused research for the African American community
- * Policies are determined/defined by research, no research on the specific to PCM
- * We must find ways to connect and collaborate with new/current entrepreneur avenues/persons, ministries, and Black institutions (sororities, fraternities, companies, etc.)
- * Resources to contribute to training and support collaborative efforts

Question 5: We have the following opportunities to significantly address the impact of HIV on the African American community in our region:

- * Collaboration of providers of PCM services to show data of what works and what doesn't and then create a document addressing the state
- * Enhance cultural affirmations
- * Support/increase Black researchers within our community

- * Develop language and models specific to Black culture to enhance critical thinking ability
- * Target/address cultural negatives
- * Media/environmental literacy
- * Training the new black entrepreneur/communities
- * Developing resources to train and maintain messages to the community
- * Social justice is about improving the human condition of black people, best accomplished by the above!

Question 6: The following recommendations and/or responses are currently in place to reach our goal of significantly reducing the impact of HIV on the African American community in the Los Angeles region:

- * PCM data collaboration
- * Develop a policy that creates a system of universal prevention measure to replace BRG model—which alienates people
- * Give timely information to client using new approach of universal prevention message—challenge will be more political, religious, etc.—dismantle BRG model and creation of universal model
- * Current BRG model is not working. A universal prevention method would benefit the African American communities of Los Angeles
- * Develop information materials which includes all preventative information
- * Creation of standardized tool(s) using collaborative, focus groups to create universal models testing to validate and evaluation
- * There is no HIV prevention methodology including cultural affirmation and critical thinking strategies
- * HIV prevention/CARE must integrate the cultural affirmation and critical thinking strategies
- * Research and development of critical affirmation thinking models; use of trained, and educated, culturally sensitive and competent staff, peer counselor and volunteers
- * Current model addressing cultural affirmation and critical thinking strategies must be integrated into current system