Dear Community Summit Participants,

Thank you for your participation in our recent summit “Community Conversation on HIV”. Your contribution to this important community dialogue on HIV planning provided an excellent foundation for identifying the actions necessary to successfully halt the spread of HIV in the District and the region.

As you know, a strategic, coordinated plan is critical to delivering services and programs that effectively address the complex issues surrounding HIV and AIDS in the DMA. Your help in developing a more effective strategy to HIV planning in the region provided us with the cornerstone for making that plan a reality.

As promised, we have posted notes, recommendations and next steps from this event on our Web site, and encourage you to stay involved as we move ahead. I believe we have designed a great framework for the future, and look forward to working with you in 2006.

Thanks again for your input and support.

Marsha A. Martin
Senior Deputy Director
Department of Health
HIV/AIDS Administration
Executive Summary

Increasingly, epidemiologic and economic trends are calling on public and private sectors to develop more comprehensive approaches to HIV planning. In an effort to address this need, the Administration for HIV Policy and Programs (AHPP) convened “A Community Conversation on HIV Planning,” on December 20, 2005. Bringing together community partners from the Washington Eligible Metropolitan Area (EMA), AHPP took the first step in constructing a roadmap to prioritize the needs of District residents and to strategize about the allocation of scarce resources.

More than 150 members of the HIV Prevention Community Planning Group (HPCPG) and the Ryan White CARE Act Title I Health Services Planning Council (PC), including community activists, health care providers, people living with HIV and AIDS, epidemiologists, behavioral and social scientists, and government officials, participated in the “Community Conversation.”

Almost 25 years after the first case of acquired immunodeficiency syndrome (AIDS) was recognized in the United States, residents of the District of Columbia find themselves in the middle of an epidemic. In the most recent years for which data are available, the District had the highest incidence of AIDS of all major metropolitan areas in the U.S. In 2003, the District had an AIDS incidence rate of 170.6 per 100,000 people (see the HIV Surveillance Report, 2004 and DC Epidemiologic Profile, 2003).

The need for such a comprehensive plan is becoming even more pressing as ironically, advances in the treatment of HIV have helped to foster a growing sense of complacency in many sectors of government, health care institutions and the general public. The “Community Conversation on HIV Planning” was developed to formulate a coordinated set of strategies to address this complacency and to maximize resources.

Joined for the first time by federal partners from the White House, the Health Resources and Services Administration, and representatives from other municipalities, members of both the HIV Prevention Community Planning Group (HPCPG) and the Planning Council were divided into working groups to address topics on HIV/AIDS that included care and treatment, prevention, data collection and the impact of HIV/AIDS on sub-populations. The consolidation of the two planning groups also made Washington, DC one of five areas (Florida, New Hampshire, Nebraska and Tennessee) to integrate planning groups.

During breakout sessions, workgroup members focused on identifying key elements to developing a strategic, coordinated effort for the development of services and programs that mirror the complex issues surrounding HIV and AIDS in this region.
Although working in tandem, each group was autonomous in assessing their specific topic area and outlining the key components of an effective regional response to planning for HIV prevention and care.

HIV remains one of the most significant public health challenges today and there is still a great deal to learn about how to slow the spread of the disease. The challenge now is to move toward a comprehensive planning agenda that will make a positive impact on the pandemic.

**Overview**

The mission of the Administration for HIV Policy and Programs (AHPP) is to reduce the HIV morbidity and mortality of the residents of the District of Columbia through the application of sound public health practices and initiatives.

Our vision is to reform the AHPP's ability to more efficiently and effectively administer programs and services and to ultimately decrease the rate of new HIV infections in the District.

The District of Columbia Department of Health is the grantee for the Ryan White CARE Act Title I Eligible Metropolitan Area (EMA) and the Administration for HIV Policy and Programs is the administrative agent. As such, DOH is responsible for disbursing funds to the neighboring jurisdictions that comprise the EMA, developing requests for proposals, creating service agreements, monitoring contracts and grants and submission of funding applications to Federal agencies.

The Administration for HIV Policy and Programs policy requires that funds allocated for HIV Prevention and CARE services closely follow the recommendations outlined by the Community Planning Group and the Planning Council. These groups represent consumers, service providers, and the Government of the District of Columbia.

In partnership with the Administration, they are charged with identifying priority

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**Key Terms Used**

- **Community Planning**: A collaborative process by which health departments work in partnership with the community to (a) develop a comprehensive HIV prevention plan that best represents the needs of populations infected with or at risk for HIV, and (b) addresses the unmet health needs of persons living with HIV disease (PLWH) by funding primary health care and support services that enhance access to and retention in care.

- **Washington Eligible Metropolitan Area**: The geographic area eligible to receive CARE Act Title I funding. The DC EMA includes the District of Columbia, Suburban Maryland, Northern Virginia and two counties in West Virginia.
populations, processing and analyzing trends, ascertaining service needs and making program recommendations for consideration. Our vision is to reform AHPP’s ability to more efficiently administer effective programs and services, and to ultimately decrease the rate of new HIV infections in the District of Columbia.

AHPP convenes the HIV Prevention Community Planning Group (HPCPG) and the Ryan White CARE Act Title I Health Services Planning Council (PC) to assist them in fulfilling their statutory and regulatory obligations.

The Role of Community Planning Groups

The primary functions of the community planning groups are to identify priority target populations in need of services and to identify services and interventions to address those needs, and to assist the District in developing comprehensive plans for HIV prevention and care, treatment and support services.

In the case of the Ryan White CARE Act Title I Health Services Planning Council, community planning includes the establishment of priorities for service areas, the allocation of CARE Act Title I funds for service areas and the assessment of the efficiency of the administrative mechanism.

The memberships of the two groups differ, but generally reflect those persons at-risk for HIV or in need of services, providers, advocates, epidemiologists, behavioral and social scientists, government officials and other stakeholders. The planning bodies operate under federal guidance and requirements, with by-laws and written procedures, with many of the operational standards derived from mandates and guidelines developed by the Centers for Disease Control (CDC) and the Health Resource Services Administration (HRSA). The community planning process is mandated for jurisdictions receiving federal funds for HIV prevention and HIV/AIDS services.

In addition to these community planning bodies, the AHPP occasionally convenes stakeholder committees and workgroups to consult on the development of strategic plans or to advise on issues of particular emphasis.

The AHPP is also responsible for conducting oversight and coordination activities for this planning process, providing technical assistance as needed and facilitating the development and dissemination of key planning documents, including the comprehensive plans and the applications for funding. This requires careful coordination of resources and expertise obtained from AHPP staff, leaders and other members of the community planning bodies, as well as
contractors with specific expertise in technical writing, research, evaluation, behavioral and social science.

**What’s the Big Idea?**
Integrating Community Planning Processes

Efforts to coordinate planning for HIV prevention and Title I/II Ryan White CARE services have increased steadily. In addition, local care and prevention groups in several areas share planning resources and statewide care and prevention groups are currently conducting joint strategic planning or are considering doing so. Paralleling coordination at the local level have been recent steps toward joint planning at the jurisdiction level. In California, the statewide CPG and HIV Comprehensive Care Working Group recently voted to merge. In Chicago, a new HIV/AIDS strategic plan calls for the merger of the city’s CPG and HIV/AIDS Services Planning Council and for joint monitoring of HIV/AIDS care and prevention contracts.

CPGs and health departments continue to make changes in their planning structure to find the right “fit” for their jurisdiction and streamline the planning process. The most significant structural changes occurred in California, where fifty-six local groups were added to the existing single-group structure. In addition, during the fifth year of planning, California’s statewide CPG was merged with the state’s HIV/AIDS care planning group. Notably, most CPGs have restructured some or all of their committees to improve their efficiency.

Although they operate fairly independently, Title I and Title II planning bodies work together in pursuit of CARE Act goals to strengthen the service continuum for people living with HIV (PLWH) and ensure that funds are used to fill gaps in care. More practical benefits can include reduced administrative and planning costs and lessened duplication of effort.

Coordination efforts are driven by both grantee initiative and such CARE Act requirements as cross-title membership in planning groups and consistency across State and local comprehensive plans, and the joint work on the Statewide Coordinated Statement of Need (SCSN). Among the more visible areas of coordination is determining use of Title II AIDS Drug Assistance Program (ADAP) dollars in Title I areas. Other areas for coordination with Title II include State programs like Medicaid and substance abuse block grants. Tools to streamline planning and enhance services might be jointly developed, thus benefiting providers who are funded under both titles.
Coordination across Title I and Title II can occur on multiple levels, from less formal information sharing to more structured efforts such as: Cooperation on planning-related tasks (e.g., needs assessment, comprehensive plans)

Joint service-related tasks (e.g., design of data collection processes, standards of care, quality management, evaluation), and consolidation or even merger of planning bodies.

Making such collaboration work requires attention to differing legislative mandates for each title. Among these are the Title I focus of responsibility on local needs and the Title II focus on the consortium area or State.

Integrating Community Planning groups in a strategic, coordinated effort is key to creating a road map for the development of services and programs that mirror the complex issues surrounding HIV and AIDS in this region, while maximizing the impact of increasingly limited resources.

AGENDA

“A Conversation about HIV Community Planning”
Academy for Educational Development (AED)
1875Connecticut Ave .NW, Washington, DC.
Tuesday, December 20, 2005
2:00 to 6:30p.m.

I. Registration 1:30-2:00

II. Welcome and Purpose 2:00-2:15
Dr. Marsha Martin, Sr. Deputy Director, HIV/AIDS Administration

III. Vision for the Department of Health 2:15-2:30
Dr. Gregg Pane, Director, Department of Health

IV. Federal and National Perspective 2:30-3:00
Carol Thompson, White House Office of National AIDS Policy
Christopher Bates, DHHS Office of HIV/AIDS Policy

V. Addressing Unmet Need in HIV 3:00-3:30
Alexandra Zuber, AIDSAction
Dea Varsovczky, AIDSAction

VI. State and Local Perspective 3:30-4:30
Thomas Liberti, Chief, Bureau of HIV/AIDS for the Florida Department of Health

VII. Networking Session 4:30-5:10
“light refreshments”

VIII. Mini Planning Workgroups: 5:15-6:00
EMA-wide
Care &Treatment
Prevention
Sub-Populations
Data Needs

IX. Summary Statement & Next steps 6:00-6:30
GROUP 1: ELIGIBLE METROPOLITAN AREA (EMA)

The Washington, DC Eligible Metropolitan Area (EMA) is comprised of the District of Columbia, Northern Virginia, Suburban Maryland and 2 counties in West Virginia. This breakout session explored the jurisdictional issues that can arise when combining the planning processes of the Community Planning Group (CPG) and the Planning Council.

Question 1: Where are we now?

1st Issue brought up by participants or moderator:

Lack of advocacy; we are complacent

Recommendations: Increase advocacy for individuals infected and impacted by the disease

2nd Issue brought up by participants or moderator:

“We do not talk about prevention in the same way that we talk about the Titles…” inequities in distribution of grants; DC returned part of grant, and No. VA has a waiting list for primary care services of 3 months [?].

Recommendations: Get rid of inequities.

3rd Issue brought up by participants or moderator: There is no objective planning and service collaboration; disparate parts.

Recommendations: Bring all the parts together, although the challenge will be how to integrate all parties—i.e. DC, MD, NoVA, & WVA.

4th Issue brought up by participants or moderator: each party (Titles) goes “its own way”, disjointed, therefore the balance of concerns is unaddressed

Recommendations: To improve Title I’s central functioning process and pull all jurisdictions in—DC Title I, MD Title II, HOPWA from different places, prevention dollars.
Additional notes on this issue:
Peer advocacy-linked to the community
Put money into outreach programs
Increase status awareness to prevent new infections
Educate/prevention/disclosure

Question 2: Where do we need to go?

1st Issue: There is no successful resource guide/directory; clients do not always have access to the internet.

Recommendations: Establish comprehensive resource document across jurisdictions.

2nd Issue: We need to know what we're talking about—not anecdotal.

Recommendations: Look at all jurisdictions together in terms of epidemiological data.

3rd Issue: There are different laws in various jurisdictions that govern the collection, reporting, and analysis of epi data.

Recommendations: Must begin to make changes at the local and state levels across jurisdictions to pass laws that will change data requirements.

4th Issue: No universal protocols related to case management, substance abuse treatment

Recommendations: Develop universal protocols related to case management, substance abuse treatment, etc.

Additional notes on this issue: Prevention and services have a clearly outlined process that is distinct and specific. However, if we want to know what kinds of activities decrease the probability of HIV infection, we must design a powerful activity plan. But how do we know whether it is working? We need to be face-to-face with people. We need peer-advocacy in areas where there is a high level of drug use and sexual activity. For some reason that's not done. We must have incentives; grassroots peers are doing all the work.

Have a problem with CDC changes – its model also needs to tap into those not infected.

CDC guidelines to formulate programs focused on individuals already HIV+ means less focus on high risks. This is a disease model but is this where prevention should be focused?
Question 3: How will we get there?

1st Issue: How do we know who is really HIV infected?

Recommendations: Increase awareness to encourage people to get tested

2nd Issue: Stigma associated with being HIV+

Recommendations: Get information and education to the community through churches/schools/hospitals/doctors’ offices/clinics

3rd Issue: We need new innovative strategies

Recommendations: Posters/PSAs/public transportation campaigns

4th Issue: Cultural competency
   You want my address, cell phones cut off/transportation

Recommendations: Remember individual cultural/ language
   Eliminate barriers to get into care
   Literacy levels

Additional notes on this question:

What are we doing to decrease the rate of new infections?
What are we doing to help individuals know their HIV status?
What are we doing to get individuals into care?

NO.VA 2-3 months to get primary care service. Portability – need to get them into DC

MD – collaboration across; duplication of services

DC – nontraditional areas
   Hiring practices- hire people that have street knowledge

Focus on comprehensive strategies that involve CTR/Surveillance

Make decisions on data – not anecdotal

Question 4: How will we monitor our progress?

1st Issue: Administering Agency/ Government Entity

Recommendations: Citizen entities – advisory committees
2nd Issue: Continuance Evaluation

Recommendation: Look at data to adjust process as we go along

3rd Issue: Northern Virginia

Recommendation: Peer review – multidisciplinary team that includes the administration agency, nurse practitioner, social worker, and clients. The question we ask is, “Are we getting the services?”

Additional notes on this question: Lack of inclusiveness

Summary:
- make clients the focus
- come out of NW
- need to go to Barry Farms, Kenilworth, etc.
- make people feel it’s about them
- have not been inclusive of individuals involved
- we need nontraditional attitudes, locations
- innovative ideas
- prevention messages that are specific to populations being outreached to
- cultural awareness/messages/sensitivities
- portability
- triage approach
- nontraditional agencies
- hire people with street sense/diversity
- think outside the box
- link people into care
- communication literacy
- advisory committees
- new ways of monitoring
- evaluation programs
- peer review team
- no biases
GROUP 2: CARE & TREATMENT

This breakout session explored the provision of professional diagnostic, therapeutic and community-based support services. Participants discussed the care and treatment needs of HIV infected clients through-out the Washington, DC Eligible Metropolitan Area.

The facilitator began by asking the participants for discussion leading to issues they felt were important to explore. The group was asked to rate each issue in terms of where we are now. The rating scale was from 1 to 10 with 1 being the least provision and 10 being the best provision. Twelve issues were identified. The highest rating was 8 and the lowest rating was 1. From these twelve issues, the group selected six major issues to be addressed and from these six issues, the group determined the three most important/major issues. The ratings were not a factor on the issues selected. The groups' ratings provided the facilitator with information as to the issues the participants felt were crucial to develop in order to provide the most effective delivery of services and it also demonstrated to agency staff the participant’s current knowledge on state, local and federal regulations as it applies to various service categories.

There was a good mixture of participants comprised of providers, PWA's, and agency staff. The participants were asked to reach a consensus in their ratings and one rating was used for each issue (agency staff did not participate in this exercise). Due to time constraints, related issues could not be collapsed and recommendations were made only on the identified 3 most important/major issues.

There was good group participation and although all issues were discussed in detail the agency staff felt they are relevant to providing sound and efficient treatment and care.

**Issues**

(1) Related to follow up, other **resource availability and insurance** (Rating 8)

(2) **Cultural sensitivity** including the illiteracy (Rating 5)

(3) **Provider capacity** such as being able to meet the needs of the people they serve. (Rating 5)

(4) **Evaluation** (Rating 3) (+), (-) and were changes made as a result of findings or recommendations

(5) **Coordination of activities between** Jurisdictions to maximize services; systems of care where all clients can receive care; and funding to make it's all able to work (Rating 4)
(6) **Access to services**: it’s all about geography. Needs of services regardless to where the person lives, not just services but quality services. *(Rating 3)*

(7) Information and Dissemination for finding services such as whom, how, and where - types of information for public use. Ex: Resource Manual *(Rating 2)*

(8) **Information Technology**: making technology more user friendly – their focus being on XPRES. *(Rating 3)*

(9) **Standards of Care** no standard in place and by not having standards it’s difficult to assess and measure care. *(Rating 1)*

(10) **Integrating HIV into primary care** in general such as it private providers, hospitals etc. *(Rating 3),*

(11) **Plan for the un-plan able** such as in the case of loss of funding to a provider and/or waiting for funding notifications *(Rating 1)*

(12) Education to both staff and clients as it relates to treatment, counseling, testing and referral importance *(Rating 3)*

(13) **Care continuity** for keeping clients in care *(Rating 1)*

Recommendations
Making sure there are mechanisms in place to keep clients in care as much as possible, even when there is a change or cut in funding - like staggering the end of grant periods or making sure providers can sustain programs.

(14) **Provider Capacity** such as being able to meet the needs of the people they serve. *(Rating 5)*

Recommendations
Making sure providers have adequate capacity to serve clients with adequate access to care in their communities. Seek out other (new) providers/resources to participate in service provisions.

(15) **Standards of Care**: no standards in place and by not having standards it’s difficult to assess and measure care. *(Rating 1)*

Recommendations
Ensure standards are in place to direct care and be able to measure provider compliance.
GROUP 3: PREVENTION

Participants of this session discussed the community planning process. Key issues centered around programs which have as their principal purpose identifying people with HIV disease so that they may become aware of and may be enrolled in care and treatment services.

**Issues:**

Combining the two groups (Ryan White Planning Council and Prevention Planning Group).

There are challenges with the operation of both groups. Maybe the place to start would be to address the existing challenges.

(a) There is some overlap in the two groups. There are different rules governing the committees in various jurisdictions. For example in Maryland, the Prevention Group is run by the state but can't figure out the planning system in Virginia. Maybe in the District, the data committees could merge. However, the question becomes if merged would both groups have the same status.

(b) Data for competent planning is not available and without data you can't go anywhere. Felt that speakers from the plenary session were not that helpful to the collaboration process.

(c) The Ryan White Planning Council is mandated by legislative authority and the Prevention Planning Group has no comparable legislation. Could the data committees be merged?

(d) Be aware of the different types of data and what you want

(e) Group felt that the role of the Planning Council and its relationship to the Administration’s planning process is unclear.

(2) CPG Planning Group

(a) What is the process for joining the CPG Planning Group?

(b) CPG may not reflect the community.

© What is the procedure for becoming a CPG member?

(d) The Age group of CPG membership: 18 to 25 age group members. The concern is that there may not be enough people from specific groups.

Recommendation

Need to engage other “non-HIV” groups

There is a need to look at the membership demographics.
(3) Merging of DC Delegation and Prevention Planning Groups.

Recommendations
Must maintain parity, the prevention planning group cannot be relegated to a subcommittee.

Maybe go with the Ryan White model but be sure to maintain parity for the Prevention Group.
Each state could have “feeder” regional committees and send representatives to the main body.

(4) How to proceed

Look at the Florida model – they couldn’t merge all the people but could have representatives. Must keep in mind that the Ryan White Planning Group has mandates and that Prevention does not.
This has the potential to be a bureaucratic nightmare
There are no cross jurisdictional models for combining the groups

Recommendations
Have a Prevention Committee as part of the Ryan White Planning Council.
Possibly a 3 chair system – Prevention, Care and government
Set up an ad-hoc committee in each jurisdiction to plan the merger.

(5) People are going to have to look closely at each committee.

Recommendation
The District should be first because it has a Ryan White Planning Group and a Prevention Group. The District should be the model.

How to get plans done and meet timelines.

Recommendation
Submit an acceptable plan for the merger.

(7) People need to be made aware of what the CPG group does and what the budget is.

Recommendation
There is a need for cross education. The Care Group needs to understand the Prevention Group and vice versa.

(8) The merging of the data committees
**Recommendation**

The Chairs of each group should go to the other’s meeting and present monthly reports. They must keep in mind that both groups have different deliverables and time tables. Also have joint meetings. Meeting notes should be shared between the groups and data merging should be an early/first step.
GROUP 4: Sub Populations

In this session the needs of sub-populations such as substance abusers, transsexuals, ex-offenders where discussed. Participants shared their understanding of published data and the need for additional studies on sub-populations.

14 sub-populations were identified in the Washington, DC EMA: Offenders, seniors, youth, commercial sex workers, Latinos, MSM, transgender, women and children, IDU/substance abusers, homeless, immigrants, mentally ill, rural and physically disabled.

Issues

(A) Needs assessment

An EMA-wide needs assessment conducted for all sub-populations identified.

(B) Limited information

It is difficult to address the needs of the subpopulations with limited information. The Washington, DC EMA does not have enough information on the specific needs of the sub-populations. The populations have peculiar/unique needs that cannot be addressed in general terms. On a grading scale of A-F, we are at a D.

Recommendations

We need a comprehensive resource inventory conducted for all providers EMA wide inclusive of agencies not receiving funding from the administration. The resource inventory will inform us of the services being offered to the identified sub-populations.

Additional Notes

Of the 14 sub-populations identified the grade for most was D to F; however there was a few that received A to B. It was difficult to give a grade that included the entire EMA because the majority of participants were DC providers and consumers that did not have adequate knowledge about the populations were being served in the other jurisdictions.

Services for transgender received A+, Youth services D+, and Mental Health services F.

(C) EMA needs comprehensive data for all sub-populations

Recommendations

Analyze the current data we have collected
Collect additional data
(D) Program Evaluations of both Planning Council and Community Planning Group

No Recommendations

Additional notes on this issue:
Numerous sub-populations must target behaviors (i.e. unprotected sex)
Better collaboration between Bureau of Prisons, Department of Corrections, and HIV/AIDS Administration.
Collaboration needs to occur between DC Coalition for Homeless and HIV/AIDS Administration.
Lack of data and more funding needed.
Not enough housing available for women with children and individuals infected/affected with HIV/AIDS.

(E) Analyze current data and collect more data

No Additional notes on this question:

(F) Quality Assurance

Recommendations

Create outcome measures and indicators
Create effective monitoring
This breakout session provided an opportunity for participants to discuss the need for certain types of data to better inform the planning process. Discussion centered around generally accepted statistics on the status of HIV disease in and around the District of Columbia and the lack of hard data to support them.

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**Issues:**

(1) DC has the highest AIDS case in the nation. Do we have the data to support that?

Recommendations
None

(2) *Lack of useful data generated in timely manner*

Recommendations
None

(3) We need coordinated inter-jurisdictional data systems that work that include service utilization and program data (EPI and Express data)

Recommendations
None

(4) Is the data useful and is it integrated

(5) What do we collect?

(6) What is the purpose of collecting the data besides for money?

*Recommendation*

Comprehensive data that include patient level. Example Pap smear

**Additional notes on this issue:**

Complete data collection forms
Find out all available data per what is funded
Identify challenges to data collection and interpretation
Evaluate data available and systems in place for data integrity
**HIV DATA**

We need HIV data

HIV data needs to be evaluated

Recommendation
Increase trust in data, more trust from the community regarding data

(9) How do you back up the data?

(10) Prenatal DATA: How many HIV positive women give birth per year? CDC perinatal programs have been cut.

*Recommendations:*
*Birth Link with other data sources such as Maternal and Child Health and Medicaid data*
Integrated EPI Profile data
Data set from other sources TB, STD
How can we start collecting late entry to care data such as CD4 counts, different kinds of service utilization data?
country of origin to be collected
Non-deadline oriented planning process
Rapid response to emerging issues/trends. Example rapid testing in MSM

**Additional notes on this issue:**

Increase understanding of data/data literacy
Data on resource inventory