Report
to the Secretary
on
HIV/AIDS
in Racial and Ethnic Communities

submitted by the

National Minority HIV Working Group

February, 1999

In memory of

In October of 1996 James Abrams participated in the Native American Institute at the National Skills Building Conference, which was the beginning of the process that brought about this Report. He was one of the two individuals who presented the recommendations from the Native American Institute at the closing. In July 1997, he was selected to be a member of the National Minority HIV Working Group, a role he carried out until the HIV he fought so valiantly prevented him from carrying out his duties. In early 1998, James passed, marking the end of one more life due to this epidemic. Those who knew James will remember his indefatigable efforts as an advocate for the Native American community. His contributions to this document were many.

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Report
to the Secretary
on
HIV/AIDS in Racial and Ethnic Communities

HISTORY

I Statistics

The Centers for Disease Control and Prevention (CDC) started tracking the HIV/AIDS epidemic in June 1981, when an announcement was made regarding a rare form of cancer afflicting homosexual men. In 1987, HIV/AIDS was added as one of the priority health issues for the Office of Minority Health. At that time, some 40 percent of the individuals who had been diagnosed with AIDS were from racial and ethnic communities. As of June 1998, 665,357 individuals had been diagnosed with AIDS -- some 55 percent from racial and ethnic minority populations.

In 1998, CDC also reported that 42,084 cases of AIDS were diagnosed in the twelve months ended on June 30, 1998, which was a decrease from the 60,634 reported in the same period a year earlier. Of this number, 26,454 were among members of minority communities. This represents approximately 63 percent of the total AIDS cases reported in that period, even though minorities comprise approximately 25 percent of the total U.S. population. Of the cases diagnosed among adolescents and young adults (ages 13-24), 65 percent are from racial and ethnic populations. Today, nearly 80 percent of all women diagnosed with HIV and more than 80 percent of pediatric AIDS cases are among racial and ethnic individuals.

While the number of AIDS cases and deaths in the U.S. has declined in the past several years, the number of new HIV infections in the United States continues at an estimated 40,000 each year. The decrease in mortality and newly diagnosed AIDS cases has been very encouraging, but it has not been proportionate in racial and ethnic populations as in non-minority populations. Research shows that members of racial and ethnic communities, especially women, youth and heterosexuals have now begun to bear the brunt of the epidemic. These populations have been historically underserved, have had limited access to services and treatment, and have traditionally not benefited at the same level from current prevention, services and research efforts. Prevention funding, by the Federal government’s own admission, is not proportionate to the caseload that the various populations face. Research shows that minorities are less likely to be prescribed triple-drug treatment combinations, and until recently, participation rates by minorities in clinical trials has lagged compared to those of non-minority males.

II Background

In 1989 the Office of Minority Health (OMH) sponsored the nation’s first national minority HIV conference, a full two years after adding HIV/AIDS to its priority health concerns. This conference focused on HIV prevention, services and research issues and how they impacted minority communities. Prior to 1989, the CDC had sponsored a series of national prevention conferences focusing on racial/ethnic communities, which were essential in providing the tools necessary for racial and ethnic communities to address the growing epidemic in their communities. The conferences also assisted Federal agencies in gaining and understanding of the unique concerns and issues to be addressed in order to successfully implement prevention, service and research programs in minority communities.

In 1991, OMH sponsored a series of eight regional minority HIV/AIDS conferences. In 1994, OMH sponsored, "Breaking Barriers, Building Bridges: The First National Congress on the State of HIV in Racial and Ethnic Communities." As part of this conference, participants and agencies were asked to develop "action plans" to implement when they returned to their homes and offices. In her plenary speech, the Secretary committed the Department to follow-up activities, and assigned OMH as the lead in developing them.

In response, OMH co-sponsored the Racial/Ethnic Institutes, which were part of the National Skills Building Conference in 1996. At these Institutes, participants presented 165 recommendations which they believed needed to be implemented in order to meet the needs of racial and ethnic populations. One specific recommendation focused on the need to develop a racial/ethnic-specific national plan to address HIV-related issues. In the view of the Institute participants, despite the continuing disproportionate impact of HIV on racial/ethnic populations, no such plan existed.

III Report Development Process

In March 1997, OMH approached the Co-chairs of the 1996 Racial/Ethnic Institutes to assist OMH in identifying the steps that would follow. The Co-Chairs asked OMH to develop a process which would allow community representatives to interact with federal agency staff and arrive at a National Plan, including specific action steps to address these recommendations made in 1996. OMH believed it important to follow the recommendation of the Co-Chairs and attempt to address as many of the recommendations as possible, involving the community and the relevant HHS agencies in the development of responses.

Working with the co-chairs and through a national nominating process, approximately 60 individuals were identified as potential members of the working group. The co-chairs recommended to the Deputy Assistant Secretary for Minority Health 20 individuals who they believed should be asked to be part of the working group. OMH and the Co-chairs were careful to ensure representation in terms of race, ethnicity, HIV status, sexual orientation, professional background and region. Individuals were nominated from across the United States, and based on established criteria (e.g., knowledge of issues, previous experience with planning documents), were asked to participate. The working group was equally balanced among the four racial/ethnic groups, as were the co-chairs. Each person was assigned to a sub-committee -- prevention, services and research -- based on their prior experience and interest.

OMH also requested that HHS operating divisions carrying out HIV/AIDS activities appoint a person to represent their agency on the Working Group. At the request of the Deputy Secretary the agency heads for the Agency for Health Care Policy and Research, Centers for Disease Control and Prevention, Food and Drug Administration, Indian Health Service, Health Resources and Services Administration, National Institutes of Health, and the Substance Abuse and Mental Health Services

Administration appointed staff to participate in the process. In addition, the Office of HIV/AIDS Policy and the Office of Women's Health were invited to participate in Working Group meetings.

The first full meeting of the Working Group and federal representatives was held in September 1997 in Miami, Florida in conjunction with the United States Conference on AIDS. It was apparent to those present that some of the recommendations were no longer applicable due to policy changes within HHS, new federal laws, or new programmatic activities by the agencies. At this meeting, the recommendations were refined and reduced from 165 to approximately 75. It was agreed that OMH would take the lead in developing potential action steps to implement the 75 recommendations, and then reconvene the Working Group and Federal representatives to discuss specific action steps.

In April 1998, OMH reconvened the Working Group and Federal representatives to discuss the 75 recommendations. Prior to the meeting, the Deputy Secretary requested each agency head send "high level individuals" to this meeting to represent their agencies, in order to ensure that decisions about specific actions steps could be made at this meeting, and that agency commitments would be honored. This was in addition to agency representatives who had been involved in the process since 1997.

Given time constraints, the Working Group was asked to identify their priority recommendations to ensure that those would be discussed during this meeting. Approximately 25 recommendations were identified, with the understanding that the remaining recommendations were still of concern to the Working Group. During the April meeting, some 75 "action steps" were developed and agreed to by agency representatives as appropriate to implement in order to address the recommendations. These "action steps," are contained in this Report to the Secretary.

The original 165 recommendations, which served as basis for discussions between the working group and Federal representatives, are presented for historical purposes in Appendix C. In addition, those recommendations discussed in detail during the April 1998 meeting are marked with an asterisk. It must be noted that several of the remaining recommendations are themselves out of date or have been superseded by federal law or Departmental policy.

IV Action Steps

The Action Steps contained in this Report to the Secretary are those which were agreed to by Federal agency representatives during the April 1998 meeting. During this meeting, each federal agency was represented at the table while each recommendation was discussed. Federal agency representatives were appointed by their agency head, at the request of the Deputy Secretary, to represent their agency at these Working Group meetings. The interaction at the meeting led to a better understanding on the part of the agencies of the needs of racial and ethnic communities and to a better understanding on the part of the minority community of the possibilities and limits in which the agencies must operate. In addition, the meeting gave a better understanding by the agencies of their sister agencies' programs and priorities. It was with good faith and trust built over many years of working in collaboration with the Office of Minority Health that community representatives were able to engage in an open, honest dialogue with the Federal agency representatives.

V Relationship to Other Departmental HIV/AIDS Activities

This Report to the Secretary must be placed in the context of other HIV/AIDS activities currently being implemented by the HHS. These include the Congressional Black Caucus Initiative, the HHS Initiative to Eliminate Racial and Ethnic Disparities in Health, and the People of Color Activities at the Center for Disease Control and Prevention.

Congressional Black Caucus Initiative

Under the leadership of the Congressional Black Caucus, Congress appropriated an additional $156 million in funding in FY 1999 specifically focusing on the HIV/AIDS needs of African American and other racial/ethnic communities. This funding was in large part in response to the call for a state of emergency in the African American community regarding HIV/AIDS. While a state of emergency was not declared, the HHS recognized a "persistent and ongoing health crisis" among African Americans and other minorities and has developed a series of programmatic responses to address this crisis.

HHS Initiative to Eliminate Racial and Ethnic Disparities in Health

On February 21, 1998 the President committed the Nation to an ambitious goal: by the year 2010, eliminate the disparities in six areas of health status experienced by racial and ethnic minority populations while continuing the progress we have made in improving the overall health of the American people. HHS is leading this effort to eliminate disparities in health access and outcomes in: 1) Infant Mortality; 2) Cancer Screening and Management; 3) Cardiovascular Disease; 4) Diabetes; 5) HIV Infection and; 6) Child and Adult Immunizations. As part of this effort, CDC is spearheading a working group to analyze current efforts and to recommend targeted technical input on HIV/AIDS programming in communities of color. The National Minority HIV Working Group understood the implication of the Congressional Black Caucus Initiative and has strived to take new funding and program priorities into consideration as it develops its report to the Secretary.

CDC People of Color Activities

CDC is currently instituting a series of activities that focus on black, Hispanic, American Indian and Alaska Native, and Asian and Pacific Islander communities which involves identifying and removing barriers to successful HIV prevention. CDC is utilizing a series of meeting with internal and external consultants to review and analyze current CDC programmatic priorities and mechanisms for working with racial and ethnic communities.

All four efforts described here (this Report to the Secretary, the Congressional Black Caucus Initiative, the HHS Initiative to Eliminate Racial and Ethnic Disparities in Health, and the CDC People of Color Activities), complement each other. This Report to the Secretary focuses equally on all four major racial/ethnic groups (Black, Hispanic, Asian and Pacific Islander, American

Indian/Alaska Native) and has had as its hallmark the need to address all four groups equally -- thus following OMH's legislative mandate. The other initiatives have been developed partly in response to the extreme impact that HIV/AIDS is having on the Black community, and thus most of their efforts are aimed at addressing the specific needs of this community.

This Report to the Secretary, and the action steps its contains, focus on three main areas (technical assistance, information dissemination, and inclusion). The other initiatives go beyond this and contain specific programmatic initiatives aimed at specific target populations (African Americans, Hispanics/Latinos, Asian/Pacific Islanders and Native Americans/Alaska Natives). Therefore, action steps contained in this Report complement the activities described in the other initiatives and which in turn complement the action steps contained herein.

In addition, the Report to the Secretary (originally the Interim National Minority HIV Plan) was used, in part, as a basis for the development of the other activities. Major portions of this Report to the Secretary are included in the Eliminating Racial and Ethnic Health Disparities Initiative initial report to the Secretary. Similarly, the activities contained in the CBC Initiative complement the actions steps contained in this Report to the Secretary. Finally, one of the action steps agreed to by CDC and included herein involves the inclusion of Working Group members in the CDC People of Color Activities working groups.

The four efforts are each necessary and address specific concerns of racial/ethnic communities. The challenge is to ensure that coordination of efforts and a sharing of information occurs on an ongoing basis. With OMH's role as the lead in following the implementation of the action steps contained in this Report, and the degree of participation in all four initiatives, the potential for this coordination and collaboration is great. OMH is represented on the CBC Initiative Implementation Group, the Eliminating Health Disparities in Racial and Ethnic Communities Working Group and National Minority HIV Working Group members will be part of the CDC People of Color Activities group.

Because of the time frame in which this Report has been developed (the first meeting of the working group was convened in September 1997), several of recommendations and actions steps are already being addressed by the agencies. In addition, it is possible that several have become obsolete and thus are no longer appropriate for consideration. However, they are still included in this Report so that the Department may report back on activities which were implemented to address them, or provide information as to why a specific recommendation is no longer appropriate (e.g., needle exchange).

Preamble

This and the issue-specific preambles were developed by the members of the National Minority HIV Working Group during the April 6-7, 1978 meeting and were read prior to the discussion at the meeting of April 6-7, 1998. The preambles represent the views of the Working Group and provide context to the discussions that followed.

> "We want to share our passion and concern for what constitutes a state of emergency for people of color communities. The way federal, state, local and communities currently conduct business relative to the HIV/AIDS pandemic in these communities is no longer acceptable.
>
> In the spirit of collaboration, we want the next day and half, that together we create new systems of responses to communities of color.
>
> Given this urgency, we need to redefine how to address the needs of each community in flexible and specific ways. Toward this end, we believe in the need for innovative and creative means which are measurable, specific and time-phased that allow for flexible responses and accountability within coordinated linkages between communities and inter/intra agencies."

Issue Areas

I Prevention

Prevention Preamble

> "In the spirit of collaboration shown at this meeting, we would like to express our concern that prevention and intervention strategies that discuss primary and secondary prevention to each community, African-American, Hispanic, American Indian and Asian and Pacific Islander, be developed regardless of the lack of epidemiological data.
>
> There is a need for an ongoing collaboration between communities of color with federal, state and local agencies. In addition, an appropriate level of resources—legislative, funding and human resources—is critical to the success of prevention efforts. While we applaud the spirit behind the Community Planning Process, it is time to reevaluate its effectiveness in working with communities of color.
>
> Our goal here is to strengthen the partnerships between our communities and the federal agencies represented so that we can prevent the continuing spread of HIV among all racial and ethnic groups."

Prevention Action Steps

A. HHS Initiative to Eliminate Racial and Ethnic Disparities in Health

(1) CDC is taking the lead on HHS activities on the HHS Initiative to Eliminate Racial and Ethnic Disparities in Health as it relates to HIV. As CDC takes steps to implement the initiative, it will make information available to minority communities, community-based organizations (CBOs) and AIDS Service Organizations (ASOs) regarding activities that are ongoing and how to provide input. This information will include updates on the establishment of ethnic-specific committees.

Agency: CDC

Time line: 6 months

Recommendation: Prevention P20

(2) CDC is in the process of recruiting consultants to assist with the various activities related to its People of Color Initiative. As this process progresses, CDC will make available information regarding how the consultants are selected and how community members can be included in that process.

Agency: CDC

Time line: 6 months

Recommendation: Prevention P20

(3) Individual members of the National Minority HIV Working Group will be selected to join the committees assisting CDC on the Presidential Initiative on Racial and Ethnic Health Disparities and the People of Color Initiative. As to the African American committee, a member of the Working Group will be selected at the earliest possible opportunity. CDC will seek the input from the National Minority HIV Working group and the Presidential Advisory Board on HIV in the development of activities under the Presidential Initiative.

Agency: CDC

Time line: 6 months

Recommendation: Prevention P20

(4) Other HHS Operating Divisions (OpDivs) will collaborate with CDC in the development and implementation of HIV activities related to the Presidential Initiative on Racial and Ethnic Health Disparities. HHS OpDivs will also assist in the dissemination of information on the Initiative Process and in the collection of input from the community.

Agency: HHS OpDivs

Time line: 12 months

Recommendation: Prevention P20

B. Coordination of HIV Prevention and Substance Abuse

(1) The Substance Abuse and Mental Health Services Administration (SAMHSA) will begin the development of an HIV/AIDS Strategic Plan during fiscal year (FY) 1998, which will include interagency coordination between HIV and substance abuse prevention and treatment. The process will include a mechanism for coordinating activities with other OpDivs. SAMHSA will disseminate information on the planning process, how the community can provide input and when the completed plan will be made available for comment.

Agency: SAMHSA

Time line: 12 months

Recommendation: Prevention P20

(2) SAMHSA will carry out a series of regional meetings in FY1998, where community representatives will have an opportunity to interact with SAMHSA staff regarding programs. SAMHSA will coordinate with the OMH Resource Center so that minority communities, CBOs and ASOs that engage in HIV Prevention and Service program may have an opportunity to attend these regional meetings.

Agency: SAMHSA

Collaborating Agency: OMH

Time Line: 6 months

Recommendation: Prevention P9

(3) SAMHSA and collaborating OpDivs will disseminate information on the interagency collaboration arising out of the Preventing Substance Abuse and HIV: A National Leadership Forum (Tampa meeting), held August 14-16, 1996. Information to be disseminated will include the current status of action items arising out of that meeting and ongoing activities where minority CBOs and ASOs can provide input. Collaborating OpDivs will also disseminate their efforts in this area and make available contact information for the community.

Agency: SAMHSA

Collaborating agency: OMH

Time line: 6 months

Recommendation: Prevention P1

(4) SAMHSA's Center for Substance Abuse Prevention (CSAP) has materials on HIV Prevention and Substance Abuse that will be made available to the OMH Resource Center for dissemination to minority communities, CBOs and ASOs that carry out HIV activities.

Agency: SAMHSA

Collaborating agency: OMH, CDC

Time line: 6 months

Recommendation: Prevention P1

(5) The National Institutes of Health (NIH), through HIVNET, a web-based system, will disseminate information to the public on issues relevant to HIV/AIDS prevention. NIH will coordinate with OMH on making available the information on HIVNET to minority communities, CBOs and ASOs.

Agency: NIH

Collaborating agency: OMH

Time line: 6 months

Recommendation: Prevention P1

C. Grant Administration

(1) HHS will develop a mechanism by which minority communities, CBOs and ASOs can obtain information regarding the criteria for evaluating proposals submitted through the grant process. The information will include the weight given the various components of the proposal, including the cultural competence of the organization requesting funding. This information will be provided on an ongoing basis in addition to what is currently provided through requests for proposals (RFPs).

Agency: Office of Minority Health (OMH)/Office of the Secretary (OS)

Collaborating agency: HHS OpDivs

Time line: 12 months

Recommendation: Prevention P11

(2) HHS will take steps to ensure that the composition of grant application review committees more closely reflect the targeted population of the RFP. In addition, review committee members shall demonstrate experience in proposal review, knowledge of HIV and related issues, and/or competency in the delivery of AIDS prevention or health services.

Agency: Office of Minority Health (OMH)/Office of the Secretary (OS)

Collaborating agency: HHS OpDivs

Time line: 12 months

Recommendation: Prevention P11

D. Technical Assistance

(1) Technical assistance (TA) areas that CDC provides to Community Planning Groups (CPGs) will include continued and expanded use of surrogate markers as identified in the HIV Prevention Indicators Project (1996), including surrogate markers that may be more prevalent in a particular population, such as relevant epidemiological and surveillance data, census data and others.

Agency: CDC

Time line: 6 months

Recommendation: Prevention P9

(2) SAMHSA will collaborate with CDC to provide Community Planning Groups (CPGs), minority communities, CBOs and ASOs with information on substance abuse surrogate markers that will assist in devising strategies for HIV prevention.

Agency: SAMHSA

Collaborating agencies: OMH and CDC

Time line: 6 months

Recommendation: Prevention P1

(3) CDC currently provides technical assistance to CPGs on a wide variety of issues. The TA topics that CDC will provide to CPGs will include information and strategies for HIV prevention among minority gay, lesbian, bisexual, transgender and questioning youth.

Agency: CDC

Time line: 12 months

Recommendation: Prevention P6

E. HIV Prevention Community Planning Groups

(1) CDC will make available to CPGs, minority communities, CBOs and ASOs statistical and funding data that may assist in the development of priorities at the local level. This data includes, but is not limited to, funding allocations by population and racial/ethnic background.

Agency: CDC

Time line: 8 months

Recommendation: Prevention P14 (P17 incorporated)

(2) CDC will provide CPGs, minority communities, CBOs and ASOs demographic and qualitative data regarding CPG composition. This data has to be compiled by health departments funded by CDC. This data will be enhanced by CDC to include qualitative data regarding the effectiveness of CPG members from communities of color.

Agency: CDC

Time line: 6 months

Recommendation: Prevention P14 (P17 incorporated)

(3) CDC is in the process of revising the Community Planning Guidance, which will be available for comment later in 1998. CDC will disseminate information regarding the availability of the guidance for comment through the *Federal Register* and other means so that minority communities, CBOs and ASOs may provide comment.

Agency: CDC

Time line: 12 months

Recommendation: Prevention P14 (P17 incorporated)

(4) SAMHSA's Block Grant Project Officers will encourage the staff of the Single State Agency on Substance Abuse to participate actively in the CPGs to encourage coordination of activities and funding. This will be particularly helpful in those states where there is an HIV set-aside as part of the block grant.

Agency: SAMHSA

Time line: 12 months

Recommendation: Services S12

F. Adolescent and School Health

(1) CDC's Divisions of HIV/AIDS Prevention (DHAP) and Adolescent and School Health (DASH) will make available to CPGs, minority communities, CBOs and ASOs information on current funding allocations for youth. DASH will also provide information on what activities are carried out by grantees at the state level.

Agency: CDC

Collaborating agency: OMH

Time line: 6 months

Recommendation: Prevention P6

II Research

Research Preamble

> "The concept of research is often intimidating to communities of color, with a legacy that is not positive and presents unique challenges to the participation of these communities in all aspects of the research process. Traditional research methodologies do not incorporate or validate cultural and community norms. However, the research of today will set the standards for the interventions and treatments of tomorrow.
>
> Therefore, it is imperative that HIV-related research ensure the participation of communities of color in order to more effectively serve them. Research activities should be conceptualized and implemented in a culturally and linguistically competent manner, including the review process leading to grant allocations, the administration of research programs and the dissemination of research findings."

Research Action Steps

A. Research Agenda

(1) HHS OpDivs will take proactive steps to obtain input from minority communities, CBOs and ASOs in the development of their research agenda. This will include the incorporation of the action steps included herein into their individual agendas and providing information to the general public regarding mechanisms for providing input into the research agendas.

Agency: DHHS

Collaborating agency: NIH, CDC, SAMHSA and HRSA

Time line: 12 months

Recommendation: Research R9

(2) DHHS agencies will collaborate and coordinate in their processes when establishing research agendas by informing each other of meetings and activities related to the development of their own research agendas.

Agency: DHHS

Collaborating agency: NIH, CDC, SAMHSA and HRSA

Time line: 12 months

Recommendation: Research R9

(3) NIH is currently working on the development of the research agenda for FY 2000, which includes regular meetings of a working group that provides input on the agenda process. NIH will make information available to minority communities, CBOs and ASOs regarding the composition of this working group and what is necessary to provide input to this process.

Agency: NIH

Time line: 6 months

Recommendation: Research R3

B. Behavioral Research

(1) CDC and NIH will explore the need for expanding the number and scope of research on behavioral interventions in minority communities. This analysis will include the extent to which current research activities are addressing the need to identify successful behavioral interventions aimed at members of racial and ethnic communities. Additional activities will be coordinated with academic institutions that serve large numbers of members of racial and ethnic communities.

Agency: CDC

Collaborating Agency: NIH

Time line: 12 months

Recommendation: R7

(2) The Office of Technology Assessment (OTA) published a document consisting of a literature review on HIV behavioral interventions targeting racial and ethnic communities. This document highlighted the lack of research on behavioral interventions targeting members of racial and ethnic communities. CDC and NIH will assist in making this report available to minority communities for use in the development of a behavioral research agenda.

Agency: CDC

Collaborating Agency: NIH

Time line: 12 months

Recommendation: R7

(3) CDC will examine the need for additional behavioral research on risk behaviors in specific racial/ethnic populations. In ascertaining the specific areas for study, CDC will seek the input of CPGs and minority CBOs and ASOs in developing research agendas for future years.

Agency: CDC

Time line: 12 months

Recommendation: Research R3

C. Surveillance and Epidemiology

(1) The Public Use Data Set contains valuable epidemiological information on HIV. These data, although available, may require additional technical assistance in order to be used by individuals unfamiliar with the data set. CDC will work with CPGs, minority communities, CBOs and ASOs on ways to make the Public Use Data Set more user-friendly.

Agency: CDC

Time line: 12 months

Recommendation: Research R3

(2) To the extent that specific cultural attributes may impact on the effectiveness of data collection, CDC will work proactively with minority communities, CBOs and ASOs to develop and implement data collection instruments and methodologies for specific populations.

Agency: CDC

Time line: 12 months

Recommendation: Research R3

(3) CDC and NIH will develop ways of working with state and local governments to encourage health care professionals to gather more specific demographic information regarding risk behavior, especially complete, self-reported information on race, ethnicity, tribal affiliation and national origin.

Agency: CDC

Collaborating Agency: NIH

Time line: 12 months

Recommendation: Research R3

(4) To the extent that specific populations are not widely represented in statistics, NIH and CDC will over sample specific populations in some studies to achieve statistically significant results. The first step in this activity will be the development of standardized criteria for determining which populations may require oversampling.

Agency: NIH

Collaborating Agency: CDC

Time line: 12 months

Recommendation: Research R6

D. Inclusion in Clinical Trials

(1) NIH will review its current target populations listed in upcoming RFPs and announcements to enhance the inclusion of youth in existing and new clinical trials. NIH will include transgenders as a population to be included in clinical trials.

Agency: NIH

Time line: 12 months

Recommendation: Research R4

(2) NIH will provide minority communities, CBOs and ASOs with data on the participation of members of racial and ethnic populations in their existing and new clinical trials. NIH will also use this data to explore new ways of increasing participation of members of racial and ethnic communities in clinical trials.

Agency: NIH

Time line: 12 months

Recommendation: Research R4

(3) FDA regulations require that informed consent forms used in the recruitment of participants in clinical trials be in language that can be understood by the participants. This regulation is clarified in guidance related to new drug applications. FDA will make this guidance available for comment by members of minority communities.

Agency: FDA

Time line: currently

Recommendation: Research R4

(4) NIH will develop new and creative ways to work with minority communities, CBOs and ASOs regarding the availability of clinical trials and the process for the recruitment of clinical trial participants. NIH will explore the use treatment advocates and peer educators to assist in this effort.

Agency: NIH

Time line: 12 months

Recommendation: Research R7

E. Dissemination of Findings

(1) NIH will work with their contractors to expand the availability of research findings to the participants in clinical trials and the general public in non-technical language. To the extent possible, NIH will also ascertain the need for developing materials in languages other than English.

Agency: NIH

Time line: 12 months

Recommendation: Research R4

(2) NIH routinely collects specific data on the participants in clinical trials, which are not generally made available to the public. NIH will compile and extract population specific data on existing and new clinical trials and provide findings to minority communities, CBOs and ASOs.

Agency: NIH

Time line: 12 months

Recommendation: Research R6

(3) NIH will conduct an analysis of the need to develop materials in various languages containing findings from clinical trial research. Materials will be produced in those instances where there is demand for materials in languages other than English.

Agency: NIH

Collaborating agency: CDC and HRSA

Time line: 12 months

Recommendation: Research R7

(4) NIH will explore the use of peer advocates for the dissemination of clinical trial information to participants. Whenever possible, peer advocates will be recruited to assist in the dissemination of clinical trial findings.

Agency: NIH

Collaborating agency: CDC and HRSA

Time line: 12 months

Recommendation: Research R7

(5) SAMHSA will disseminate information and findings of their Exemplary Models initiative, which evaluates substance abuse prevention projects and makes them available for replication. HRSA will disseminate similar information regarding the Models That Work initiative, which encourages the replication of effective community-based primary care models.

Agency: SAMHSA

Collaborating agency: HRSA, OMH

Time line: 12 months

Recommendation: Research R9

(6) CDC will continue to identify, recognize, support and make available information on reputationally strong HIV prevention models and programs.

Agency: CDC

Timeline: 12 months

Recommendation: Research R9

F. Health Care Services Research

(1) The Agency for Health Care Policy and Research (AHCPR) is in the process of completing the Health Care Services Utilization Study (HCSUS), which will provide data on the use of health care services by people living with HIV, including members of racial and ethnic communities. The findings of this study will be made available six (6) months after its completion. AHCPR will take steps to ensure that minority communities, CBOs and ASOs have access to this information.

Agency: AHCPR

Time line: FY 1999

Recommendation: Research R6

G. Alternative Medicine

(1) The NIH Office of AIDS Research (OAR) will seek ways of expanding collaboration with the NIH Office of Alternative Medicine, in particular in the development of activities specific to racial and ethnic communities.

Agency: NIH

Time line: 12 months

Recommendation: Research R7

H. Research Nomenclature

(1) HHS OpDivs currently use specific nomenclature in the development of research protocols and program activities, but some of the terms are not used consistently across all the OpDivs. The OpDivs will coordinate the use of language used in research and program development so that there can be a common understanding of what the terms mean, especially primary and secondary prevention.

Agency: NIH

Collaborating agency: CDC, SAMHSA and HRSA

Time line: 12 months

Recommendation: Research R7

I. Grant Administration

(1) NIH will expand the availability of information on the structure and operations of clinical and behavioral research activities. NIH will also seek new and creative ways, including the use of treatment advocates and peer educators, to provide information on NIH operations to members of minority communities.

Agency: NIH

Time line: 12 months

Recommendation: Research R4

(2) HHS OpDivs will work to ensure the participation in grant review panels individuals who have specific knowledge of the target community in all levels of the grant review process.

Agency: DHHS

Collaborating agency: NIH, CDC, SAMHSA and HRSA

Recommendation: Research R9

(3) All HHS OpDivs will take steps to standardize and implement the use of culturally competent, appropriate and sensitive instruments to capture data.

Agency: DHHS

Collaborating agency: NIH, CDC, SAMHSA and HRSA

Time line: 12 months

Recommendation: Research R9

J. Capacity Building

(1) HHS agencies will work together to find ways to strengthen academic institutions serving large numbers of members of racial and ethnic communities to increase the number of health care providers and researchers.

Agency: DHHS

Time line: 12 months

Recommendation: Research R9

III Services

Services Preamble

> "We, the Services Issues Committee, believe that the Department of Health and Human Services, territorial, state and local health departments should ensure that adequate and comprehensive HIV care should be made available and provided in all communities of color, regardless of health status, income, immigration status, language ability or level of education. Access to culturally appropriate care and its provision must be designed with the collaboration of each community."

Services Action Steps

A. Program Data

(1) HRSA will provide information on how Ryan White Titles III/IV activities are impacting racial and ethnic communities. This information will be made available to minority communities, CBOs and ASOs for use in determining what services are available in a particular community.

Agency: HRSA

Time line: 12 months

Recommendation: Services S18

(2) One of the primary questions regarding the distribution of service funding in minority communities is the actual number of minority subgrantees currently receiving this funding and the funding levels being distributed. HRSA will develop a list of minority subgrantees divided by Title and will make it available to Planning Councils and other entities that may need this information.

Agency: HRSA

Time line: 12 months

Recommendation: Services S18

(3) HRSA will conduct an evaluation of HIV service activities of its Ryan White Titles to ascertain the impact of HIV related services in minority communities. Based on the results of this evaluation, HRSA will seek ways and developing mechanisms to develop information on models and of addressing unmet needs in racial and ethnic communities.

Agency: HRSA

Time line: 12 months

Recommendation: Services S18

B. Grievance Procedures

(1) HRSA will establish a mechanism for providing information regarding the currently available and projected grievance procedures available at the state and local level. This information will be accompanied by technical assistance on the most effective way of having grievances addressed and information on what alternative means are available to consumers and to the public in general in situations where there are conflicts.

Agency: HRSA

Time line: 12 months

Recommendation: Services S18

C. Capacity Building

(1) HRSA will provide evaluation information regarding Ryan White CARE Act-related technical assistance activities to Ryan White Planning Councils, minority communities, CBOs and ASOs. HRSA will use this information in order to conduct an assessment of the need for capacity building activities regarding minority communities.

Agency: DHHS

Collaborating agency: CDC and HRSA

Time line: 12 months

Recommendation: Research S18

(2) HRSA will provide expanded and additional TA on the legislative requirements of the CARE Act so that minority communities will have the information available on the roles and responsibilities of HRSA, grantees and subgrantees.

Agency: HRSA

Time line: 12 months

Recommendation: Services S18

D. Program Nomenclature

(1) The various HHS Operating Divisions use the terminology developed by the Office of Management and Budget (OMB) to determine whether an individual is a member of a minority community. In terms of what constitutes a minority CBOs or ASOs, the definition is not clearly stated for all the HHS agencies. This has created some confusion as to the exact criteria for applying for funding earmarked for minority CBOs and ASOs. The HHS OpDivs will take steps to standardize the definition of minority CBO and ASO.

Agency: Office of Minority Health (OMH), Office of the Secretary (OS)

Collaborating agency: CDC and HRSA

Time line: 12 months

Recommendation: Research S18

(2) HRSA has developed a specific enumeration of the requirements for effective case management. This information is contained in a report developed by HRSA, which will be made available to minority communities, CBOs and ASOs along with specific technical assistance regarding the implementation of the case management model.

Agency: HRSA

Collaborating agency: SAMHSA

Time line: 12 months

Recommendation: Services S5 and S14

(3) Programs serving communities of color are not monitored closely enough to determine whether services are being delivered in a consistent basis. HRSA will seek to develop mechanisms to monitor program activities to ensure that programs are being delivered in a consistent and effective manner and will develop new guidance that will specify programmatic requirements. In the development of these mechanisms and guidance, HRSA will actively seek input from minority communities, CBOs and ASOs.

Agency: HRSA

Time line: 12 months

Recommendation: Services S5 and S14

E. Substance Abuse Treatment

(1) SAMHSA will provide minority CBOs and ASOs with information regarding the operations of the Federal Substance Abuse Treatment and Mental Health Services Block Grant. This information will include who administers the funding at the state level and the guidelines for the calculation and administration of the 5% set-aside for HIV activities.

Agency: SAMHSA

Time line: 6 months

Recommendation: Services S12

(2) SAMHSA will provide other OpDivs CBOs and ASOs with the list of Block Grant Project Officers and their assigned states. DHHS OpDiv staff will share information on program staff in the various states as a means of increasing communication and collaboration at the state level.

Agency: DHHS

Time line: 2 months

Recommendation: Services S12

(3) SAMHSA is currently reviewing, along with OMB, the regulations that control the disbursement and administration of the Block Grants. This review will include the extent and types of information that SAMHSA can request from the states regarding Block Grant administration. As part of this review, SAMHSA will seek ways of obtaining community input regarding Block Grant and HIV set-aside administration.

Agency: SAMHSA

Time line: 12 months

Recommendation: Services S12

(4) One of the issues being reviewed as part of the Block Grant regulation review will be the practice of using substance treatment funds in lieu of other available funding. SAMHSA will review this issue of supplantation of funds as part of the process of updating block grant regulations.

Agency: SAMHSA

Collaborating agency: HRSA

Time line: 12 months

Recommendation: Services S12

(5) SAMHSA has information available regarding the standard of care to be used for substance abuse treatment programs. This information is contained in the Treatment Improvement Protocols (TIPs) that SAMHSA makes available to treatment providers. These are currently available in English.

Agency: SAMHSA

Time line: 12 months

Recommendation: Services S12

F. Services for American Indians/Alaska Natives

(1) Due to jurisdictional limitations, the Indian Health Service (IHS) provides care to American Indians/Alaska Natives on Indian Reservations, while HRSA provides care to qualifying American Indians/Alaska Natives who live outside the reservation. These limitations adversely impact American Indians who move from the reservation and later return. HRSA and IHS currently collaborate on specific projects. This informal collaboration will be expanded by creating staff collaboration mechanisms. Among the issues to be developed as part of this formal collaboration will be a continuum of care for American Indians/Alaska Natives who move to and from the reservations.

Agency: HRSA

Time line: 12 months

Recommendation: Services S5 and S14

G. AIDS Drug Assistance Program (ADAP)

(1) HRSA currently receives voluntary monthly ADAP reports from certain states, including utilization statistics. Although these reports contain information that can be used for trend analyses of ADAP utilization. HRSA will provide what information is available to interested parties.

Agency: HRSA

Time line: 12 months

Recommendation: Services S5

(2) HRSA will provide information on the utilization of State ADAP programs and technical assistance on how to use the information and statistics regarding ADAP to CBOs and ASOs.

Agency: HRSA

Time line: 12 months

Recommendation: Services S5 and S14

H. Standards of Care

(1) HRSA and several other entities have conducted studies that have looked at compliance issues for people living with HIV. Among these is the Women’s Natural History Study, which contains information regarding compliance among women. HRSA will make this information available to minority CBOs and ASOs for use with their clients.

Agency: HRSA

Time line: 12 months

Recommendation: Services S5 and S14

(2) Since 1991, the Special Programs of National Significance (SPNS) have worked in the development of innovative service delivery models, many of them in communities of color. As these programs are completed, HRSA will provide information and findings on programs to CBOs and ASOs.

Agency: HRSA

Time line: 12 months

Recommendation: Services S5 and S14

(3) The HRSA Bureau of Primary Health Care (BPHC), Division of Migrant and Community Health, provides primary care and support services to migrant communities. BPHC has developed materials that address standards of care for migrant populations, including migrant worker women. HRSA will take proactive steps to disseminate this information to CBOs and ASOs providing services in migrant communities.

Agency: HRSA

Time line: 12 months

Recommendation: Services S5 and S14

(4) HRSA and other DHHS OpDivs will examine the demand for information on HIV treatment in languages other than English. To the extent that there is an identifiable need for these materials, HRSA will develop necessary information on treatment in those languages for which there is demand.

Agency: DHHS

Collaborating agency: CDC, HRSA, NIH and SAMHSA

Time line: 12 months

Recommendation: Services S27

(5) In order to ascertain the demand for information and materials on treatment in languages other than English, CDC will examine the utilization of the AIDS Treatment Information System (ATIS). This utilization information will not only be used in determining what materials are needed in other languages but will also be shared with minority CBOs and ASOs.

Agency: CDC

Collaborating agency: OMH

Time line: 6 months

Recommendation: Services S27

I. Grant Administration

(1) In order to have the most qualified people of color participating in grant review committees, there is a need to collaborate with colleges and universities that have historically served racial and ethnic communities. While OMH has worked with many of these institutions, it has not developed linkages with institutions of higher learning that enroll large numbers of Asians and

Pacific Islanders. OMH will take steps to establish these linkages so as to increase the number of Asians and Pacific Islanders that are available to participants on grant review committees.

Agency: OMH

Time line: 12 months

Recommendation: Services S19

(2) DHHS will expand their grants reviewer pool to include greater participation of racial and ethnic communities.

Agency: DHHS

Collaborating agency: CDC, HRSA, NIH and SAMHSA

Time line: 12 months

Recommendation: Services S19

IV Policy Development

A. National Minority HIV Plan

(1) HHS OpDivs will seek ways of pooling available funds to assist the Office of Minority Health with the implementation and follow-up necessary for the National Minority HIV Plan.

Agency: HHS

Time line: 12 months

Recommendation: Prevention P20

B. Executive Orders

(1) In order to make the process for the development of Executive Orders more inclusive, OMH will explore ways of working with members of the National Minority HIV Working Group in this area.

Agency: OMH

Time line: 12 months

Recommendation: Services S19

V Pending Issues

The following issue was discussed at the April meeting but no specific action steps were put forth due to time limitations.

A. Surveillance and Epidemiology

(1) CDC will make available information regarding policies behind data collection and how input can be provided in the area of data collection.

Agency: CDC

Collaborating Agency: NIH

Recommendation: P15

APPENDIX A – RECOMMENDATIONS

The following recommendations were used as a basis for discussion and development of the action steps contained in this report. Not all recommendations listed were discussed in detail during the Working Group's meeting, and thus not all have specific action steps to address them. The recommendations are included in this report for historical purposes and to allow the Department to gain a better understanding of the unique needs and concerns of racial and ethnic communities.

PREVENTION

Prevention Recommendation: P1

Fund community-based organizations (CBOs) and AIDS service organizations (ASOs) specifically to develop programs and materials on links between injecting drugs, non-injection drugs (including alcohol) and HIV/AIDS.

Related Action Steps: Prevention B(3), B(4), B(5), D(2)

Prevention Recommendation: P2

Develop and support more HIV prevention programs targeting heterosexuals.

Prevention Recommendation: P3

CDC should provide TA to CBOs on how to articulate and document the effectiveness of their prevention strategies and interventions. CDC would facilitate the dissemination of that information.

Related Action Steps: Prevention F(1)

Prevention Recommendation: P4

CDC should expand, with the collaboration of racial and ethnic groups, its national multilingual AIDS hotline, to include community service providers.

Prevention Recommendation: P5

The CDC and territorial, state and local health departments should modify current data collection methods and surveillance systems, to disaggregate racial and ethnic communities by race, ethnicity, language, national origin and tribal affiliation; report by oversampling where necessary; and conduct studies.

Prevention Recommendation: P6

CDC should increase funding for comprehensive HIV education for in-school and out-of-school youth, including minority gay, lesbian, bisexual, transgender and questioning youth.

Related Action Steps: Prevention D(3), F(1)

Prevention Recommendation: P7

CDC and SAMHSA should fund culturally, linguistically and gender appropriate needle exchange programs that target communities of color.

Prevention Recommendation: P8

CDC should increase funding for HIV prevention interventions, TA, training and capacity building specifically targeting lesbians, gay men, bisexuals and men who have sex with men in rural communities.

Prevention Recommendation: P9

Surrogate markers, such as sexually transmitted disease (STD) and unplanned pregnancy rates, should be used to estimate HIV risk and to evaluate the effectiveness of risk reduction in prevention programs.

Related Action Steps: Prevention B(2)

Prevention Recommendation: P10

CDC should increase funding for HIV prevention interventions, TA, training and capacity building specifically targeting gay, bisexual, transgender and other men who have sex with men in all racial and ethnic communities. These programs should include racial, ethnic, sexual and gender identity. Program funding should reflect increases in rates, prevalence and morbidity in these groups.

Prevention Recommendation: P11

All requests for proposals (RFPs) should ensure that the cultural and linguistic needs of the target population are addressed in the prevention message. Inclusion of the target population in the design, implementation and evaluation is essential. Targeted messages are the most effective means of outreach.

Related Action Steps: Prevention C(1), C(2)

Prevention Recommendation: P12

Increase funding to support the use of peers and mentors to deliver prevention activities, as specified by the CBOs or ASOs.

Prevention Recommendation: P13

Require funded CBOs, ASOs and state and local health departments to provide rapid access to confidential counseling and testing as a part of their comprehensive HIV activities.

Prevention Recommendation: P14

CDC should convene a panel of planning group members to evaluate the participation of communities of color in the planning process, based on the latest year's reported AIDS cases. Participation should be in the proportion that the epidemic has impacted on their particular racial and ethnic community and population as defined by risk factor.

Related Action Steps: Prevention E(1), E(2), E(3)

Prevention Recommendation: P15

CDC should require that states continue to offer anonymous HIV testing. Partner notification would be carried out on a voluntary basis with the consent of the individual.

Related Action Steps: Pending A(1)

Prevention Recommendation: P16

The Secretary of Health and Human Services should review the restrictions and federal rules regarding needle exchange programs and allow federal funds to support such activities.

Prevention Recommendation: P17

CDC should mandate state and local health departments to provide training to Community Planning Group members in support of parity, inclusion and representation.

Related Action Steps: Prevention E(1), E(2), E(3)

Prevention Recommendation: P18

CDC should release a public service announcement specifically targeting minority gay, lesbian, bisexual, transgender, questioning and asking youth.

Prevention Recommendation: P19

SAMHSA should release a program announcement specifically targeting minority youth that would educate about the link between HIV transmission and underage alcohol use.

Prevention Recommendation: P20

Develop a national agenda focusing on prevention of HIV in people of color, to include: 1) identifying effective programs for each community of color; 2) disseminating information through a comprehensive plan; and 3) setting funding priorities for prevention and research.

Related Action Steps: Prevention A(1), A(2), A(3), A(4), B(1), Policy Development A(1)

RESEARCH

Research Recommendation: R1

DHHS OpDivs should develop public information campaigns with various levels of messages for racial and ethnic communities. The messages should include primary and secondary prevention information and must be tailored to the specific communities and risk factors. Evaluation methodologies should be developed to measure the effectiveness of these campaigns.

Research Recommendation: R2

NIH should continue and expand efforts to find more effective women-controlled prevention devices, contraceptives and microbicides, and provide information on these to communities and individuals in terms that can be easily understood. The efforts should include incentives to industry for the development of new products, in particular those that would benefit people of color.

Research Recommendation: R3

The CDC should fund a multi-site, multi-year longitudinal study of epidemiological trends in HIV and AIDS incidence and prevalence among all racial and ethnic communities and populations.

Related Recommendations: Research A(3), B(3), C(1) , C(2), C(3)

Research Recommendation: R4

NIH should actively recruit and retain members of racial and ethnic communities -- in particular women, youth and transgenders -- for existing and new clinical treatment trials and vaccine trials. In order to facilitate this, NIH should develop a centralized database containing demographic information and provide resources to address transportation, interpretation and translation needs. In particular, the use of community-based research sites will assist with this effort. In populations where there is under representation, over sampling will be necessary. NIH should look for new and improved ways of addressing increased recruitment and retention needs among racial and ethnic communities.

Related Action Steps: Research E(1), I(1)

Research Recommendation: R5

NIH should facilitate the distribution of research findings to participants in clinical trials. To ensure that the findings of research reach the communities and populations in need, increased treatment education and materials should be made available in the languages of the populations that require them. Materials required for individuals to participate in research should be provided in the language of the person included in the research. Among the documents that should be made available are: informed consent information and forms, medical alerts, treatment findings and guidelines.

Research Recommendation: R6

NIH should fund multi-city HIV clinical treatment and vaccine trials in all racial and ethnic communities and populations according to risk, with a special focus on people living with HIV and AIDS. Among the options are short-term single community research and long-term infrastructure development in health services research models. The areas to be researched include: clinical trials, vaccines, service delivery and cost utilization.

Related Action Steps: Research C(4), E(2), F(1),

Research Recommendation: R7

CDC, HRSA and NIH should promote and fund culturally appropriate innovative research methodologies -- including new recruiting methods and survey methodologies -- to effectively study racial and ethnic communities and risk populations. NIH should continue research on alternative and complimentary medicines in racial and ethnic communities.

Related Action Steps: Research G(1), H(1)

Research Recommendation: R8

NIH should encourage the development of public and private partnerships for research of women-controlled prevention devices. NIH should provide information on progress in the use of funding the Secretary pledged for this purpose: $100 Million.

Research Recommendation: R9

Programs targeting people of color should incorporate cultural norms in the methodology design, and include these norms in the theory, methods, sampling, recruitment and retention practices. In those instances where there is undercounting of a particular population, oversampling should be used to obtain adequate representation. Panels should make funding decisions on these programs to reflect the racial and ethnic background of the populations being targeted.

Related Action Steps: Research A(1), A(2), E(5), I(2), I(3), J(1)

Research Recommendation: R10

Targeted committees must establish research guidelines for their community. These research guidelines must contain, at a minimum: 1) an observational database containing information on current and past participants in clinical trials; 2) increased training and funding opportunities for minority researchers; and, 3) increased interagency and interdepartmental coordination of research efforts.

In the case of the American Indians/Alaska Native community, two separate processes should be implemented to address the research needs of the community:

1. Urban Indians should work with HRSA and the SPNS program to obtain necessary funding; and

2. IHS should work with the Tribal Consultation Process and the various tribes.

SERVICES

Services Recommendation: S1

Federal and state agencies should provide incarcerated populations with lubricant, condoms and dental dams upon request. HIV prevention and education materials, substance abuse treatment, mental health and primary health care and other services should also be available.

Services Recommendation: S2

Ensure the representation and participation of all racial and ethnic groups and individuals living with HIV and AIDS in the development, implementation and evaluation of HIV and AIDS programs. Federal agencies should include these groups in the process for the development of RFPs.

Services Recommendation: S3

DHHS, the Department of Housing and Urban Development (HUD), territorial, state and local health departments should fund interpretation and translation services for HIV and AIDS prevention and care services that are appropriate culturally and linguistically, in all communities where English is not the primary language of choice.

Services Recommendation: S4

CDC and HRSA should create capacity for community-based service delivery and infrastructure within community organizations of color. TA and the flexibility to contract with TA consultants (nationally and local) should be made available to CBOs and ASOs.

Services Recommendation: S5

HRSA, NIH and territorial, state and local health departments should ensure that all persons living with HIV and AIDS have access to newly developed treatments and drug therapies, including persons with insurance, the under-insured and the uninsured, regardless of immigration status.

Related Action Steps: Services D(3), F(1), G(1), G(2), H(1), H(2), H(3)

Services Recommendation: S6

CDC, HRSA, NIH and HUD should fund comprehensive HIV and AIDS health and social services and resources for women, including pre-and post-test counseling, HIV education and prevention, emotional and practical support, harm reduction, substance abuse treatment, gynecological care and family counseling.

Services Recommendation: S7

CDC, territorial, state and local health departments should include a female-to-female transmission category in all HIV and AIDS surveillance data collection mechanisms.

Services Recommendation: S8

HRSA and the Federal Bureau of Prisons (BoP) should support ongoing education and training of HIV, health and social service providers regarding issues of gender and sex roles and gender discrimination.

Services Recommendation: S9

CDC and HRSA should fund comprehensive HIV and AIDS health and social services for transgenders of all racial and ethnic groups. Transgenders should participate and be represented in the development, implementation and evaluation of HIV programs.

Services Recommendation: S10

DHHS, territorial, state and local health departments should ensure that-comprehensive prenatal care is available to all pregnant women, regardless of health status, health insurance, income or immigration status, to ensure access to HIV medical standards of care.

Services Recommendation: S11

DHHS should continue to support voluntary, culturally and linguistically appropriate HIV testing of pregnant women and access to appropriate HIV treatment and services.

Services Recommendation: S12

SAMHSA should increase funds for culturally and linguistically appropriate substance abuse prevention and treatment services to meet the needs of affected individuals and their families. Services should include harm reduction and needle exchange programs.

Services Recommendation: S13

HRSA should allow and encourage the use of Ryan White CARE Act funding for the development of secondary prevention programs that are culturally and linguistically appropriate in racial and ethnic communities.

Services Recommendation: S14

HRSA should address those unique cultural, social and economic factors for new immigrants that may create barriers to access to care.

Related Action Steps: Services D(2), D(3), F(1), G(2), H(1), H(2), H(3)

Services Recommendation: S15

There is a need for better and more accurate data on health care indicators of American Indian/Alaska Natives, Alaska Natives and Pacific Islanders. This can be accomplished by closer work with service providers, consumers, epidemiologists and providers in Native communities.

Services Recommendation: S16

The various tribes must be allowed to participate in the Ryan White CARE Act planning bodies (consortia and councils) at the state level. Historically, the tribes have been excluded on a belief that all HIV and AIDS services are covered by IHS.

Services Recommendation: S17

HRSA and the Special Project of National Significance (SPNS) should review the mechanism within Title V of the Ryan White CARE Act in order to provide ongoing funding for American Indian/Alaska Native HIV programs.

Services Recommendation: S18

Federal agencies should explore alternative funding mechanisms and criteria for directly funding minority CBOs and ASOs, so that dollars are set aside for maintenance of these organizations.

Related Action Steps: Services A(1), A(2), A(3), B(1), C(1), C(2), D(1)

Services Recommendation: S19

Federal agencies should demonstrate that minority CBOs, ASOs and individuals infected with HIV and AIDS are included in the composition of grant review committees. The review committee composition should reflect the epidemic.

Related Action Steps: Services I(1), I(2), Policy Development B(1)

Services Recommendation: S20

The needs of American Indians/Alaska Natives must be prioritized as components of planned services in the CARE Act and CDC prevention programs, even in those areas where the sovereign tribes receive direct funding from the federal government.

Services Recommendation: S21

The special needs and situation of American Indians/Alaska Natives living in urban areas must be addressed by HRSA through the SPNS program and IHS to ensure the accessibility of needed services.

Services Recommendation: S22

HRSA should provide access to information on physicians who have been trained by the AETCs.

Services Recommendation: S23

HRSA should audit state AIDS Drug Assistance Programs (ADAPs) to ensure access to needed medical services.

Services Recommendation: S24

Provide training and education to health and social workers who provide services to clients living with HIV and AIDS -- including prison personnel -- regarding mental health and alcohol and other drug abuse treatment issues.

Services Recommendation: S25

Access to mental health services should be provided to all individuals living with HIV and AIDS, including those in prisons.

Services Recommendation: S26

Federal agencies responsible for mental health services should not expect HRSA to address all mental health problems for all HIV clients.

Services Recommendation: S27

HRSA should provide data on the extent of access and utilization by people of color of current DHHS – recommended standards of care, and provide and implement a timeline on how that percentage will increase to reflect the people of color utilization of care services provided through the Ryan White CARE Act and Medicaid.

Related Action Steps: Services H(4), H(5)

Other

Other Recommendation: O1

The Immigration and Naturalization Service (INS) to confer deferred status for immigrants with AIDS.

Other Recommendation: O2

The Assistant Secretary for Health should conduct a monthly meeting in which the issues and recommendations discussed here are addressed. The meetings should provide a forum for the OpDivs to provide updates on progress made in implementation.

APPENDIX B - ACTION STEPS BY OPERATING DIVISION

I Agency for Health Care Policy and Research

Prevention: A(4), C(1), (2)
Research: F(1)

II Centers for Disease Control and Prevention

Prevention: A(1), (2), (3), (4), B(4), C(1), (2), D(1), (2), (3), E(1), (2), (3), F(1)
Research: A(1), (2), B(1), (2), (3), C(1), (2), (3), (4), E(2),(3), (4), H(1), I(2), (3)
Services: C(1), D(1), H(4), (5), I(2)
Pending Issues: A(1)

III Food and Drug Administration

Prevention: A(4), C(1), (2)
Research: D(3)

IV Health Resources and Services Administration

Prevention: A(4), C(1), (2)
Research: A(1), (2), E(3), (4), (5), H(1), I(2), (3)
Services: A(1), (2), (3), B(1), C(1), (2), D(1), (2), (3), E(2), (4), F(1), G(1), (2), H(1), (2), (3), (4), I(2)

V Indian Health Service

Prevention: A(4), C(1), (2)

VI National Institutes of Health

Prevention: A(4), B(5), C(1), (2)
Research: A(1), (2), B(1), C(3), (4), D(1), D(2), D(4), E(1), (2), (3), (4), G(1), H(1), I(1), (2), (3)
Services: H(4), I(2)

VII Substance Abuse and Mental Health Services Administration

Prevention: A(4), B(1), (2), (3), (4), C(1), (2), D(2), E(4)
Research: A(1), (2), (3), E(5), H(1), I(2), (3)
Services: D(2), E(1), (2), (3), (4), (5), H(4), I(2)

VIII Office of the Secretary/Office of Minority Health

Prevention: A(4), B(2), (3), (4), B(4), (5),C(1), (2), D(2), F(1)
Research: A(1), (2), E(5), I(2), (3), J(1)
Services: C(1), D(1), E(2), H(4), (5), I(1), (2)
Policy Development: A(1), B(1)

APPENDIX C - GLOSSARY

ACRONYM	**TITLE**
ACF	Administration for Children and Families, Department of Health and Human Services
ADAP	AIDS Drug Assistance Program, an initiative under the CARE Act, administered by the Health Resources and Services Administration
AETCs	AIDS Educational Training Centers, a Health Resources and Services Administration Initiative
AHCPR	Agency for Health Care Policy and Research, Department of Health and Human Services
AMR	ADAP Monthly Report
ASO	AIDS Service Organization
BIA	Bureau of Indian Affairs, Department of the Interior
BoP	Bureau of Prisons, Department of Justice
CAPTs	Centers for the Application of Prevention Technologies, a SAMHSA/CSAP initiative
CARE Act	The Ryan White Comprehensive AIDS Resources Emergency Act, provides funding for HIV services through four Titles
CBO	Community Based Organization
CDC	Centers for Disease Control and Prevention, Department of Health and Human Services
CHSTP	Center for HIV/STD/TB Prevention, Centers for Disease Control and Prevention
CMHS	Center for Mental Health Services, Substance Abuse and Mental Health Services Administration
Cooperative Agreement	The funding mechanism for providing funding to state and other non-federal entities
CPG	Community Planning Group, the body created to develop HIV prevention priorities at the state/local level

CSAP	Center for Substance Abuse Prevention, Substance Abuse and Mental Health Services Administration
CSAT	Center for Substance Abuse Treatment, Substance Abuse and Mental Health Services Administration
CSTE	Council of State and Territorial Epidemiologists
DASH	Division of Adolescent and School Health, Center for Chronic Disease Prevention and Health Promotion, Centers for Disease Control and Prevention
DHAP	Division of HIV/AIDS Prevention, Center for HIV/STD/TB Prevention, Centers for Disease Control and Prevention
DHHS	U.S. Department of Health and Human Services
DOJ	Department of Justice
DSS	Division of Support Services, HIV/AIDS Bureau, Health Resources and Services Administration
FDA	Food and Drug Administration, Department of Health and Human Services
FY	Fiscal Year, generally the federal fiscal year, October 1 – September 30, designated by the calendar year in which the fiscal year begins (i.e., FY98 began on October 1, 1998)
HAB	HIV/AIDS Bureau, Health Resources and Services Administration
HARS	HIV/AIDS Reporting System, a Centers for Disease Control initiative
HCFA	Health Care Financing Administration, Department of Health and Human Services
HOPWA	Housing Opportunities for People with AIDS, a HUD initiative
HRSA	Health Resources and Services Administration, Department of Health and Human Services
HUD	Department of Housing and Urban Development
IDU	Injecting Drug User
IHS	Indian Health Service, Department of Health and Human Services
IND	Investigational New Drug applications
INS	Immigration and Naturalization Service, Department of Justice
KDA	Knowledge Development Application, a SAMHSA Initiative

NAH	National AIDS Hotline, a Centers for Disease Control and Prevention initiative
NASTAD	National Alliance of State and Territorial AIDS Directors
NDA	New Drug Application
NIAAA	National Institute on Alcohol Abuse and Alcoholism, National Institutes of Health
NIDA	National Institute on Drug Abuse, National Institutes of Health
NIH	National Institutes of Health, Department of Health and Human Services
NIMH	National Institute on Mental Health, National Institutes of Health
NRMO	National/Regional Minority Organization, a Centers for Disease Control and Prevention initiative
ONAP	Office of National AIDS Policy, Executive Office of the President
OpDiv	Operating Division, a term used to define federal agencies that carry out program operations
OSE	Office of Service Evaluation, Health Resources and Services Administration
SAMHSA	Substance Abuse and Mental Health Services Administration, Department of Health and Human Services
SAPT	Substance Abuse Prevention and Treatment Block Grant, administered by CSAT/SAMHSA
SPNS	Special Projects of National Significance, an initiative under the CARE Act, administered by the Health Resources and Services Administration
TA	Technical Assistance
YSAPI	Youth Substance Abuse Prevention Initiative, a DHHS Secretarial Initiative