The Challenge of HIV/AIDS in Communities of Color

National Commission on AIDS

WASHINGTON, DC • UNITED STATES OF AMERICA

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The National Commission on Acquired Immune Deficiency Syndrome (AIDS) was established by Public Law 100-607 "for the purpose of promoting the development of a national consensus on policy concerning AIDS and of studying and making recommendations for a consistent national policy" concerning the HIV epidemic. The Commission is a bipartisan body whose members were appointed by the President, the United States Senate, and the United States House of Representatives.

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TABLE OF CONTENTS

PREFACE

During the past three years, the National Commission on AIDS has conducted public hearings and site visits to foster a greater understanding of the challenges facing communities of color as they confront the HIV/AIDS epidemic. These activities served as a crucial part of the Commission's effort to meet its statutory mandate of "promoting the development of a national consensus on policy concerning AIDS."

Since December 1990 the Commission has collected information and advice from hundreds of individuals within communities of color in forums that examined issues specific to African American, Native American, Hispanic/Latino, and Asian American/Pacific Islander communities. This report is a result of the Commission's finding that the HIV/AIDS epidemic presents unique challenges to communities of color and, in this context, to all public policymakers.

For people of color, America's racial divides are an ever-present reality–this is particularly true for those who are HIV infected. The abiding and widespread stigmatization of people of color creates enormous difficulties in mobilizing effective responses to the HIV/AIDS epidemic. Racial inequality in the United States is preeminent among the festering social problems that HIV highlights and upon which the epidemic feeds. It forms the backdrop against which efforts to deal with HIV/AIDS take place. Therefore, as a nation we have no choice but to take account of race if we are to alter the course of the epidemic. If we succeed, we will have learned much that is important to the country as a whole and of particular significance to those who would safeguard the public's health.

This report does not address the entire range of issues related to HIV disease in communities of color. As a national advisory body, the Commission seeks to highlight key issues for consideration by the President and Congress in the formulation of HIV/AIDS policy. The Commission feels strongly that the challenges raised in this report warrant diligent attention and present opportunities for collaboration in creating the best possible response to the HIV/AIDS epidemic. Effective intervention requires that each of us appreciates that communities themselves are significant units and that they must be taken into account when developing programs geared toward the health of the public as a whole.

June E. Osborn, M.D.
Chairman

David E. Rogers, M.D.
Vice Chairman

ACKNOWLEDGMENTS

During the past three years, the Commission has heard from individuals and organizations in all parts of the country who are involved in programs of prevention, care, and advocacy in communities of color. Through hearings and site visits from New York City to Los Angeles, from Chicago to Florida, and from the Pine Ridge Oglala Sioux Reservation to rural townships we have witnessed the remarkable commitment of such people in the struggle to confront the HIV epidemic effectively. We must express our sense of obligation as well as gratitude to all those who helped further our understanding of the impact of AIDS in their communities. In particular, the Commission thanks those who presented formal testimony. They are named in Appendix A.

In addition, the Commission received valuable support and advice from a number of individuals and entities without whose help an exploration of issues confronting communities of color would not have been possible. They are: Jacob Gayle, Ph.D.; Ron Rowell, M.P.H.; Mark Smith, M.D., M.B.A.; Aida Giachello, Ph.D.; Miguel Gomez; Steve Lew; the board members of the National Minority AIDS Council; Mayor Kurt Schmoke of Baltimore; Former Mayor Art Agnos of San Francisco; Mayor Richard Daley of Chicago; chiefs, chairpersons, tribal leaders, and AIDS service providers of the Pascua-Yaqui, Tohono O'odham, Navajo, Comanche, Muskegee (Creek), Mdewakanton Sioux, Oglala Sioux, Rosebud Sioux, Sac & Fox, Winnebago, Chippewa, and Cherokee Nations; members of the Hispanic Hearing Planning Committee (see Appendix C); COSSMHO; members of the Asian American and Pacific Islander Planning Committee (see Appendix C); Frank Arcari, M.P.A.; Nat Blevins, M.Ed.; Stacey Bush; Renée Peterson; Joan Piemme, R.N.; Jane Silver, M.P.H.; Jeff Stryker; and Ellen Tynan, M.A.

Part I

The Challenge of HIV/AIDS in Communities of Color

Introduction

The HIV/AIDS epidemic is composed of thousands of uniquely *personal* tragedies. Behind every statistic is a flesh and blood human being whose life is filled with pain and whose death will come much too soon. Yet, as a nation, we are profoundly unable to identify with the majority of people living with HIV disease–they remain faceless and their suffering distant and unreal.

This is especially true of people of color. Their plight as individuals has been overshadowed by their identification with communities that have been pushed to the margins of our society. Race, and to a lesser extent social class, is used to define people as different, as "not like us," and as therefore not the concern of the majority of Americans.

We must recognize that the HIV/AIDS epidemic affects communities as well as individuals. The term "community" is used here to describe people who have particular characteristics in common, such as race or ethnicity, and to describe the social and cultural networks they form. In this report, we have chosen to focus on four such communities: African Americans, Asian Americans and Pacific Islanders, American Indians and Alaskan Natives (Native Americans), and Hispanics/Latinos.

Three of these communities are defined by race. The fourth–the Hispanic/Latino community–is a multiracial ethnic group. Socially and to some extent by law, however, Hispanics/Latinos have been treated in much the same way as racial minorities; therefore, we include this unique ethnic group along with the three "minority" races, noting differences where appropriate.

Race and the HIV Epidemic

The term "race" has no fixed biological or anthropological meaning. In the United States, people are lumped into one of four racial categories based broadly on physical characteristics (principally skin color, hair texture, and facial features) and/or ancestry. In so doing, we sometimes lump together cultures that have been historical antagonists and have little in common except that they are viewed as indistinct by the majority of Americans. The "Asian American/Pacific Islander" category is a striking example, for in that official designation is coalesced four thousand years of human history and conflict, brought only recently to American shores.

All races are marked by cultural heterogeneity. For example, within the Native American designation are many nations (commonly called "tribes," a term that minimizes sovereignty) that differ markedly from one another. As the current strife in the former Republic of Yugoslavia makes abundantly clear, the same is true of white "tribes." Although "race" and "ethnicity" are sometimes used interchangeably, the latter usually refers to cultural commonality and is associated with people who once shared a common geographic region and language. For example, the official designation "Hispanic" is applied by the government to people of many nationalities whose racial heritage is varied but who share common cultural roots.

"Race" itself would be irrelevant to the HIV/AIDS epidemic if as a nation we ascribed no special meaning to it or if people of all races were treated equally. That, unfortunately, has not been the American way. For much of our history, racial lines have been drawn *not* with an eye toward capturing and honoring that which is distinctive about each grouping, but instead to assert control and maintain power. Those who have had the power to define race have used it to construct inequalities and maintain a racially stratified society in which persons who are nonwhite (people of color) have been consigned to the bottom.

Until relatively recently, people of color were subjugated on the basis of race and purposely, even forcibly, kept from competing with whites on terms of equality. The specific history of each group differs: slavery, Jim Crow laws, lynching, and segregation for African Americans; physical conquest, land expropriation, treaty abrogation, and a guardian/ward relationship for Native Americans; racially restrictive immigration quotas, Alien Land Laws, and internment for Asian Americans; land annexation, occupational subordination, and forced mass repatriation for Hispanics/Latinos. Although their specific historical experiences have varied, each of these communities of color has faced broad, sustained, systematic discrimination designed to maintain racial inequality.

Of course, much has changed in recent decades, but the legacies of the past still surround us. The cumulative effects of racial discrimination, the chronic lack of access to resources, and the resulting underdevelopment of community infrastructures have had lasting effects. For communities of color, the sense of economic inequity, social distance, discrimination, and social stratification–of not being accorded full equality–is undoubtedly strong and persistent. The relative impoverishment of African Americans, Hispanics/Latinos, Native Americans, and many Asian Americans/Pacific Islanders (contrary to the "model minority" myth) bears testament to the enduring nature of yesterday's burdens, and the difficulty of playing catch-up at a time when the dominant society is apt to discount matters of race. In addition, barely concealed appeals to racial hatred remain a staple of our national political life, promoting prejudice and discrimination against people of color and reinforcing social and institutional arrangements that limit opportunities for members of these communities.

The continuing widespread stigmatization of people of color creates enormous difficulties for effectively combatting the HIV/AIDS epidemic. Perhaps the greatest of these is that communities of color fear that stigmatization and discrimination are likely to increase as the public becomes more aware of the disproportionate number of people of color who are infected with HIV. For these communities, disproportionate representation raises the fear that they will be saddled with the disease–blamed for it, stigmatized by it, and left to deal with it on their own. As one witness stated:

> As the American public becomes increasingly aware of AIDS as a significant health problem in the black community, there will both be danger and opportunity. The opportunity is to deal comprehensively rather than haphazardly with the problem as a whole–to see it as a social catastrophe brought on by years of economic deprivation and to meet it as other disasters are met, with an adequacy of resources. The danger is that AIDS will be attributed to some innate weakness of black people and used to justify further neglect and to rationalize continued deprivation. (Thomas, 1992)

In short, racial inequality in the United States is preeminent among the festering social problems that HIV highlights and upon which the epidemic feeds. It forms the backdrop against which efforts to deal with HIV/AIDS take place. Therefore, as a nation we have no choice but to take account of race if we are to alter the course of the epidemic. If we succeed, we will have learned much that is of importance to the whole country and of particular significance to those who would safeguard the public's health.

The Commission recommends that:

- **Federal, state, and local governments should squarely confront problems associated with racial inequality and its effect on the public health. Public health officials should ensure that effective and equitable HIV policy, program, and funding efforts are brought to bear in communities of color.**

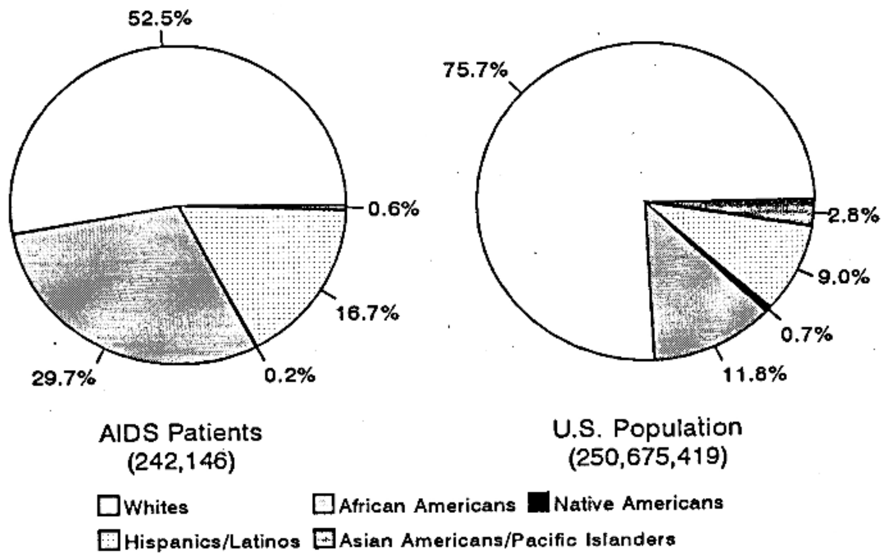
Epidemiology

People of color have been affected by the HIV/AIDS epidemic since its inception. The first report of AIDS in an African American man was made in June 1981; by August 1981, one in nine of the reported homosexual males with AIDS were African American. The first case-series report on women with AIDS, published in April 1982, described five women: three Hispanics/Latinas, one white, and one African American. Indeed, as early as 1982, statistical evidence suggested that the epidemic posed a disproportionately serious problem for African Americans and Hispanics/Latinos and that most of the people at risk for infection in these groups were of relatively low socioeconomic status.

In 1982 African Americans and Hispanics/Latinos accounted for just under half of the males, more than three-fourths of the females, and almost two-thirds of the children diagnosed with AIDS in the United States. Of all those who died of AIDS from 1981 through 1990 (a total of 100,777 people), 28 percent were African American and 15.7 percent were Hispanic/Latino. As early as 1988, HIV disease was the leading cause of death among African American women aged 15 to 44 in New York State and New Jersey (CDC, 1991b). African American and Hispanic/Latino men with AIDS have comprised between 30 percent and 40 percent of all AIDS cases among adult and adolescent men; the proportions of African American and Hispanic/Latino women and children with AIDS have remained considerably more than half of all cases among women and children.

As of September 1992, reported U.S. AIDS cases totaled 242,146 and deaths from AIDS totaled 158,243 (CDC, 1992e). HIV disease has continued to have a profoundly disproportionate impact on African Americans and Hispanics/Latinos. African Americans constitute 12 percent of the United States population, but account for nearly 30 percent of AIDS cases–71,984 as of September 1992. Hispanics/Latinos constitute 9 percent of the population, but account for 17 percent of AIDS cases–40,353 as of September 1992. (See Figure 1.) Thus, African Americans and Hispanics/Latinos together account for 46 percent of U.S. AIDS cases so far. Death rates from HIV-related causes have been highest for African Americans and Hispanics/Latinos. During 1990, the number of reported deaths per 100,000 population was 29.3 for African Americans and 22.2 for Hispanics/Latinos, as compared with 8.7 for whites (CDC, 1991b).

Figure 1: Comparison of U.S. AIDS Cases (through September 1992) and Estimated 1991 Population, by Race/Ethnicity



SOURCE: Centers for Disease Control/National Center on Infectious Diseases/Division of HIV/AIDS.

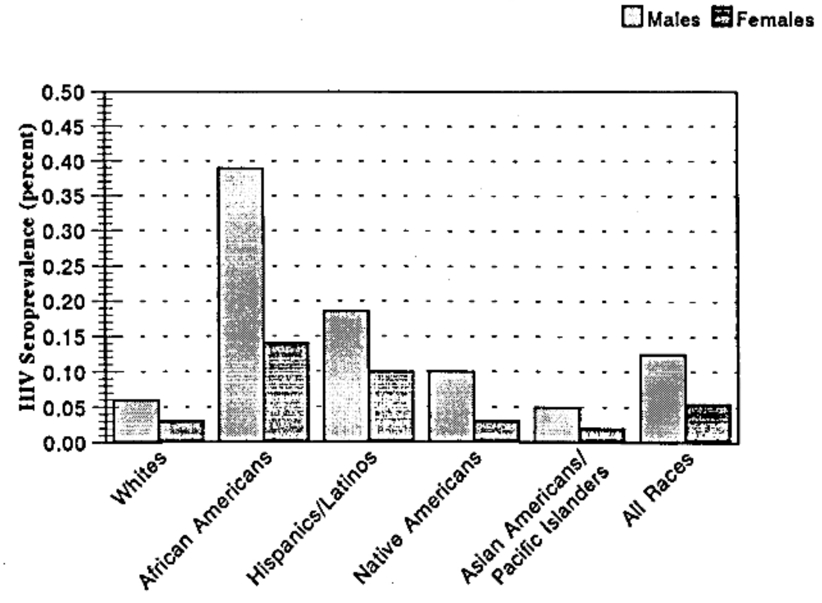
The impact of the epidemic has been particularly profound on the African American community. It is striking to note that in 1989 the age-adjusted HIV-related death rate among African American males was three times that of white males (40.3 deaths per 100,000, as compared with 13.1 deaths per 100,000). African American females were nine times more likely to die from HIV than white females (8.1 deaths per 100,000, as compared with 0.9 per 100,000). Accordingly, the years of potential life lost per 100,000 population due to HIV was 177 percent higher for African American males than white males and 796 percent higher for African American females than white females (Department of Health and Human Services, 1992).

Examination of trends in AIDS diagnosis and HIV infection shows that this disproportionate impact is likely to continue. In 1991 the reported number of AIDS cases rose 5 percent overall as compared to 1990. However, cases increased by 11.5 percent among Hispanics/Latinos, increased by 10.5 percent among African Americans, and decreased by 0.5 percent among whites. African Americans and Hispanics/Latinos were, respectively, nearly five and three times more likely to be diagnosed with AIDS than were whites in 1991 (CDC, 1992c). The Centers for Disease Control noted that during 1991 the proportion of reported cases rose most among women, African Americans, Hispanics/Latinos, persons exposed through heterosexual contact, and persons living in the South.

The number of reported AIDS cases does not, however, accurately portray the scope of the epidemic in these communities because such figures represent only a portion of the total number of people now infected with HIV. Although data are uneven and sparse, there are strong indications that people of color are also disproportionately represented among persons with HIV infection. One study in South Carolina has examined the distribution of newly identified HIV infection as compared to that of AIDS cases. The proportion of new HIV infection in women (27%) and African Americans regardless of gender (71%) was significantly higher than that observed for AIDS cases–19 percent for women and 60 percent for African Americans (CDC, 1992a).

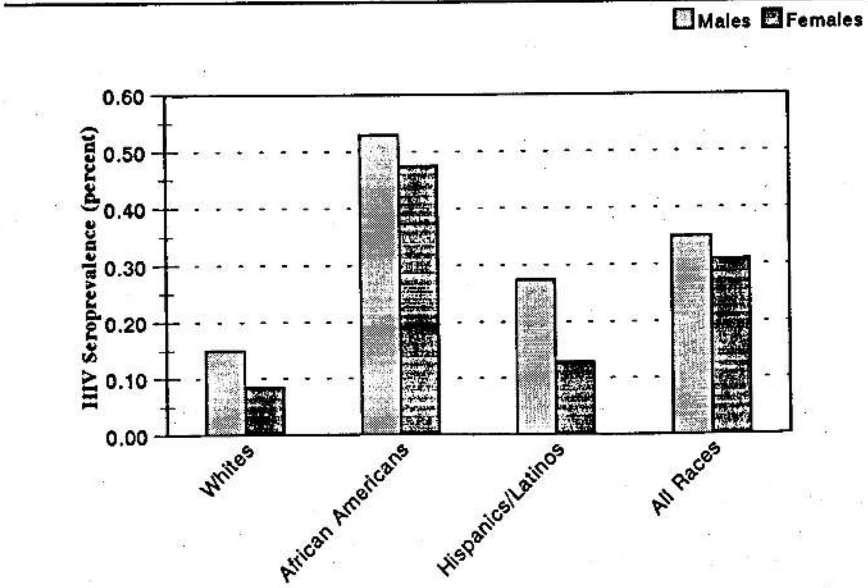
The rates of HIV infection among applicants to the military and the Job Corps also give cause for concern. With the exception of Asian Americans/Pacific Islanders, for whom HIV antibody seroprevalence rates were comparable to whites, communities of color had significantly higher prevalence of HIV infection, indicating a disproportionate future impact of HIV disease. Since most persons with HIV infection are unaware that they are infected, present rates of HIV transmission in racial/ethnic groups are likely to parallel the disproportionate prevalence of infection. (See Figures 2 and 3.)

Figure 2: HIV Seroprevalence in Civilian Applicants for Military Service by Sex and Race/Ethnicity, United States, October 1985-December 1990



SOURCE: Department of Defense; CDC, 1991 National HIV Serosurveillance Summary.

Figure 3: HIV Seroprevalence in Job Corps Entrants by Sex and Race/Ethnicity, January 1988-December 1990



SOURCE: Department of Labor; CDC 1991 National HIV Serosurveillance Summary

In addition, estimates of the percentage of youth in the United States who have been or will be left motherless by the HIV epidemic suggests that by the year 1995, 17 percent of U.S. children and 12 percent of U.S. adolescents whose mothers die will lose their mothers to HIV/AIDS. More than 80 percent of all youth whose mothers have died or will die of HIV/AIDS (an estimated 36,560 youth) are offspring of African American or Hispanic/Latina women (Michaels and Levine, 1992).

In contrast to the experience of African Americans and Hispanics/Latinos, Native Americans and Asian Americans/Pacific Islanders are as yet underrepresented among AIDS cases in proportion to their numbers in the total population. As of September 1992, Asian Americans/Pacific Islanders, who make up 3 percent of the U.S. population, accounted for 0.6 percent of the AIDS cases so far. As of September 1992, Native Americans accounted for 0.8 percent of the U.S. population and 0.17 percent of the AIDS cases reported to the Centers for Disease Control.

While the number of AIDS cases in Asian American/Pacific Islander and Native American populations is relatively low at present, these communities are still in the early stages of a growing HIV epidemic. Because of their relative insularity, which magnifies the effect of infectious diseases once they take hold, the course of the epidemic in these communities could come to resemble that of the African American and Hispanic/Latino populations if effective prevention interventions are not brought to bear. Focusing on the relatively low number of Native Americans and Asian Americans/Pacific Islanders with AIDS has resulted in complacency and a lack of attention to efforts targeting these communities both by public health officials and by community members. Even more troubling, the relatively low number of cases has sent an inaccurate message to these communities that they do not have to worry about AIDS.

Careful attention should be given to how HIV/AIDS statistics are interpreted and used. An effort must be made to assure that populations that are currently underrepresented are not overlooked in HIV prevention efforts. If we wait to see large numbers of AIDS cases before we begin targeted HIV prevention, we will have missed a brief opportunity to prevent those cases from ever occurring.

It is important to note that from 1989 to 1990 the number of Native American AIDS cases increased faster than cases among any other ethnic or racial group (Metler, Conway, and Stehr-Green, 1991). AIDS cases among Native Americans rose 23 percent, as compared to 13 percent for Hispanics/Latinos, 12 percent for African Americans, and 2.5 percent for whites. Additionally, the number of actual AIDS cases may be significantly undercounted in these communities. A Centers for Disease Control study of death certificates and AIDS service organization records in Los Angeles and Seattle reported that between two-thirds and three-fourths of Native American AIDS cases were misrepresented as white or Hispanic/Latino (Conway, 1990). Additionally, studies of applicants for military service from 1985 to 1990 indicate that Native American male recruits have a seropositivity rate twice that of white male recruits.

There is currently a dearth of information regarding the HIV/AIDS epidemic among Asian Americans/Pacific Islanders and Native Americans. Demographic information by racial group and nationality is critically needed for health planning and public policy use.

The Commission recommends that:

- **The Centers for Disease Control and Prevention should review the adequacy of demographic information regarding HIV/AIDS currently available by race, ethnicity, and nationality, particularly with regard to Asian Americans/Pacific Islanders and Native Americans. Additionally, the National Center for Health Statistics should make information available regarding HIV/AIDS knowledge, attitudes, beliefs, and behaviors among Asian Americans/Pacific Islanders and Native Americans.**

- **The federal government should work with the states to establish and support foster care programs for children with HIV infection and noninfected youth orphaned by the loss of parents to HIV/AIDS. Federal and state government should also support programs designed to assist family members in caring for children whose lives have been affected by HIV/AIDS.**

Toward an Understanding of the Disproportionate Impact of HIV/AIDS on Communities of Color

In discussing race and its relevance to the HIV/AIDS epidemic, it is important to stress that there is no evidence that race is a *biological* risk factor for HIV infection. That is, even though greatly disproportionate numbers of African Americans and Hispanics/Latinos have developed AIDS, there is no demonstrated genetic reason why HIV/AIDS has had a disparate impact on these communities. Therefore, in trying to understand racial differences in HIV seroprevalence, in AIDS diagnosis, and in the length of time from diagnosis to death, it is important to look for *social* explanations.

Social and Economic Factors

Currently, it is impossible to determine the extent to which differentials in HIV/AIDS can be explained by differentials in income, education, and other social and economic differences between the races. However, even though we cannot sort out the complex interactions among these factors, we do know from past experience that disease incidence is associated with particular social arrangements, especially economic inequality. Thus, while HIV is transmitted by individual behavior, we can infer that social and economic factors have a powerful influence on how individuals behave as well as on the overall shape of the epidemic.

It has often been demonstrated that underdevelopment (comparatively fewer economic, material, and organizational resources), unemployment, poverty, and illiteracy are correlated with decreased access to health education and to health care, which in turn result in poor health prospects and increased risk of disease. These factors, combined with high rates of sexually transmitted diseases and injection drug use, favor the spread of HIV.

Over all, people of color fare poorly in indices that determine socioeconomic status. On average, people of color have higher rates of unemployment and lower incomes than white Americans. In 1991 the poverty rate among whites was 11.3 percent, among Asian Americans/Pacific Islanders it was 13.8 percent, among Hispanics/Latinos it was 28.7 percent, and among African Americans it was 32.7 percent (Bureau of the Census, 1992).[1] In September 1992 the unemployment rate was 6.7 percent for whites, 11.9 percent for Hispanics/Latinos, and 13.7 percent for African Americans (Department of Labor, 1992). In 1991 the median income was $15,332 for whites, $14,754 for Asian Americans/Pacific Islanders, $10,877 for Hispanics/Latinos, $10,542 for African Americans, and $10,503 for Native Americans (Bureau of the Census, 1992).

As noted above, low income and poor health are strongly linked. Persons with low incomes generally experience a higher incidence of illness and a poorer survival rate than do the economically advantaged. The association of poverty, underdeveloped community structures, and disease is well demonstrated by the impact of the HIV epidemic in communities of color. Poor people of color often are isolated from all but the most rudimentary health care. Urban public hospitals that serve a high proportion of African Americans and Hispanics/Latinos are often overcrowded and are increasingly less able to meet the growing needs of the communities they serve. Poor people of color are less likely to seek early treatment for HIV infection, are likely to have been less healthy when they contracted the virus, and are likely to have more advanced symptoms when they present themselves for treatment. Consequently, African Americans and Hispanics/Latinos tend to die sooner from AIDS.

Another disease illustrates the links between race, poverty, and disease. Tuberculosis (TB) is a disease caused by a bacterium known as *Mycobacterium tuberculosis*. Transmission of this organism occurs most commonly in cough-generated air droplets from a person with active (infectious) pulmonary tuberculosis. Transmission occurs more frequently where persons are routinely in close proximity with inadequate ventilation. Such conditions--crowded housing, shelters for the

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[1] The Census Bureau has not calculated the poverty rate for Native Americans owing to the smallness of the sample size.

homeless, prisons–are disproportionately shared by persons of color. Exposure to the causative organism for tuberculosis may result in infection followed fairly rapidly by active disease, or in latent (nontransmissible) infection, which may last for years. About 5-10 percent of immunologically normal persons who are latently infected will later in life develop active tuberculosis.

In the United States, African Americans, Hispanics/Latinos, and Native Americans have historically had higher rates of TB than whites, probably because the conditions under which they live favor higher rates of infectious exposure. The present social conditions of a disproportionate number of people of color and their relative lack of access to curative care also perpetuate the cycles of exposure–disease–exposure and exposure–latent infection–disease–exposure. In recent times,. Asian and Pacific Islander immigrants to the United States have had high rates of tuberculosis because of high rates in their countries of origin (which result in high rates of latent infection and subsequent reversion to disease).

Roughly fifty percent of persons infected with both HIV and *M. tuberculosis* are likely to develop active tuberculosis within two years, compared with the lifetime risk of TB of 5-10 percent for persons infected with *M. tuberculosis* alone. Hence exposure to or latent infection with *M. tuberculosis* is a significant risk for persons with HIV infection. Thus, many persons of color are in triple jeopardy: from a greater likelihood of latent infection with *M. tuberculosis*, from a greater likelihood of HIV infection, and from a resultant greater likelihood of developing active tuberculosis.

Injection Drug Use

Injection drug use has played a significant role in the disproportionate impact of AIDS on African Americans and Hispanics/Latinos. In these communities the proportion of AIDS cases attributable directly to injection drug use is four times that for whites (40 percent, as compared to 9 percent). Similarly, of persons with AIDS whose disease is linked to injection drug use, fully half have been African American (as of 1992) and another 29 percent have been Hispanic/Latino (CDC, 1992e).

According to National Institute on Drug Abuse estimates, there are 1.1 to 1.3 million injection drug users in the United States, all of whom are potentially at risk for HIV infection, as are their sexual partners and children (NIDA, 1990). The Public Health Service estimates that in communities with large populations of illicit drug users, such as New York City, between 30 percent and 40 percent of injection drug users aged 15 through 24 are infected with HIV (PHS, 1990). Furthermore, numerous studies have shown the HIV infection rates among African American and Hispanic/Latino drug users to be higher than among white drug users.

Although members of subordinated racial and ethnic groups are not the only people who use illicit drugs, in the United States injection drug users tend disproportionately to be African American and Hispanic/Latino. The National Household Survey on Drug Abuse found that African Americans are twice as likely as whites to have used drugs intravenously. While the reasons for this greater prevalence are not fully understood, several factors seem implicated.

Certainly significant is the fact that over the last several decades, African Americans have migrated to and been abandoned in inner-city areas, where drug trafficking is heaviest. Although the injection of illicit drugs is thought to have begun in the American South (O'Donnell and Jones, 1968), centers of narcotic distribution historically have been located in impoverished urban areas of the northeast where they are less likely to generate a police response or political opposition. As a result, injection drug use has been disproportionately associated with northeastern urban life. It is estimated, for instance, that between one-fourth and one-half of injection drug users live in New York City alone (Turner, Miller, and Moses, 1989), a disproportionate number of whom are African American and Hispanic/Latino (Friedman et al., 1987). As some researchers have suggested, African American injection drug use has been "a concomitant of urbanization" (Courtwright, Joseph, and Des Jarlais, 1989). As a result of the mass migration of the African American population from the rural South to urban centers, African Americans, who prior to World War II were not considered heavy drug users, increasingly were exposed to narcotics and to conditions that spawned illicit narcotic use (Singer, 1991). Unlike the immigrants who lived in these same or similar neighborhoods before them, low-income African Americans have been unable to distance themselves from decaying inner-city conditions in which heroin has become a staple of the local economy. According to researchers, "by 1970, African-Americans had become an urbanized population, even more so than the U.S. population generally" (Singer, 1991). Demographic trends indicate that one of the fastest-growing groups of African Americans are those who are poor and live in census-defined poverty areas of central cities (Bureau of the Census, 1992).

A similar set of circumstances has occurred in the Hispanic/Latino community, especially with regard to Puerto Ricans. In the 1950s and 1960s, Puerto Rico's shift from an agricultural to an industrial economy brought about an increase in migration–from the island to the continental United States. In search of jobs, Puerto Ricans settled in urban areas where they were likely to find employment as unskilled laborers. Their experience in these urban areas was not unlike that of African Americans. In these urban areas, Puerto Ricans often found open drug markets, oppressive conditions, and few economic opportunities. As one researcher observed, "Heroin is seemingly everywhere in black and Puerto Rican ghettos and young people are aware of it from an early age" (Waldorf, 1973). Furthermore, during the late 1970s and early 1980s there was a substantial increase in the supply of both heroin and cocaine in many urban areas. This led to increases in the use of these drugs, primarily among persons who already had histories of injecting drugs.

A permanent African American and Hispanic/Latino "ghetto," characterized by a virtually unchecked heroin trade, widespread unemployment, and poverty, among other factors, has assured that urban African American and Hispanic/Latino populations suffer high rates of addiction to injection drugs (Courtwright, Joseph, and Des Jarlais, 1989).

Not only is injection drug use disproportionately high among African Americans and Hispanics/Latinos within the universe of injection drug users, HIV infection is also highest among these same groups. The reasons are several. It is increasingly clear from a decade of research that where sharing of injection equipment is common, frequency of injection is positively correlated with likelihood of HIV infection. A study in New York City found that white users inject less frequently than African Americans or Hispanics/Latinos (Friedman, Des Jarlais, and Sterk, 1990). In addition, the use of shooting galleries–places where one may rent reusable drug injection equipment–provides a mechanism for the spread of HIV to large numbers of other injection drug users and has also been linked to HIV exposure. White users patronize shooting galleries less often than other groups (Des Jarlais et al., 1989). Also, HIV may have entered African American and Hispanic/Latino injector groups earlier than white groups and may have saturated these drug-using communities, resulting in a high prevalence of infection in the local drug population network (Schoenbaum et al., 1989).

Significantly, injection drug use has played a major role in spreading HIV among heterosexuals and newborn babies. Of all AIDS cases attributed to heterosexual contact, 53 percent involved persons who reported sexual contact with an injection drug user. Three-fifths (59%) of all heterosexual AIDS cases related to injection drug use are African American. Whites represent 21 percent of these cases and Hispanics/Latinos represent another 19 percent. In addition, perinatal transmission associated with a mother's exposure to HIV owing to injection drug use represents 40 percent of all cases among children. Of these cases three-fifths (59%) are African American, one-fourth (25%) are Hispanic/Latino, and one-seventh (15%) are white. Perinatal transmission associated with a mother's exposure to HIV owing to sexual contact with an injection drug user represents 17 percent of all cases among children. Of these cases African Americans represent 45 percent, Hispanics/Latinos 39 percent, and whites 15 percent (CDC, 1992e).

Societal and Community Influences: Looking Beyond HIV as Solely an Individual Behavioral Problem

As noted earlier, AIDS cannot be seen as solely an individual behavioral problem. In communities of color, attention must be paid to the social and economic setting of risk behaviors. To the extent that poverty and unemployment are risk factors, proposed interventions must take these conditions into account. Where communities are unable to support healthy behaviors, AIDS intervention efforts will not work. As one witness stated,

> The one thing we know about poverty in this country in the last twenty years is that it has really altered the structure of many of the neighborhoods in the United States. Blacks and Latinos are increasingly concentrated in areas that are becoming poorer and poorer, and with that concentration has come a tremendous increase, not just in HIV infection, but a whole host of other serious social problems ranging from crime to just about anything that you can possibly describe.... Until we're able to stabilize these communities, there simply is no place for the seed of the individual prevention measure to take fruit. Unless we're able to do something dramatically to alter the economic structure of these neighborhoods, we really fear very, very strongly that the things we have embarked on for the last nine or ten years simply are not going to see the kind of results that we desire. (Fullilove, 1991)

We cannot continue to teach individuals about the dangers of certain behaviors as if they choose to engage in them indiscriminately. We would do well to take account of social forces and institutions that undermine individuals' capacity to adopt and sustain a healthy lifestyle. It is difficult to change practices effectively without changing circumstances. As another witness stated,

> The first decade of AIDS was characterized by an almost single-minded focus on interrupting the cycle of HIV transmission. Our approach to AIDS prevention reflected an illusion that we as a society are all educated individuals eager to do the right thing if only we have all the appropriate information. We cannot expect a national prevention campaign based only on information alone to change recalcitrant problems. The spread of HIV has highlighted the complex relationship among social class, gender, and race in a society where health care facilities are impoverished, access to care is inadequate, and prevention technology is devalued. We must enter the second decade of AIDS with the knowledge that existing public health efforts have failed to stop the disproportionate spread of HIV infection. (Thomas, 1992)

This is not to say that AIDS prevention efforts should wait for a solution to our overall social ills. Obviously, they cannot. But as with other facets of the epidemic, if we use this tragic stimulus of HIV as a prod to readdress old problems that have been bandaged or ignored, we have the opportunity to emerge a stronger society.

The Commission recommends that:

- **Public health officials should work with researchers, health professionals, and community-based service providers to gain a better understanding of the role of cultural and socioeconomic factors in the transmission of HIV, the disease process, and access to care. Information gleaned from these efforts should be taken into account in designing HIV prevention messages, services, and programs, and in providing expanded treatment opportunities.**

Assessing the Federal Response to the HIV/AIDS Epidemic in Communities of Color

Prevention

In this second decade of the HIV epidemic, there will be an increasing need to supplement individual behavior change strategies with a concept of intervention that focuses on the community as a whole. Interventions aimed at changing the norms of entire communities are among the most promising HIV prevention strategies. These interventions have proven to be effective in promoting a variety of health behaviors, such as family planning, cardiovascular risk reduction, and smoking cessation.

For such interventions to be successful, health educators must first understand the behavior patterns and cultural norms of the community. More often than not, health departments and AIDS service organizations have failed to integrate such knowledge into their planning and programming processes. This is especially true with regard to the Native American and Asian American/Pacific Islander communities.

Improving channels of communication with communities of color is crucial to successful prevention efforts. For example, efforts at communication must employ appropriate language. Language is more than a catalog of words and grammatical rules; it is an integral part of culture. The values, beliefs, incentives, hopes, and fears of a people are absorbed in it. For cultures constantly under siege, both by subtle and by obvious forces, language is a means by which the community preserves its distinct way of life and makes sense of its experience, history, and struggle. Thus, understanding the importance of language and ascertaining its potential as a point of entry to a community is essential to public health efforts.

Health education must be developed in a manner that properly informs the community about the benefits and risks of HIV interventions and treatments. Health education must also empower the community by providing sufficient guidance and technical information for communities to undertake public health efforts themselves. The potential for misinformation must be explicitly recognized and addressed.

The Commission recognizes that the Centers for Disease Control and Prevention (CDC) has worked hard to listen to, understand, and address concerns voiced by people of color. In many instances the CDC has borne the burden of the frustration individuals and communities have felt in the face of government failure to respond adequately to the threat of HIV in communities of color. In particular, the CDC has played an important role in responding to community suggestions on how to improve surveillance efforts and prevention activities. In addition, the CDC has provided much-needed funds to programs serving racial and ethnic populations at risk of HIV infection and worked to establish credibility for the targeting of resources to specific populations in need.

With regard to programs sponsored by the CDC, communities of color have benefitted most from those that have provided direct funding to national minority organizations and to community-based organizations. These programs have been important because they have helped communities of color embrace HIV/AIDS as a serious concern, enabled better targeting of resources, and in many instances provided desperately needed resources to direct service providers.

Federal efforts to design, fund, and implement prevention programs that reach communities of color have not, however, been without problems. First, serious questions have been raised as to whether the populations most at risk for AIDS within communities of color are being appropriately targeted. For example, fully half of African American and Hispanic/Latino male adults with AIDS are men who have sex with men. Yet, HIV services in communities of color are often not designed to reach them. Since the same can be said of services in predominantly white gay organizations, gay men of color frequently are left in limbo.

Second, funds allocated by Congress and budgeted by the CDC for programs in communities of color have simply not been enough to support the intense and sustained national effort needed to ensure that effective prevention efforts reach these communities.

Third, the CDC must act more vigorously to provide sustained funding or help organizations build the capacity to effectively seek alternative funds from other sources. In addition, program dollars have been awarded without ensuring that the necessary technical assistance for fiscal management is provided to help organizations comply with federal regulations and effectively manage these scarce resources.

Fourth, national education programs such as the "America Responds to AIDS" campaign have been generally ineffective in reaching communities of color. The information provided is often vague and targeted toward an anonymous general public.

The Commission recommends that:

- **The Centers for Disease Control and Prevention should ensure that the prevention and education needs of persons of color who engage in high-risk behaviors are appropriately addressed by current and future prevention initiatives and funding efforts. Programs specifically targeted toward men of color who have sex with other men, toward injection drug users, and toward women are needed.**

- **Federal, state, and local governments should join forces with the private sector in providing long-term support to community-based organizations serving communities of color. As part of this effort, the U.S. Public Health Service should expand and promote comprehensive and integrated programs for technical assistance to and capacity building in these communities.**

Health Care

There are many people of color in the early phases of HIV disease who could benefit from treatments designed to retard the onset of symptoms, as well as from social and mental health services. Unfortunately, many of these people have no point of entry into the health care system. Access to care for people of color has been impeded both by a lack of sufficient health insurance coverage and by a dearth of appropriate health services.

People of color historically have had difficulty in gaining access to and paying for primary care services. In many instances, limited income precludes the purchase of insurance. For example, individuals who are employed in low-paying or minimum wage jobs in the service industry often do not have any health insurance coverage, or at least not adequate coverage. For those who are forced to rely on public programs, Medicaid eligibility criteria in some states are very restrictive (GAO, 1992). Persons living with HIV disease can attest to the difficulties they confront in the absence of insurance. Even those with insurance may exhaust the coverage and be left with limited government support and community assistance.

Lack of access to health care has many ramifications. Delay in seeking care may result in complications and more clinically serious and costly conditions. As with other chronic diseases, waiting until symptoms are persistent or severe can result in preventable morbidity and can shorten survival time. In the era of *Pneumocystis carinii* pneumonia prophylaxis, aggressive TB therapy, and antiretroviral therapy, health care is optimally begun early in the course of HIV infection. However, many people of color are diagnosed with HIV disease for the first time only when serious symptoms of opportunistic infections develop.

In order to more adequately meet the health needs of people of color living with HIV disease greater priority must be given to delivery of comprehensive services and primary care, with a focus on prevention of illness, early intervention in the disease process, continuity of care, and coordinated service delivery, as well as better integration of medical and social services. Improvements in these areas will depend in part on achieving a better supply and distribution of primary care providers.

Unfortunately, for many medically underserved communities the only access to care is the emergency room or a hospital bed. This situation is both economically foolish and medically unsound. Much greater priority should be given to the development of outpatient ambulatory care services. When such services are available persons with HIV disease are able to avoid inpatient hospitalization during much of the course of their illness, thus lowering their medical costs and increasing their sense of control over their lives. For example, many drugs previously administered on an inpatient basis during lengthy hospitalizations can safely be offered in a clinic setting.

Increasingly, hospitals are giving higher priority to providing ambulatory care services that focus, in particular, on better primary care delivery. The availability of primary care services can also be facilitated by ensuring that community-based health services such as community health centers, migrant health centers, and clinics funded by the Indian Health Service are given increased support. In many communities of color, such centers provide primary care services as well as mental health and social services. Such care is cost-effective as well as more accessible to patients.

Awareness that HIV disease is a serious threat to our nation's young people is growing. The number of teenagers with AIDS almost doubles each year. An estimated 75,000 teenagers are now infected with HIV. Over 20 percent of all reported AIDS cases are among individuals in their teens and twenties, most of whom were infected during adolescence. The majority of these cases are among young adults of color. Of all AIDS cases among 13- to 19-year-olds, approximately 38 percent are African American and 20 percent are Hispanic/Latino (CDC, 1992b). Meeting the health needs of the adolescent population will require innovative approaches to the design of health services that address the host of risk factors leading to behaviors that place individuals at risk of HIV infection. Also needed are targeted initiatives such as improvements in school-based health, mental health, and social services.

As the epidemic grows and resources become chronically strained, it is increasingly important to maximize available funding by ensuring that health and social service delivery systems are coordinated. This has become particularly true in inner cities where available resources fall far short of what is needed to confront the HIV epidemic effectively. Thus, state and federal funding sources have encouraged localities to develop consortia and institutionalize mechanisms for sharing resources. Funds made available under the Ryan White CARE Act are the only resources targeted for addressing the crisis in HIV care brought on by the growing epidemic. The CARE Act provides critically needed relief to cities hardest hit by the HIV epidemic and to all states. Title I of the CARE Act distributes "emergency assistance" to metropolitan areas with more than 2,000 diagnosed AIDS cases. Each eligible area is required to establish an HIV planning council, whose task it is to set service priorities and to allocate resources for health care and support services for the geographic area, across all affected populations and subpopulations. Title II of the CARE Act provides funds for states to respond to an array of primary care needs. Such state responses include the creation of HIV care networks in both urban and rural areas, drug reimbursement, COBRA premium payments, and the delivery of home care services. Each state must document that 15 percent of their funds are targeted to women and children with HIV/AIDS, the vast majority of whom are people of color. Title III of the CARE Act provides crucial early intervention, primary care, and mental health services through community migrant and homeless health centers, as well as sexually transmitted disease, family planning, and tuberculosis clinics.

The extent to which CARE Act funds have resulted in greater access to quality care has not yet been adequately documented. It is clear, however, that the effectiveness of the CARE Act in providing relief to cities and states hard hit by HIV has been hampered by inadequate funding levels. The shortfall between needed and available funds has been particularly detrimental to communities of color, where resources are needed for financial relief of institutions providing care to underserved and indigent patients. Strained public hospitals and health clinic infrastructures, which for too long have borne the burden of HIV care, require urgent and ongoing assistance, both to continue providing current services and to expand to meet the rising demands of both the HIV positive and seronegative populations. The Commission strongly believes that the Ryan White CARE Act should be funded at the fully authorized level. While comprehensive health reform is desperately needed in order to rescue a health care delivery system heading for collapse, full funding of the Ryan White CARE Act can help to fill the breach by creating cost-effective alternatives to hospitalization.

By establishing HIV Health Service Planning Councils and local consortia, the CARE Act creates an innovative community partnership process by which affected individuals and community-based organizations are empowered to participate in the decision-making process of setting priorities and allocating resources. While many communities participating in the planning process have reported frustrations regarding the adequacy of efforts to ensure that all communities are represented, this nontraditional model for decision-making has challenged many of the existing power structures and worked increasingly to allow community entities to share responsibility for determining how HIV health services are provided. The Commission is encouraged that many of these frustrations are being addressed by efforts to ensure that communities of color are adequately represented in the planning process and appropriately served by the resources available. In recent guidance to grantees, the Health Resources and Services Administration has made clear its commitment to increasing the objectivity of local needs assessment and subsequent resource allocation decisions, and to ensuring a participatory HIV Health Services Planning Council process. The Commission believes that it is important to explore the Ryan White CARE Act planning council experience and the role of representatives of communities of color as participants. This must be done in order to begin to understand what these communities have set as priorities and why, how they perceive their funding needs and their relationship to other communities, the nature of their organizational infrastructure, and the capacity of the Ryan White CARE Act to help them provide services both in the present and in the future.

The Commission believes that in addition to ensuring the availability of primary care services, it is also important to recognize that people of color living with HIV disease may not have sufficient information about the benefits of early care or may not learn of their HIV infection until far along in the disease process, despite contacts with health care providers. It is important that people of color be educated about the availability and effectiveness of early care. Thus far, educational efforts have focused on information about transmission risks and have emphasized the mortality of AIDS. Not enough effort has been made to communicate to people of color that many of the manifestations of HIV disease are amenable to prophylaxis and/or treatment. In addition, information about treatment options may be inadequate.

Many people of color are initially tested for HIV because of institutional requirements. Testing is often a condition for admission to drug treatment programs and military service, required within the criminal justice system, offered by legislative mandate (for example, to prenatal patients), or routinely practiced because of provider perception of high risk (for example, in hospital emergency and operating rooms). Except in the case of the military, the attendant counseling is often cursory, and testing frequently is not linked to the provision of medical care for HIV infection. Improvement on both counts is needed.

Increased emphasis also should be placed on training and equipping health care practitioners in communities of color to provide care to persons infected with HIV. The federal government has made important strides in this area through the development of the AIDS Education and Training Centers and through increased efforts by the National Institute of Allergy and Infectious Diseases (NIAID) to provide updates on developments in HIV care to physicians. The need continues, however, for better coordination of government dissemination of the results and implications of clinical research. Also needed is better information on the regulatory status of investigational therapies and their availability, for example, through expanded access/parallel track mechanisms. Information should also be disseminated on epidemiologic trends, such as those in tuberculosis, which may affect clinical management of persons with HIV. An effort should be made to target physicians who practice in communities of color. Similarly, there must be increased assistance to schools and professional associations that traditionally have trained and educated minority health professionals in order to assure that the populations they serve have the benefit of current developments in AIDS care and treatment. The importance of these efforts cannot be overstated, given the growing complexity of HIV-related care and treatment.

The Commission believes there is an urgent need to improve the availability of primary care services in communities of color. To accomplish this a multifaceted approach is needed, including but not limited to the following efforts.

- **The President and the Congress should increase support for community-based primary care, including community health centers, migrant health centers, and clinics funded by the Indian Health Service to ensure delivery of prevention and care services, including those for HIV/AIDS.**

- **The President and the Congress should fully fund the Ryan White CARE Act and ensure that communities of color are adequately represented in the planning process and appropriately served by the resources available.**

- **The President and the Congress should provide additional incentives for health care professionals to work in underserved areas by increasing support for programs such as the National Health Service Corps and programs such as the Disadvantaged Minority Health Improvement Act of 1990 targeted specifically at increasing the number of minority health care professionals.**

- **Likewise, state and local jurisdictions should increase support for public hospitals and other locally supported components of comprehensive primary care systems that deliver HIV prevention and care services.**

- **Additionally, the Health Resources and Services Administration should assess the capacity of special initiatives, such as the Ryan White CARE Act and the Health Care for the Homeless Program, to develop and support a strong primary care infrastructure in communities of color.**

- **The federal government should provide adequate resources to community programs designed to improve access to health care and support services and to prevent the spread of HIV among adolescents. Passage of legislation similar to the proposed Comprehensive Services for Youth Act of 1992 would foster coordination and collaboration among educators, health care providers, and community-based organizations through the development and operation of citywide and statewide youth service center systems.**

- **The Agency for Health Care Policy and Research, the Health Resources and Services Administration, and the National Institute of Allergy and Infectious Diseases should conduct a review of current efforts to educate physicians on developments in HIV/AIDS care and aggressively pursue methods to improve the quality of HIV/AIDS care. In order to assure that people of color living with HIV receive the benefit of current developments in HIV/AIDS care these agencies should strive to coordinate better the dissemination of information, target physicians who practice in communities of color, and work intensively with schools and professional associations that have traditionally trained minority health professionals.**

Clinical Trials

Historically, the National Institutes of Health-sponsored AIDS Clinical Trials Group (ACTG) protocols have included significantly lower numbers of people of color living with HIV than their proportion among the HIV-infected population would warrant. This is particularly true regarding African Americans. As of August 1992, the ACTG has enrolled 20,070 individuals in clinical trials. Of this total, 68.6 percent were white, 15.7 percent were African American, and 14.3 percent were Hispanic/Latino. Whites, African Americans, and Hispanics/Latinos account for, respectively, 53 percent, 29 percent, and 16 percent of all adult and adolescent AIDS cases (NIH, 1992).

It is also apparent that landmark studies on the treatment of HIV disease have failed adequately to enroll patients of color. In a special communication that appeared in the *Journal of the American Medical Association*, researchers from Harlem Hospital and Columbia University College of Physicians analyzed the racial composition of participants in a number of studies that dramatically influenced the treatment of HIV disease and found that the number of minority patients was disproportionately small (El-Sadr and Capps, 1992).

As a result of the underrepresentation of people of color in HIV-related clinical trials, members of racial and ethnic minorities have not had equal access to the investigational treatments available through trials. While the Commission recognizes that a relative lack of access to health care seriously hampers efforts to recruit people of color into clinical trials, this does not mean it is impossible to do so. Current efforts at the National Institutes of Health (NIH) to expand the recruitment of underrepresented populations in the ACTG have enjoyed initial success and should be continued and increased. ACTG accrual of people of color has improved over the last five years: African American and Hispanic/Latino representation in ACTG trials increased by 8.7 percent and 3.3 percent, respectively, between 1987 and 1992. (See Table 1.)

TABLE 1: Patient Accrual to ACTG Trials as of August 1992.

Population Group	Percent of Total Population	Percent of AIDS Cases	Percent in Clinical Trials 1987	Percent in Clinical Trials August 1992
Sex				
Male	48.7	88.6	95	87.0
Female	51.3	11.4	5	13.0
Race				
White	80.9	52.8	82	68.6
African American	11.7	29.5	7	15.7
Hispanic/Latino	7.4	16.5	11	14.3
Other		<1		1.4
Injection Drug Use		28.6		
Never			88	88.1
Previous/Current			12	11.9
Number of People in Trials			2,503	20,070

SOURCE: National Institutes of Health

Over the last three years people of color have been offered greater access to clinical trials through the Terry Beirn Community Programs for Clinical Research on AIDS (CPCRA) of NIAID. Established in October of 1989, the CPCRA involves 17 community-based research programs at about 160 sites in 13 U.S. cities. The program includes groups of primary care physicians and nurses who care for large numbers of people with HIV infection at community health centers and hospitals, private clinics and practices, and drug treatment facilities. The CPCRA enables community-based physicians to be involved in setting research priorities and conducting clinical trials, thereby enhancing the participation of underrepresented populations. The CPCRA has played a significant role in ensuring that research opportunities are available to people of color living with HIV. Of the 5,334 patients entered into CPCRA trials as of August 1992, more than 57.1 percent are people of color. (See Table 2.)

TABLE 2: Patient Accrual to CPCRA Studies as of August 1992.

Population Group	Percent of Total Population	Percent of AIDS Cases	Percent in Clinical Trials August 1992
Sex			
Male	48.7	88.6	80.6
Female	51.3	11.4	19.4
Race			
White	80.9	52.8	42.9
African American	11.7	29.5	39.5
Hispanic/Latino	7.4	16.5	16.0
Asian American/Pacific Islander		< 1	0.4
Native American		< 1	0.3
Other		< 1	0.7
Injection Drug Use		28.6	~40
Number of People in Trials			5,334

SOURCE: National Institutes of Health

Efforts by NIH to ensure that its HIV-related research programs more appropriately reflect the demographics of the HIV epidemic are also apparent in some of its recently implemented programs. For example, as of August 1992, 30.9 percent of all individuals (albeit only a total of 49 to date) enrolled in the NIAID-sponsored Division of AIDS Treatment Research Initiative (DATRI) program were people of color. The DATRI program provides rapid evaluation of potential therapeutic agents and regimens against manifestations of HIV disease (NIH, 1992). (See Table 3.)

Nevertheless, HIV-infected people of color continue to encounter considerable obstacles to participation in trials. Overall, the single most important factor is poor access to quality health care. Without a primary care provider knowledgeable about HIV disease, access to clinical trial opportunities is severely limited. For patients who have no previous involvement with or understanding of clinical trials and who are not well connected in the AIDS establishment, it is both difficult and frustrating to acquire and digest information about clinical trial opportunities.

In addition, the strict entry criteria traditionally associated with controlled clinical research have excluded many who wish to participate in HIV-related trials, particularly drug users and women of childbearing age. Persons with HIV who are subject to these exclusions are disproportionately people of color. This correlation can, in part, account for the racial imbalance of the ACTG accrual. By inference we can assume that efforts to improve access for persons who have been excluded owing to

TABLE 3: Patient Accrual to DATRI Studies as of August 1992.

Population Group	Percent of Total Population	Percent of AIDS Cases	Percent in Clinical Trials August 1992
Sex			
Male	48.7	88.6	87.8
Female	51.3	11.4	12.2
Race			
White	80.9	52.8	67.4
African American	11.7	29.5	26.5
Hispanic/Latino	7.4	16.5	4.1
Asian American/Pacific Islander		< 1	2.0
Native American		< 1	
Other		< 1	
Number of People in Trials			49

SOURCE: National Institutes of Health

these entry criteria would also improve access for people of color. Efforts have been initiated to address these concerns. For example, through collaboration with the National Institute on Drug Abuse (NIDA), the NIAID-sponsored ACTG has received supplementary funding of $2 million in FY 1991 to expand the inclusion of injection drug users in its trials. The ACTG and the CPCRA have also both established women's health committees to initiate new protocols to study specific manifestations of HIV infection in women, improve accrual of women, develop guidelines for uniform enrollment criteria for women, and make recommendations for further analysis of existing data on issues related to women.

In addition, both the ACTG and the CPCRA have required their sites to develop community advisory boards to ensure participation of underrepresented populations and to increase awareness of specific community requirements for participation in protocols. NIH has also instituted biannual institutional performance assessments of NIAID-sponsored ACTG and CPCRA sites to assure participation of underrepresented populations. The Commission believes these efforts should be commended and should be continued and expanded, since greater participation by traditionally excluded groups will not only provide increased access to experimental therapies for many people with HIV disease but will also contribute to a more realistic understanding of how certain experimental drugs will actually work outside a scientifically controlled environment, in all populations that might receive them.

Long-term success in incorporation of persons of color into research programs, however, can only be achieved if the concerns of people of color are addressed. Many complain that the relationship between the community and the researchers ends abruptly after data are collected, and that the community fails to reap the benefits of the research. Information does not flow back into the community to assist in setting priorities, developing programs, or providing technical assistance. Additionally, research on these populations has been undertaken without cultural considerations in the design and implementation of the research (Marín, Marín, and Juárez, 1990). It is time to overhaul these practices and provide real assistance by fostering community and/or culturally sensitive investigators, by developing culturally relevant research, and by translating research findings into community programs.

Many people of color, especially African Americans, have concerns about exploitation that has taken place in the research context in the past. The Commission heard powerful testimony about the shadow of the Tuskeegee syphilis study and the significant impact the memory of this disturbing incident has had on views of many African Americans regarding clinical research. Much must be done about the antipathy and distrust for research felt by many African Americans. Increasing the number of racial and ethnic minority health professionals would be an important step toward addressing this concern. Every effort must be made to identify, nurture, and support researchers indigenous to the communities they serve.

Attention must be focused on ethical issues surrounding research as well. The HIV epidemic has substantially changed the dynamics of power in the research environment and raised new issues regarding access to limited treatment opportunities. People of color have had to make a difficult transition–from thinking about research as something from which they should be protected to something from which they may benefit. The cognitive and behavioral dissonance created by the need for such a transition must be recognized. Focused attention should be paid to the complexities of developing a new ethos around research in communities of color and raising the awareness of researchers and others to these issues.

The Commission recommends that:

- **The National Institutes of Health, in conjunction with other appropriate agencies within the Department of Health and Human Services, should intensify efforts to assure access to HIV/AIDS clinical trial information, with regard to trial opportunities, the results of research efforts, and their significance for clinical management. Emphasis should be placed on reaching populations that have had poor or underrepresentative access to clinical trial opportunities. Efforts should include the collection and dissemination of trial-related research and information on new developments in treatment. Dissemination should be carried out in a manner that ensures that information is current, accurate, and comprehensible to target populations and the health professionals who serve them.**

The Challenge for Policymakers and Program Implementers

The Commission believes that effective intervention requires that officials understand that communities themselves are a significant unit for public health purposes. A culture is a whole way of life grounded in a particular past experience and environmental context. In important ways, it differs from any other culture in content and form. One challenge to policymakers is to comprehend and respond to the distinctiveness of varying cultural experiences, including each community's fundamental assumptions and beliefs, ethical and aesthetic values, ritual and material preferences, and historical burdens.

It is important then to recognize that each community has distinctive features, that no two communities will be alike in their response to HIV disease, and that as a consequence the process whereby a response to the HIV epidemic is mobilized in communities will vary. Understanding more about how to respond to HIV/AIDS involves understanding and respecting what each community regards as problems and priorities, acknowledging its social organization and structure, studying the historical context in which it interprets disease, and then identifying the community's available resources and the solutions it will be ready to employ. Information gathering of this sort must be supported, funded, documented, and evaluated to broaden the reach of HIV efforts.

The Commission believes that our best efforts in communities of color will be those developed by and for the people the policies are intended to influence and protect, through community-based projects at the local level. Accordingly, it is essential to include people of color in HIV policy development. In addition, HIV risk-reduction programs must be built on solid assessments of community perceptions and needs and must include ongoing involvement of community members in planning and evaluation efforts. For many communities, having people in the decision-making process who are directly affected by the policies developed will help ensure that issues of particular concern are addressed and will help overcome the distrust that pervades many communities of color. At local and national levels, this role is by no means limited to professionals, but must include community activists from a variety of backgrounds. When people of color, particularly gay men, teenagers, women, illicit substance users, and people who are HIV infected, are not consulted in the design and implementation of HIV policies and programs, efforts directed toward these audiences will not be effective.

Policymakers also must recognize that distrust on the part of the community is a legitimate barrier rooted in histories of discrimination, insufficient regard for the health of people of color, and inappropriate scientific experimentation. If it fails to recognize and pay attention to this widespread distrust, the public health community may further alienate members of the community and may miss opportunities to alter belief patterns (Thomas, 1992). Many public health officials will object that they are hearing the same old complaints from communities of color. The response to such objections is that these "old" concerns still exist in these communities as they have yet to be addressed. The failure of policymakers and public health professionals to comprehensively address community concerns contributes to the maintenance of barriers between the community and health care providers.

Policymakers and public health professionals must be willing to listen to community views and fears and, where appropriate, should acknowledge the limitations of their public health initiatives. Adopting such an approach may help public health authorities gain the credibility and the trust of communities of color. Such trust is needed to successfully implement HIV risk-reduction strategies and improve access to care in underserved communities (Thomas, 1992).

Conclusion and Recommendations

Prospects for preventing and treating HIV disease in communities of color give cause for grave national concern, notwithstanding current efforts by many committed individuals inside and outside of government. The complex link between race, socioeconomic status, and poor health has assured a difficult road ahead in our efforts to effectively confront the HIV epidemic in communities of color. The National Commission on AIDS puts forward the following recommendations as a step toward focusing greater attention on the needs of these communities and facilitating the increased availability of critical resources.

Race and Socioeconomics

- **Federal, state, and local governments should squarely confront problems associated with racial inequality and its effect on the public health. Public health officials should ensure that effective and equitable HIV policy, programs, and funding efforts are brought to bear in communities of color.**

- **Public health officials should work with researchers, health professionals, and community-based service providers to gain a better understanding of the role of cultural and socioeconomic factors in the transmission of HIV, the disease process, and access to care. Information gleaned from these efforts should be taken into account in designing HIV prevention messages, services, and programs, and in providing expanded treatment opportunities.**

Prevention

- **The Centers for Disease Control and Prevention should review the adequacy of demographic information regarding HIV/AIDS currently available by race, ethnicity, and nationality, particularly with regard to Asian Americans/Pacific Islanders and Native Americans. Additionally, the National Center for Health Statistics should make information available regarding HIV/AIDS knowledge, attitudes, beliefs, and behaviors among Asian Americans/Pacific Islanders and Native Americans.**

- **The Centers for Disease Control and Prevention should ensure that the prevention and education needs of persons of color who engage in high-risk behaviors are appropriately addressed by current and future prevention initiatives and funding efforts. Programs specifically targeted toward men of color who have sex with other men, toward injection drug users, and toward women are needed.**

- **Federal, state, and local governments should join forces with the private sector in providing long-term support to community-based organizations serving communities of color. As part of this effort, the U.S. Public Health Service should expand and promote comprehensive and integrated programs for technical assistance to and capacity building in these communities.**

Health Care

The Commission believes there is an urgent need to improve the availability of primary care services in communities of color. To accomplish this a multifaceted approach is needed, including but not limited to the following efforts.

- **The President and the Congress should increase support for community-based primary care, including community health centers, migrant health centers, and clinics funded by the Indian Health Service to ensure delivery of prevention and care services, including those for HIV/AIDS.**

- **The President and the Congress should fully fund the Ryan White CARE Act and ensure that communities of color are adequately represented in the planning process and appropriately served by the resources available.**

- **The President and the Congress should provide additional incentives for health care professionals to work in underserved areas by increasing support for programs such as the National Health Service Corps and programs such as the Disadvantaged Minority Health Improvement Act of 1990 targeted specifically at increasing the number of minority health care professionals.**

- **Likewise, state and local jurisdictions should increase support for public hospitals and other locally supported components of comprehensive primary care systems that deliver HIV prevention and care services.**

- **Additionally, the Health Resources and Services Administration should assess the capacity of special initiatives, such as the Ryan White CARE Act and the Health Care for the Homeless Program, to develop and support a strong primary care infrastructure in communities of color.**

- **The federal government should provide adequate resources to community programs designed to improve access to health care and support services and to prevent the spread of HIV among adolescents. Passage of legislation similar to the proposed Comprehensive Services for Youth Act of 1992 would foster coordination and collaboration among educators, health care** providers, and community-based organizations through the development and operation of citywide and statewide youth service center systems.

- The Agency for Health Care Policy and Research, the Health Resources and Services Administration, and the National Institute of Allergy and Infectious Diseases should conduct a review of current efforts to educate physicians on developments in HIV/AIDS care and aggressively pursue methods to improve the quality of HIV/AIDS care. In order to assure that people of color living with HIV receive the benefit of current developments in HIV/AIDS care these agencies should strive to coordinate better the dissemination of information, target physicians who practice in communities of color, and work intensively with schools and professional associations that have traditionally trained minority health professionals.

Clinical Trials

- The National Institutes of Health, in conjunction with other appropriate agencies within the Department of Health and Human Services, should intensify efforts to assure access to HIV/AIDS clinical trial information, with regard to trial opportunities, the results of research efforts, and their significance for clinical management. Emphasis should be placed on reaching populations that have had poor or underrepresentative access to clinical trial opportunities. Efforts should include the collection and dissemination of trial-related research and information on new developments in treatment. Dissemination should be carried out in a manner that ensures that information is current, accurate, and comprehensible to target populations and the health professionals who serve them.

Social Services

- The federal government should work with the states to establish and support foster care programs for children with HIV infection and noninfected youth orphaned by the loss of parents to HIV/AIDS. Federal and state government should also support programs designed to assist family members in caring for children whose lives have been affected by HIV/AIDS.

In addition to the recommendations offered above, many of the recommendations set forth in previous reports and statements issued by the Commission are relevant to efforts to address the HIV/AIDS epidemic in communities of color. In particular, the Commission directs attention to the following reports and statements: *America Living with AIDS, HIV Disease in Correctional Facilities, The Twin Epidemics of Substance Use and HIV, The HIV/AIDS Epidemic in Puerto Rico, Housing and the HIV/AIDS Epidemic,* and *Resolution on U.S. Visa and Immigration Policy.*

Part II

Community Profiles

The African American Community

Community Description

The African American community is the largest community of color in the United States, constituting 12 percent of the U.S. population and consisting of many different groups with different cultural backgrounds, religious beliefs and affiliations, and political views. It contains not only those whose ancestors were brought here as slaves as early as the 17th century, but also recent immigrants who come from areas as diverse as the Caribbean islands, Europe, and Africa. African Americans live in all parts of the country and are found in every socioeconomic stratum. As many as half of all African Americans live in inner cities, in areas with pervasive poverty, poor schools, and inadequate social services, housing, and job opportunities; a third of African Americans live below the poverty line.

Epidemiology

Of the four communities of color, the African American community is by far the most disproportionately represented with respect to HIV/AIDS. As of October 1992, the Centers for Disease Control reported 71,984 cases of AIDS so far among African Americans in the United States (CDC, 1992e). (See Table 4.) This represents nearly 30 percent of all documented AIDS cases. By 1990, AIDS had become the leading cause of death nationwide for African American men between the ages of 35 and 44 and the second leading cause of death for African American men and women between the ages of 25 and 36. It is estimated that in 1992 one African American person per hour will die of AIDS in the United States.

Of the 71,984 total AIDS cases among African Americans, 56,081 (78%) have been in adult men (13 years of age or older) and 13,711 cases (19%) in adult women (13 years of age or older); the remaining 2,192 cases (3%) are classified as pediatric (in children younger than 13 years of age). (See Table 4.) For African American men, who account for 26 percent of AIDS cases in all adult men in the nation, homosexual contact accounts for 43 percent of the cases and injection drug use accounts for 36 percent. Men who have sex with men and also inject drugs account for another 7 percent of the cases.

TABLE 4: Adult/adolescent AIDS Cases by Sex, Exposure Category, and Race/ethnicity, Reported through September 1992, United States.

	African American		Total[4]	
	Number	Percent	Number	Percent
ADULT/ADOLESCENT				
MALE				
Exposure category				
Men who have sex with men	24,287	(43)	136,912	(65)
Injection drug use	20,000	(36)	41,631	(20)
Men who have sex with men and inject drugs	4,198	(7)	15,203	(7)
Hemophilia/coagulation disorder	152	(0)	1,910	(1)
Heterosexual contact:	4,138	(7)	5,983	(3)
Sex with injection drug user	1,438		2,448	
Sex with person with hemophilia	3		12	
Born in Pattern II[1] country	1,975		2,003	
Sex with person born in Pattern II country	52		105	
Sex with transfusion recipient with HIV infection	24		94	
Sex with HIV-infected person, risk not specified	646		1,321	
Receipt of blood transfusion, blood components, or tissue[2]	476	(1)	2,956	(1)
Other/undetermined[3]	2,830	(5)	7,553	(4)
Subtotal	56,081	(100)	212,148	(100)
FEMALE				
Exposure category				
Injection drug use	7,410	(54)	12,844	(50)
Hemophilia/coagulation disorder	8	(0)	43	(0)
Heterosexual contact:	4,870	(36)	9,238	(36)
Sex with injection drug user	2,837		5,612	
Sex with bisexual male	268		789	
Sex with person with hemophilia	12		110	
Born in Pattern II country	830		841	
Sex with person born in Pattern II country	75		90	
Sex with transfusion recipient with HIV infection	33		196	
Sex with HIV-infected person, risk not specified	815		1,600	
Receipt of blood transfusion, blood components, or tissue	400	(3)	1,877	(7)
Other/undetermined	1,023	(7)	1,945	(7)
Subtotal	13,711	(100)	25,947	(100)

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[1] "Heterosexual contact" cases include persons who report either specific heterosexual contact with a person with, or at increased risk for, HIV infection (e.g., an injection drug user), or persons presumed to have acquired HIV infection through heterosexual contact because they were born in countries with a distinctive pattern of transmission termed "Pattern II" by the World Health Organization (MMWR 1988;37:286-8,293-5). Pattern II transmission is observed in areas of sub-Saharan Africa and in some Caribbean countries. In these countries, most of the reported cases occur in heterosexuals and the male-to-female ratio is approximately 1:1. Injection drug use and homosexual transmission either do not occur or occur at a low level.

[2] Nineteen adults/adolescents and two children developed AIDS after receiving blood screened negative for HIV antibody. Five additional adults developed AIDS after receiving tissue or organs from HIV-infected donors. Two of the five received tissue or organs from a donor who was negative for HIV antibody at the time of donation.

[3] "Other" refers to seven health care workers who developed AIDS after occupational exposure to HIV-infected blood, as documented by evidence of seroconversion; and to two patients who developed AIDS after exposure to HIV within the health care setting, as documented by laboratory studies. "Undetermined" refers to patients whose mode of exposure to HIV is unknown. This includes patients under investigation; patients who died, were lost to follow-up, or refused an interview; and patients whose mode of exposure to HIV remains undetermined after investigation.

[4] Includes 551 persons whose race/ethnicity is unknown.

SOURCE: Adapted from CDC HIV/AIDS Surveillance, October 1992.

TABLE 4 continued: Pediatric AIDS Cases by Sex, Exposure Category, and Race/ethnicity, Reported through September 1992, United States.

	African American		Total[4]	
	Number	Percent	Number	Percent
PEDIATRIC				
Exposure category				
Hemophilia/coagulation disorder	25	(1)	183	(5)
Mother with/at risk for HIV infection via:	2,050	(94)	3,480	(86)
Injection drug use	967		1,634	
Sex with injection drug user	320		704	
Sex with bisexual male	27		77	
Sex with person with hemophilia	5		18	
Born in Pattern II[1] country	266		271	
Sex with person born in Pattern II country	15		17	
Sex with transfusion recipient with HIV infection	5		17	
Sex with HIV-infected person, risk not specified	87		176	
Receipt of blood transfusion, blood components, or tissue	33		75	
Has HIV infection, risk not specified	325		491	
Receipt of blood transfusion, blood components, or tissue[2]	67	(3)	303	(7)
Other/undetermined[3]	50	(2)	85	(2)
Subtotal	2,192	(100)	4,051	(100)

NOTE: See technical notes and source from Table 4.

Among African American women, who account for 53 percent of AIDS cases in all adult women in the nation, injection drug use is by far the most common mode of transmission, accounting for 54 percent of cases. Heterosexual contact with an injection drug user accounts for another 21 percent. Six percent of the cases in African American women have been due to heterosexual contact with an HIV-infected person who is not an injection drug user.

African American children have accounted for 54 percent of all the reported pediatric AIDS cases in children of all races in the nation (CDC, 1992e). Of the 2,192 pediatric AIDS cases among African American children, 94 percent have been due to perinatal transmission from mothers infected with HIV. Only 4 percent have been due to hemophilia-related blood products or the receipt of an HIV-contaminated blood transfusion. The mode of transmission of the remaining 2 percent cannot be determined.

Although numbers of cases of CDC-defined AIDS are useful in assessing HIV's impact on a community, measurements of the prevalence and incidence of antibody to HIV are helpful predictors of the direction the epidemic will take in the future. Certain studies of HIV antibody prevalence have reported valuable data on the African American community. The results of HIV screening of all active-duty U.S. Army soldiers in 1985 through 1989 showed a seroprevalence among African Americans of 0.51 percent, or 5.1 per 1,000 soldiers (Kelley et al., 1990). Applicants for U.S. military service were screened in a second survey, which found a seroprevalence among African American teenage applicants of 1.0 per 1,000 (0.1%), compared with 0.17 per 1,000 for whites and 0.29 for Hispanics/Latinos (Burke et al., 1990). Another study looked at applicants for the Job Corps, who tend to be from lower socioeconomic backgrounds. Among African American applicants, the seroprevalence rate was 0.53 percent, or 5.3 per 1,000 (St. Louis et al., 1991).

Besides seroprevalence, seroconversion (to HIV-antibody positive) is also a useful predictor of the impact HIV/AIDS will have on a community. One military survey found a seroconversion rate among African American active-duty soldiers in the U.S. Army of 0.73 per 1,000 person-years during the last two years of the study, 1988 to 1989 (McNeil et al., 1991).

Knowledge, Attitudes, Beliefs, and Behaviors

Questions about AIDS have been included in the National Health Interview Survey (NHIS) since 1987. The National Center for Health Statistics (NCHS) conducted a study on knowledge and attitudes about HIV and AIDS in different racial and ethnic minorities, using the data gathered in the 1990 NHIS. The single most important finding was that the highest levels of knowledge among African Americans were found in the younger groups and in those with the most education (Hardy and Biddlecom, 1991).

The study found that 88 percent of African Americans surveyed had received some form of information concerning HIV or AIDS in the previous month. Television was the most popular source of information (77%), followed by newspapers (45%), and magazines (40%). Radio was a source of information for 30 percent of the respondents. Men were much more likely than women to list radio as a source of information (34% and 27%, respectively). Overall, those with higher levels of education tended to use print media as a source of information more often than electronic media.

Among those surveyed with children 10 to 17 years old, 79 percent of women reported discussing HIV and AIDS with their children, compared with only 56 percent of the men. A similar gender difference was found among white parents of children 10 to 17, with 80 percent of women and 58 percent of men reporting discussion on HIV/AIDS with their children. Seventy-five percent of African American parents stated that their children 10 to 17 years old had received AIDS education in school. Approximately the same proportion of white adults, 74 percent, also said that their children received AIDS education in school.

In the area of general AIDS knowledge, a majority of the African Americans surveyed knew the major modes of transmission of HIV (unprotected sex, injection drug use, and perinatal transmission). However, misconceptions still existed about other possible modes of transmission. For example, only 42 percent of those surveyed who had more than 12 years of education correctly indicated that it is highly unlikely for a person to acquire HIV via mosquito bites and only 47 percent correctly indicated that transmission is unlikely to occur from being coughed or sneezed on. Such misconception regarding HIV transmission is troubling because it can lead to unwarranted fear and discrimination.

Only 68 percent of African Americans surveyed knew about the availability of an HIV-antibody test; only 14 percent reported that they had been tested. Of that 14 percent, 51 percent did so voluntarily while the other 44 percent reported being tested mandatorily. Fifty-two percent of those tested reported receiving pretest counseling, and 43 percent reported receiving posttest counseling. When asked if they were aware of the availability of medications that could prolong the life of a person with HIV disease or AIDS, 52 percent of the respondents with more than 12 years of education answered affirmatively. Only 31 percent of those with less than 12 years of education answered affirmatively to this question.

Finally, in response to questions on the perceived efficacy of condom use, 28 percent answered that they thought that condoms were "very effective" in preventing HIV transmission. Another 44 percent believed that condoms were "somewhat effective" (Hardy and Biddlecom, 1991).

A different NCHS study looked at the knowledge and attitudes about HIV among women. The study surveyed a total of 8,450 women (641 Hispanic/Latina, 2,771 African American, and 5,354 white). Overall, the study showed that the majority of women surveyed, 85 percent, had correct information. Small differences were found among race, income, and marital status groups, with all groups showing levels of misinformation at or below 8 percent. For most items discussed in the report, low-income women and African American women were more likely to have misinformation on HIV transmission and more likely to say they had a greater chance of contracting the disease. However, both these groups were likely to report making changes in their sexual behavior since hearing of AIDS (McNally and Mosher, 1991).

Several studies have been conducted to define African American adolescents' level of knowledge about HIV and practices related to injection drug use. One such study (Holtzman et al., 1991) looked at injection drug use among adolescents and the effects of education on this behavior. A small percentage (1.3%) of African American male adolescents reported having used injection drugs in the previous year. The researchers also found a high correlation between lack of HIV education and the use of injection drugs. Finally, the study showed that, of the adolescents who had been given adequate HIV education, African American males were less likely than any other racial or ethnic group to inject drugs or share needles.

Other studies have looked at sexual behavior and practices in subpopulations of the African American community. The Youth Risk Behavior Survey of high school students (CDC, 1992b) found that 60 percent of the African American males and 20 percent of the African American females reported having had four or more sex partners. Furthermore, the survey results showed that only 55 percent of the males and 37 percent of the females reported having used a condom during their most recent intercourse. In a second survey of 16- to 19-year-olds, only 28 percent of African American adolescents reported always using a condom (Hingson and Strunin, 1990).

The National Survey of Adolescent Males (1988) conducted by the Urban Institute found that 69 percent of African Americans had had sexual intercourse by the age of 15; this compares with an average of 33 percent of all participants in the study, regardless of race. Moreover, the study found that 96 percent of 19-year-old African American males had had sexual intercourse, compared with 86 percent of all participants of the same age (Sonenstein, Pleck, and Ku, 1989).

The National Survey of Family Growth conducted by the National Center for Health Statistics looked at the same variables with regard to African American women aged 15 to 44 and found that 17 percent of 15-year-olds, 50 percent of 17-year-olds, and 81 percent of 19-year-olds had had sexual intercourse. This compares with averages of all the females surveyed (regardless of race) in these age groups of 10 percent of 15-year-olds, 35 percent of 17-year-olds, and 63 percent of 19-year-olds (Miller, Turner, and Moses, 1990).

Health Status

The African American community has major health concerns besides HIV disease that must be confronted if the community as a whole is to thrive. Many of these concerns are directly related to the fact that African Americans as a group receive lower levels of routine and preventive health services than other ethnic groups. According to one report, 20 percent of African Americans do not have any usual source of medical care, 22 percent have no private or public health insurance, and as many as 20 percent of African American children are incompletely immunized against the common vaccine-preventable diseases (Department of Health and Human Services, 1992).

This lack of regular health care permeates every aspect of the health of the African American community. For example, African American men have a 25 percent higher incidence of all cancers and a 45 percent higher risk of lung cancer than men in general. Furthermore, only 38 percent of African Americans survive 5 years after cancer is diagnosed, compared with 52 percent in the nation as a whole (Department of Health and Human Services, 1992).

The average life expectancy in the African American community is far lower than the national average. In 1989 African Americans in the United States had an average life expectancy of 69.2 years, compared with 75.3 years for the population as a whole. Between 1984 and 1989, the life expectancy of African Americans decreased from a high of 69.7 years. The infant mortality rate of African Americans is much higher than that of the overall population; African American infants are twice as likely as white infants to die before their first birthday. Many of these deaths are due to prematurity and low birth weight; however, other causes include sudden infant death syndrome, respiratory distress syndrome, infections, and injuries. The maternal mortality rate in the African American community stands at 18.6 deaths per 100,000 live births; this is more than twice the national average of 7.3 deaths per 100,000 live births (Department of Health and Human Services, 1992).

African American teenage pregnancy rates have been dropping since the 1960s (Department of Health and Human Services, 1992); nevertheless, because of the increase in the number of teenage girls in the population, the actual number of African American teenage pregnancies has increased and is several times larger than the number of teenage pregnancies among white teenagers and other ethnic groups.

The incidence of death from stroke in the African American population is twice the national average (Department of Health and Human Services, 1992). This is probably related to the very high incidence of hypertension and diabetes, both of which affect African Americans at disproportionate rates. In addition, the prevalence of tobacco use in the African American community is high and in some areas is rising. One particularly chilling statistic is that for African Americans 15 to 34 years old, homicide is the leading cause of death (Hammett et al., 1992).

Sexually transmitted disease incidence in the African American community is extremely high. African Americans accounted for 78 percent of all reported cases of gonorrhea and 76 percent of all reported cases of primary and secondary syphilis in the United States in 1988. The prevalence of antibody to the herpes simplex virus type 2 was also much higher in the African American community than in any other group. The average prevalence was 41 percent and increased with age; African American women aged 60 to 74 had the highest prevalence at 80 percent (Moran et al., 1989).

Programs

Since the mid-1980s, prevention activities have been increasingly targeted toward African American communities. Funding by Public Health Service agencies such as the Centers for Disease Control, the National Institute on Drug Abuse, and the Office of Minority Health have contributed to the support of a variety of African American community-based organizations working with AIDS, such as Blacks Educating Blacks about Sexual Health Issues (BEBASHI) in Philadelphia and Support Organization for AIDS Prevention (SOAP) in Los Angeles. In addition, funding has been provided to national organizations serving African Americans in an effort to increase the involvement of traditional leadership organizations in the fight against HIV/AIDS. Organizations that have been supported under this program include the National Medical Association, the National Urban League, and the Southern Christian Leadership Conference. As awareness about the disproportionate impact of the HIV/AIDS epidemic on African American communities has grown, funding from private sources has also increased.

Despite support from both public and private funding sources, organizations providing HIV/AIDS services in African American communities face considerable hardship, as they often do not have access to adequate and sustained funding. For these organizations, developing a sufficient infrastructure to provide ongoing and increasingly comprehensive services and to compete successfully for scarce resources are significant challenges. Thus, a large portion of resources has been devoted to technical assistance and informational materials on the development and management of resources.

In addition, volunteering and activism related to HIV/AIDS in the African American communities have increased in importance. While many African Americans have devoted significant time and effort to AIDS activities, they often lack sufficient support. To some degree, AIDS program efforts in African American communities and in other communities of color have suffered because there has not been a united effort within the community to pressure public health authorities and other governmental agencies to provide resources and services. In part this has been due to bias against gays and injection drug users and to the continuing need to focus attention on longstanding political and social problems, including significant health concerns other than AIDS.

Most importantly, HIV program efforts in the African American community have suffered because governmental entities have failed to adequately comprehend the sociological, attitudinal, behavioral, and gender complexities of the African American community–all of which play a role in the course of the HIV/AIDS epidemic. Attention to the cultural aspects of the HIV/AIDS epidemic in this community is critically needed.

Community Concerns

In December 1990, the Commission held a hearing in Baltimore on HIV disease in African American communities. In addition, over the past two years the Commission has heard from individuals, organizations, and service providers in a variety of settings regarding the impact of HIV/AIDS on African American communities. Among the concerns raised were:

Conspiracy theories. Many in the African American community contend that the virus was man-made. A vocal contingent believes that HIV was the result of biological warfare development by the U.S. Army or the CIA or some other agency. Some in this contingent believe that the virus was deliberately introduced into African and African American communities as part of a genocidal plan. Similarly, the drug epidemic in African American communities is seen as part of a conspiracy to destroy the community. People who believe these theories are inclined to distrust governmental efforts to combat the HIV epidemic and to disbelieve government prevention and treatment messages.

Discrimination. There is great concern in African American communities about the degree to which being HIV positive adds to the already substantial burdens of race, gender, class, and sexual orientation. These burdens may include discrimination that limits opportunities for employment, education, housing, and health care in ways that might not apply to more affluent white gay men who have greater resources and support systems.

Disproportionate impact. Unquestionably, HIV/AIDS has hit the African American community hard. Indeed, if one speaks about women and AIDS, one is speaking about African American women. If one speaks about children and AIDS, one is speaking about African American children. If one speaks about injection drug users and AIDS, one is speaking about people in the African American community. Similarly, if one speaks about gay men and AIDS, one is speaking about African American men, since roughly half of African American men who are infected are men who have sex with other men.

Drug users. African Americans who are infected by virtue of drug use or sexual contact with drug users have an experience of the health care system marked by alienation. They are often victims of the prejudice against substance users that permeates the health care system. Health care providers tend to blame them for their problems and treat them with something less than the dignity with which all would like to be treated when ill. In addition, drug users face considerable obstacles in obtaining community support. Many African American communities bear the brunt of the disastrous consequences of the drug epidemic and governmental efforts to mount a war on drugs (e.g., gang warfare, violence, crime, and addiction). In these communities there is some ambivalence about using scarce resources to assist people who engage in drug use and commerce and who on the whole are viewed as a threat to the community.

History of mistrust. Another tragic dimension of the HIV/AIDS epidemic is that in striking the African American community the HIV epidemic affects a population already alienated from the health care system and the government, a population that is somewhat cynical about the motives of those who arrive in their communities to help them. Alienation is, in part, a product of the historical relationship between African Americans and whites in the United States. This relationship was born in the peculiar institution of slavery. In 1990, we as a nation are still living out the legacy of that history. Until and unless that reality is taken into account, a full understanding of how to deal with AIDS insofar as it differentially affects African Americans will be impossible.

Homophobia. As in mainstream culture, many individuals, families, and formal leadership structures in the African American community (such as churches, fraternities, professional organizations, and others) have difficulty dealing with issues of sexual orientation. Thus, issues of concern to the African American gay, bisexual, and lesbian community are often ignored, and African American gays, bisexuals, and lesbians themselves have been rendered invisible. Testing HIV positive has added an extra burden to many gay and bisexual men of color already struggling to maintain a support base of family and friends. Indeed the stigma of homosexuality among African Americans has led many to misrepresent their mode of exposure to HIV.

Immigration. U.S. immigration policy, which currently excludes persons who are HIV seropositive from traveling to, immigrating to, or seeking refuge or asylum in the United States, has had a disproportionately harsh impact on HIV-seropositive Haitian asylum-seekers. Currently, more than 270 Haitians are confined by the U.S. government to a detention camp on Guantanamo Naval Base, Cuba, despite having been found by the Immigration and Naturalization Service to have a "credible" fear of persecution if forcibly returned to Haiti.

Kemron. Individuals and organizations in the African American community have expressed interest in a government-sponsored trial of the drug Kemron/Immuviron in the United States. Kemron/Immuviron is an oral, alpha-interferon preparation that was first tested as a treatment for AIDS at the Kenya Medical Research Institute in Nairobi.

Leadership. Although organizations and leaders in the African American communities are certainly more active in the fight against AIDS in general than they were a few years ago, questions regarding the adequacy of leadership efforts continue to be raised. As the devastation in these communities becomes more and more inescapable, there is a growing resolve not to wait for leadership from the federal government. Additionally, while many in the community believe that engaging traditional African American leadership organizations such as the church is very important, it has become increasingly clear that it may be a mistake to rely solely on traditional mechanisms for the response needed to effectively confront the HIV epidemic. AIDS may never be as high a priority for some of these organizations as one might like it to be. As the epidemic has progressed, new organizations have grown up around AIDS in African American communities and new leaders have emerged. It is important to nurture and support these individuals and entities as work continues to involve traditional leadership organizations more fully in HIV/AIDS efforts.

Needle exchange. It has been suggested that the controversy over needle exchange is in a way a metaphor for the deep skepticism in the African American community about the motivations of the AIDS establishment. There is a continuing uneasiness in many quarters about the focus on AIDS in the African American community while many other health problems seem to be receiving less and less public attention and funding. In the face of remarkable inattention to and disregard for the health status of African Americans in general, many people ask, "Are they interested in the spread of AIDS because they are concerned about us or are they interested in us because they are concerned about the spread of AIDS?" In addition, many people in the African American community are convinced that needle exchange programs will only lead to greater availability of needles, which in turn will result in an increase in injection drug use.

Origins of HIV. The question of the origin of HIV has commanded a great deal of attention in the African American community, since a body of scientific research suggests that the virus first appeared in central Africa. Many people in the African American community resent the speculation about the origin of HIV being in Africa, because they fear that they are being blamed for the epidemic.

Orphans and abandoned children. Thousands of African American children are being orphaned as their parents die from AIDS. This reality has spawned concern regarding the future of these children, the burden placed on other family members (particularly grandparents), and the ability of an already overloaded foster care system to effectively care for them. Abandoned children who have been drug exposed and/or HIV infected are a part of the boarder baby problem in many inner city hospitals.

Other health concerns. In the African American community, as in other communities of color, one must contend with the reality that there are many other health and social problems that, although interacting with the HIV epidemic, preceded it. Thus, AIDS is but one of many health concerns affecting African American communities. Currently, African Americans suffer disproportionately from a number of health problems, including high rates of infant mortality, heart disease, diabetes, certain cancers, and homicide. Furthermore, HIV/AIDS is increasingly intertwined with problems of poverty, poor education, drug dependence, homelessness, and inadequate health care.

Research. The African American community's perspective on medical research has a historical basis that sometimes outweighs the demonstrable integrity and commitment of the individual investigators or institutions conducting AIDS or other biomedical research. Countless witnesses spoke to the Commission about the history of the Tuskeegee Syphilis Study as a foundation for African American fear of experimentation and distrust of research initiatives.

Stigmatization. Many people fear that emphasizing the differential impact of HIV/AIDS on African Americans serves only to reinforce stereotypes and to foster discrimination. The community's fear of stigmatization is in many ways informed by the experience of the Haitian community, who early in the epidemic suffered severe stigmatization after being designated a risk group for AIDS.

Women. African American women who are HIV infected have reported numerous barriers to accessing health care services. Some women fail to seek care for themselves because they are preoccupied by caring for their mates or children. Others face discriminatory circumstances when they attempt to secure care because they are injection drug users, are the sexual partners of injection drug users, or are of childbearing age. Many women, however, face moral scrutiny regarding their reproductive choices when they seek health care services. A number of disturbing reports have surfaced regarding the refusal of clinics that serve poor women of color to perform abortions on women known to be HIV positive. Ironically, women have also reported being forcibly or unknowingly sterilized because of their HIV status or drug use.

The Hispanic/Latino Community

Community Description

The ethnic community recognized by the federal government as Hispanic is extremely diverse; it includes people, both African American and white, whose roots can be traced to Spanish-speaking countries in Central America, South America, the Caribbean, and Spain. This diversity provides for a variety of traditions and regional and demographic characteristics, some of which may be unique to a particular group; nevertheless, the people in this ethnic group are linked by shared cultural values. The largest group among Hispanics/Latinos in the United States are the Mexican Americans (64%), followed by other Central and South Americans (14%), Puerto Ricans (11%), and Cubans (5%). The states with the largest Hispanic/Latino populations are California, Texas, and Florida, but large numbers of Hispanics/Latinos also live in Arizona, New Mexico, Colorado, New York, New Jersey, and Illinois. Puerto Rico, which is almost entirely Hispanic/Latino, has a population of 3.6 million.

According to the 1990 Census Profile, the Hispanic/Latino population in the United States increased by 53 percent in the 1980s (from 14.6 million to 22.42 million), with the highest growth rate concentrated in the West (62%). This growth can be attributed to several factors, such as immigration and natural increase (births minus deaths), and can be determined by fertility rates and the age of the population (Bureau of the Census, 1991a).

The median age of Hispanics/Latinos is 26 years, compared with 34 for non-Hispanics. Half of the Hispanic/Latino population are younger than 18 years old, and a third are younger than 15. The socioeconomic status of Hispanics/Latinos has remained the same since 1980 (Giachello, 1991); 25 percent of Hispanic/Latino families were living in poverty in 1990, compared with 9.5 percent of non-Hispanic families (Bureau of the Census, 1991b). Given these conditions, HIV/AIDS is one of many issues to be dealt with, together with unemployment, inadequate housing, generally poor health, and others.

Epidemiology

According to CDC-reported data (CDC, 1992e), 17 percent of all reported AIDS cases have occurred among members of the Hispanic/Latino community although this ethnic group makes up only 9 percent of the total population of the United States. Of AIDS cases among Hispanic/Latino adults and adolescents, 46 percent are reported as arising from exposure between men who have sex with men, 40 percent (for males and females) are from exposure via injection drug use, and 7 percent are from exposure due to heterosexual contact. (See Table 5.)

TABLE 5: Adult/adolescent AIDS Cases by Sex, Exposure Category, and Race/ethnicity, Reported through September 1992, United States.

	Hispanic/Latino		Total[4]	
	Number	Percent	Number	Percent
ADULT/ADOLESCENT				
MALE				
Exposure category				
Men who have sex with men	15,671	(46)	136,912	(65)
Injection drug use	13,077	(39)	41,631	(20)
Men who have sex with men and inject drugs	2,233	(7)	15,203	(7)
Hemophilia/coagulation disorder	158	(0)	1,910	(1)
Heterosexual contact:	786	(2)	5,983	(3)
Sex with injection drug user	416		2,448	
Sex with person with hemophilia	2		12	
Born in Pattern II[1] country	10		2,003	
Sex with person born in Pattern II country	10		105	
Sex with transfusion recipient with HIV infection	22		94	
Sex with HIV-infected person, risk not specified	326		1,321	
Receipt of blood transfusion, blood components, or tissue[2]	293	(1)	2,956	(1)
Other/undetermined[3]	1,732	(5)	7,553	(4)
Subtotal	33,950	(100)	212,148	(100)
FEMALE				
Exposure category				
Injection drug use	2,627	(48)	12,844	(50)
Hemophilia/coagulation disorder	3	(0)	43	(0)
Heterosexual contact:	2,152	(40)	9,238	(36)
Sex with injection drug user	1,650		5,612	
Sex with bisexual male	97		789	
Sex with person with hemophilia	6		110	
Born in Pattern II country	7		841	
Sex with person born in Pattern II country	3		90	
Sex with transfusion recipient with HIV infection	33		196	
Sex with HIV-infected person, risk not specified	356		1,600	
Receipt of blood transfusion, blood components, or tissue	256	(5)	1,877	(7)
Other/undetermined	381	(7)	1,945	(7)
Subtotal	5,419	(100)	25,947	(100)

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[1] "Heterosexual contact" cases include persons who report either specific heterosexual contact with a person with, or at increased risk for, HIV infection (e.g., an injection drug user), or persons presumed to have acquired HIV infection through heterosexual contact because they were born in countries with a distinctive pattern of transmission termed "Pattern II" by the World Health Organization (MMWR 1988;37:286-8,293-5). Pattern II transmission is observed in areas of sub-Saharan Africa and in some Caribbean countries. In these countries, most of the reported cases occur in heterosexuals and the male-to-female ratio is approximately 1:1. Injection drug use and homosexual transmission either do not occur or occur at a low level.

[2] Nineteen adults/adolescents and two children developed AIDS after receiving blood screened negative for HIV antibody. Five additional adults developed AIDS after receiving tissue or organs from HIV-infected donors. Two of the five received organs or tissue from a donor who was negative for HIV antibody at the time of donation.

[3] "Other" refers to seven health care workers who developed AIDS after occupational exposure to HIV-infected blood, as documented by evidence of seroconversion; and to two patients who developed AIDS after exposure to HIV within the health care setting, as documented by laboratory studies. "Undetermined" refers to patients whose mode of exposure to HIV is unknown. This includes patients under investigation; patients who died, were lost to follow-up, or refused an interview; and patients whose mode of exposure to HIV remains undetermined after investigation.

[4] Includes 551 persons whose race/ethnicity is unknown.

SOURCE: Adapted from CDC HIV/AIDS Surveillance, October 1992.

TABLE 5 continued: Pediatric AIDS Cases by Sex, Exposure Category, and Race/ethnicity, Reported through September 1992, United States.

	Hispanic/Latino		Total[4]	
	Number	Percent	Number	Percent
PEDIATRIC				
Exposure category				
Hemophilia/coagulation disorder	28	(3)	183	(5)
Mother with/at risk for HIV infection via:	868	(88)	3,480	(86)
Injection drug use	409		1,634	
Sex with injection drug user	276		704	
Sex with bisexual male	17		77	
Sex with person with hemophilia	2		18	
Born in Pattern II[1] country	3		271	
Sex with person born in Pattern II country	1		17	
Sex with transfusion recipient with HIV infection	7		17	
Sex with HIV-infected person, risk not specified	48		176	
Receipt of blood transfusion, blood components, or tissue	19		75	
Has HIV infection, risk not specified	86		491	
Receipt of blood transfusion, blood components, or tissue[2]	71	(7)	303	(7)
Other/undetermined[3]	17	(2)	85	(2)
Subtotal	984	(100)	4,051	(100)

NOTE: See technical notes and source from Table 5.

Quantifying homosexual/bisexual AIDS cases is difficult because of the cultural belief held by many in the Hispanic/Latino community that, of men who have sex with other men, only the receptive partner in anal intercourse is homosexual, whereas the insertive partner is not considered homosexual (Carrier and Magaña, 1991; Magaña and Carrier, 1991). This belief may skew statistics dealing with homosexual/bisexual infection rates since there are Hispanic/Latino men who fit these categories but who do not identify themselves accordingly (Chu et al., 1992). Heterosexual transmission is responsible for 7 percent of AIDS cases, and another 39 percent of the Hispanic/Latino men with AIDS have become infected through injection drug use (CDC, 1992e).

The Hispanic/Latino community has been hard hit in other ways. As of the end of September 1992, Hispanic/Latina women accounted for 21 percent of all reported AIDS cases among women and 20 percent of cases among adolescents (ages 13 to 19) and Hispanics/Latinos accounted for 24 percent of all pediatric cases (CDC, 1992e).

Pediatric cases are primarily due to perinatal transmission from a mother who contracted the virus via unprotected sex with an injection drug user (32%) or through her own use of injection drugs (47%). Maternal exposure via sex with bisexual men accounts for another, albeit smaller, element of infection in children (2%) (CDC, 1992e).

National seroprevalence surveys conducted in a variety of clinical settings in 44 metropolitan areas provided disheartening information regarding the spread of HIV. From 1988 to 1990, results reported from surveys conducted in sexually transmitted disease (STD) clinics in 44 areas found a nationwide median HIV seroprevalence of 2.1 percent. The highest HIV-seropositivity rates among injection drug users tested in the STD clinics were found in Florida, Puerto Rico, and the Mid-Atlantic states–areas in which a large number of Hispanics/Latinos, particularly Puerto Ricans, reside. Of all the STD clinics in the sample, the highest median rates of HIV positivity were found in San Juan, Puerto Rico (13.6%); Miami, Florida (10.9%); and Newark, New Jersey (7.8%)–all of which have large Hispanic/Latino populations (CDC, 1991c).

Surveys conducted among teenage applicants for military service showed HIV-seropositivity rates of 0.29 percent among Hispanics/Latinos (Burke et al., 1990). Additionally, screening of Job Corps applicants, traditionally of lower socioeconomic backgrounds, found a prevalence rate among Hispanics of 0.26 percent (St. Louis et al., 1991).

Blinded studies conducted from 1988 to 1990 in STD clinics, drug treatment centers, and women's health clinics in 20 selected metropolitan areas included approximately 30,000 Hispanic/Latino clients. According to an analysis of the data, the highest median seroprevalence rates in the drug treatment centers were found among Puerto Ricans (19.1%) and the lowest among Mexican Americans (below 0.1 percent). Cubans had the highest median seroprevalence rates in the STD clinics (15.2%), compared with 8.9 percent for Puerto Ricans and below 0.1 percent for Mexican Americans. The median seroprevalence rates for women's clinics showed Puerto Ricans, Mexican Americans, and Cubans below 0.1 percent. Overall, Hispanic/Latina women had median seroprevalence rates of below 0.1 percent in women's clinics, 2.5 percent in STD clinics, and 3.8 percent in drug treatment centers (Guereña et al., 1990).

Seroprevalence data collected in 1990 in public HIV-antibody testing and counseling sites in 50 states, the District of Columbia, and the U.S. dependencies and possessions showed a 3.7 percent HIV seropositivity rate for all races and a 6 percent rate for Hispanics/Latinos (CDC, 1991d).

Knowledge, Attitudes, Beliefs, and Behaviors

The National Center for Health Statistics (NCHS) conducted a study on knowledge and attitudes about HIV and AIDS in different racial and ethnic minorities, using data gathered in the 1990 National Health Interview Survey (NHIS). Questions about AIDS have been included in the NHIS since 1987; the survey also covers general information and knowledge, modes of transmission, blood donation and the blood supply, and HIV testing.

One of the most important findings about the Hispanic/Latino community (Biddlecom and Hardy, 1991) concerned their levels of education and knowledge regarding HIV. In every section of the survey, there was a definite correlation between years of education completed and number of questions answered correctly. However, it is also important to note that even those with higher education had many misconceptions or lacked adequate information.

According to NHIS, 88 percent of Hispanic/Latino adults reported having received some HIV- or AIDS-related information in the previous month. Of those people, 77 percent received their information from television, 43 percent from newspapers, and 37 percent from magazines.

Of the adults with children 10 to 17 years old, only 57 percent reported having talked with their children about HIV or AIDS, compared with 70 percent of their white counterparts. This number was lowest for the Mexican American parents (50%). Of those parents who answered the questions about discussing AIDS with their children, 66 percent of the women said they had, compared with only 45 percent of the men.

On the general knowledge section of the survey, the proportion of Hispanic/Latino adults who correctly identified the major modes of HIV transmission was uniformly high; however, there were still many misconceptions about other transmission risks. For example, under half of those surveyed with 12 or more years of education correctly indicated that it is highly unlikely or definitely not possible for a person to acquire HIV via mosquito bites. Many of those surveyed also thought there was a possibility of becoming HIV-infected by being coughed or sneezed on. This level of misinformation gives cause for concern.

Concerning HIV testing, 69 percent of Hispanics/Latinos knew that a test was available and 16 percent reported having been tested, compared with 81 percent and 9 percent of whites. Moreover, many of these were tested mandatorily, not voluntarily, because of immigration, employment, and hospitalization requirements. Of those who had been tested, only 39 percent reported receiving pretest counseling and only 35 percent received posttest counseling.

The NHIS also asked Hispanic/Latino adults about their perceptions of the efficacy of condoms. Seventy-one percent believed that condoms were "very" or "somewhat effective" protection in preventing transmission of HIV. Puerto Ricans were more likely than other Hispanic/Latino groups to say that condoms were "very effective" (32%, compared with 22%). When asked if they knew about medications that could extend the life of a person infected with HIV, 25 percent, 42 percent, and 49 percent of respondents with less than 12 years of education, 12 years of education, and more than 12 years of education, respectively, indicated that they were aware of the existence of such medications.

A study conducted from January 1989 through June 1990 by the Northeast Hispanic AIDS Consortium, concerning knowledge, attitudes, beliefs, and behaviors about HIV/AIDS among Hispanic/Latino residents of Connecticut, Massachusetts, New York, New Jersey, Pennsylvania, and Puerto Rico (sample of 2,541), reflected that knowledge gaps still exist. While a majority of Hispanics/Latinos were familiar with risks of transmission through needle sharing and unprotected sex, significant percentages of participants were unaware of the risk involved in having unprotected sex with a person with a history of injection drug use (8%-25%), thought HIV-infected persons could be identified visually (20%-34%), thought there was a vaccine available for AIDS (21%-57%), and were unaware of the availability of the HIV antibody test (10%-20%). Most study participants reported engaging in one or more risk behaviors in the previous year (Amaro and Gornemann, 1992).

Women of childbearing age demonstrated more knowledge about prevention, but felt less able to reduce the risks of infection because of a perceived lack of equal power in their relationships. Twenty-seven percent of the sample of self-identified gay men surveyed reported having had unprotected sex with a woman in the previous year. Bisexuality is an important factor in the spread of HIV in the Hispanic/Latino community (Amaro and Gornemann, 1992).

Health Status

Complete national vital statistics for Hispanics/Latinos are currently unavailable as many localities do not separately collect or tabulate data on Hispanics/Latinos. The information that is available indicates that on many points they do not differ greatly in their health status from the rest of the nation; however, there are areas where the community lags behind. Indeed, a diversity of health issues face the Hispanic/Latino community today.

Infant mortality varies greatly among the different subgroups of Hispanics/Latinos, but overall the community has a higher infant mortality rate than the national average. Puerto Ricans as a group have the highest rate, 9.6 infant deaths per 1,000 live births, in contrast to the Cuban rate of 7.4 deaths per 1,000 live births (NCHS, 1992). This may in part be explained by the higher utilization rates of prenatal care in the Cuban community. Overall, Hispanics/Latinas have a lower rate of prenatal care, with 13 percent of pregnant women receiving care late or not at all.

The major causes of death are the same in the Hispanic/Latino community as in the rest of the nation–i.e., heart disease and cancer. AIDS is in many geographic areas among the leading causes of death for Hispanics/Latinos. Substance use is a major concern in the Hispanic/Latino community; teenagers report very high rates of alcohol consumption, and cocaine use is also reported to be very high, especially among Cuban Americans 12 to 17 years old. The number of cocaine-related deaths of Hispanics/Latinos tripled between 1982 and 1984 (NIDA, 1982; NIDA, 1984).

STD incidence in the Hispanic/Latino community is higher than in the population at large. Hispanics/Latinos accounted for 12 percent of all reported cases of primary and secondary syphilis in the United States in 1988. Although the community accounted for only 5 percent of the reported gonorrhea cases, the incidence rate per 100,000 population was four times that of the white population (Moran et al., 1989).

Overall, some of the most serious concerns regarding Hispanic/Latino health are cultural, geographic, and linguistic barriers to care, lack of available preventative and primary care services, and alarmingly low levels of health insurance coverage.

Programs

The Hispanic/Latino community has put in place an array of programs to respond to the HIV epidemic. Examples of the programs throughout the nation include community-based efforts such as Proyecto Amor in San Juan, regional efforts such as the Midwest Hispanic AIDS Coalition in Chicago, innovative communications programs such as the productions at KCET (PBS) in Los Angeles, and national programs such as the AIDS Center at National Council of La Raza in Washington, D.C.

Programs that seem to be successful in reaching Hispanics/Latinos share many common elements. They are community based. They maintain a personal, nonjudgmental relationship with clients and often adopt a family-centered approach. They are accepted by the community and in many instances are tailored to the specific needs of the participants and include messages that are clear, simple, and applicable to a specific Hispanic subpopulation.

Funding by Public Health Service agencies such as the Centers for Disease Control, the National Institute on Drug Abuse, and the Office of Minority Health have contributed to the support of a variety of Hispanic/Latino community-based organizations working with AIDS. The Hispanic/Latino community, however, is still facing tremendous programmatic challenges in its response to the HIV epidemic. Hispanic/Latino organizations have had difficulties in accessing the financial resources needed to operate successful HIV/AIDS programs. Many Hispanic/Latino organizations have been established only recently and are not part of the network of information that benefit larger and more established organizations.

They lack experience in accessing current information about funding sources. Other organizations, because of limited infrastructure, insufficient work force, and limited management expertise also lack the capacity to successfully respond to requests for proposals. Thus, even when organizations have received information about funding opportunities, they may also need technical assistance in order to submit a competitive proposal.

For organizations that have received financial assistance from private and public sources, funding has often proven difficult to sustain. Issues regarding sustained funding are various and complex. For example, programs are usually funded for a period of 3 to 5 years, with the expectation that the grantee will have fulfilled the goals of the project or attracted new funding sources at the end of the funding cycle. Many organizations, however, have not been able to secure alternative funding sources or to diversify their funding base. Many organizations do not have the strong evaluation components in their programs that would enable them to document the success of their initiatives. Even where experienced AIDS organizations have been able to document the effectiveness of their programs, they have not been able to compete with larger and more established organizations in the community, even though the latter may lack experience providing HIV-related services. Many Hispanic/Latino organizations find it difficult to provide services on a reimbursable basis to cover gaps in funding. As a result, many organizations have not been able to provide services because federal, state, or local funding has not come through on time or has been withheld owing to budget deficits or appropriations delays.

Although these issues are not unique to the Hispanic/Latino community, they have a profound effect on the availability of services in many Hispanic/Latino communities. As with other service providers, there is an increasing need for organizations serving the Hispanic/Latino to strengthen their infrastructure and document their effectiveness in serving persons who engage in behaviors that place them at risk of HIV infection.

Another challenge facing the Hispanic/Latino community is ensuring that HIV/AIDS services are effectively distributed. Some communities have a myriad of organizations, all of which provide similar services to a limited catchment area. In other communities, perhaps only one program provides a range of services to a disproportionately large population. Decreases in government funding have resulted in a decrease in the number of minority programs funded. This has created instances where an organization is funded to provide services to all communities regardless of its lack of contacts within a particular community or its ability to serve the needs of individuals who engage in high-risk behaviors. In such instances, many people may not be effectively served, while others may not be served at all.

Community Concerns

In March 1991 the National Commission on AIDS held hearings specifically addressing issues of concern to the Hispanic/Latino community. Beyond this hearing, which was held in Chicago, the Commission has met with and received testimony from leaders of the Hispanic/Latino community at various times over the past three years. Some of the community concerns that have been brought to the Commission's attention include:

- ***Community diversity.*** Many have expressed their frustration with the lack of available data on Hispanic/Latino subgroups. The use of a broad-based "Hispanic/Latino" category does not allow for a true picture of the effects of the epidemic among the different groups that comprise the term Hispanic/Latino.

- ***Community empowerment.*** Hispanics/Latinos have been underrepresented in policy positions at the local, state, and federal levels. The majority of Hispanics/Latinos affected by the AIDS epidemic live under conditions of poverty. Consequently, there is a need to address the issues of HIV/AIDS in the context of poverty.

- ***Drug users.*** For the Hispanic/Latino population, drug use is quickly becoming the primary means of transmission, and it is already the principal transmission factor in the Hispanic/Latino population in the Northeast, the Midwest, and the Commonwealth of Puerto Rico. This population is also very difficult to reach, owing to the transient nature of the population itself. Programs to reach this population have been hampered by the failure to assure treatment on demand or access to harm-reduction programs such as methadone maintenance or needle exchange.

- ***Education.*** School-based education programs have been the primary focus of AIDS education programs targeted toward children and adolescents. However, many Hispanic/Latino children and adolescents do not benefit from these programs because the community has the highest dropout rate in the nation. It is estimated that only 50 percent of Hispanics/Latinos aged 25 and older have completed high school, compared with 80 percent of the non-Hispanic/Latino population.

- ***Families.*** There is a concern that present HIV programs do not target the family as a whole. Whether it strikes a gay man or a substance user, among Hispanics/Latinos HIV disease is a family and community issue; thus, when a member of the family becomes ill, the family tends to respond in unison.

- ***Hispanic/Latino gay men.*** There is a concern among Hispanic/Latino gay men that homophobia is pervasive in the Hispanic/Latino community. Gay men in the Hispanic/Latino community are concerned with the perceived inappropriateness of funding and lack of responsiveness and support for the development of programs to target exclusively the needs of the Hispanic/Latino gay male.

- *Immigration.* The current immigration policy excluding HIV-infected individuals from entry and residency in the United States has had a disproportionately negative impact among the large numbers of undocumented and migrant workers in the Hispanic/Latino community. The Immigration Reform and Control Act granted legal status to a large number of undocumented aliens. However, those who tested positive for HIV have been forced to apply for waivers, which are rarely granted. Others have not come forward to apply for amnesty or seek care for HIV-related conditions for fear of deportation. The Commission was also told about incidents of migrant workers becoming infected with HIV while in the United States but being refused reentry into the country by American-based companies after testing positive for HIV.

- *Language.* Language and culture present additional obstacles in providing prevention and service programs for Hispanics/Latinos. For those who are monolingual Spanish speakers, health care providers often do not have resources for effective translation, which impairs service delivery and forces inappropriate situations, such as when minor children must translate for parents in situations where confidentiality may be an issue.

- *Leadership.* Although some community leaders and elected officials have shown outstanding support for AIDS prevention and service organizations, there is currently a need to further educate and encourage the involvement of Hispanic/Latino community leaders and elected officials on the issue. As in other communities of color, HIV/AIDS has not been a popular cause with the leadership of the Hispanic/Latino community. Among these leaders AIDS is seen as something that will damage the image of the Hispanic community.

- *Migrant workers.* The migration patterns of migrant farm workers force many individuals to live in camps and move from state to state, never establishing the permanent residence needed to qualify for services from local communities. Many have to live in remote communities, where sanitation and close living quarters produce unique health problems. Health care for these communities, particularly HIV-related services, is limited or nonexistent.

- *Orphans.* The Hispanic/Latino community is extremely concerned about the surviving children of HIV-infected families. As HIV disease continues to expand among injection drug users and their partners, the need arises to develop a plan for the future of the children of an infected couple or single parent. In order to avoid having these children become part of the already overburdened foster care system, parents must be assisted in making arrangements for the care of their children after their death.

- *Prevention.* There is concern that national HIV/AIDS information and prevention efforts have not reached the Hispanic/Latino community because of the inadequate number of programs that target the community from a linguistic as well as a cultural perspective. The majority of the public information and education efforts have targeted the mainstream population.

- *Research.* Hispanics/Latinos are concerned that cultural elements will affect the results of studies conducted to determine the knowledge, attitudes, beliefs, and behavior of Hispanics/Latinos. Inappropriate research methodologies have resulted in significant variances in findings, depending on where interviews are conducted and whether the subject is alone or with his or her partner.

- *Women.* There is concern in the Hispanic/Latino community that women's issues have not been adequately addressed in the context of HIV prevention and care. In the Hispanic/Latino community women play an important role in educating Hispanic families about health and in securing health care for immediate and extended family members. Too often, Hispanic/Latina women who are HIV infected do not receive the support they need to care for their families and at the same time address their own health needs. In addition, for a large number of Hispanic/Latina women, issues of reproductive rights have become increasingly critical. Many women feel pressured to terminate their pregnancy in the face of moral scrutiny regarding their reproductive choices. HIV-infected Hispanic/Latina women have also reported a high incidence of violence in the home, apparently as a result of their HIV status.

The Asian American and Pacific Islander Community

Community Description

Asian Americans and Pacific Islanders are two separate and culturally distinct groups, but they are combined for reporting purposes. Even these broad nomenclatures underscore the differences between the two. "Asian American" is a term applied to persons in the United States "having origins in any of the original people of the Far East." "Pacific Islander" is a more ambiguous term that includes persons who live in a group of predominantly small island nations that have a close relationship with the United States (i.e., Guam, American Samoa, the Republic of Palau, the Republic of the Marshall Islands, the Commonwealth of the Northern Mariana Islands, and the Federated States of Micronesia), Native Hawaiians, and others who are immigrants or long-standing American citizens whose ancestors came from South Pacific islands.

Asian Americans/Pacific Islanders compose the third-largest minority group after African Americans and Hispanics/Latinos. They are also the fastest-growing community of color in the United States. The diversity of the Asian American/Pacific Islander population is extraordinary. Federal data collectors currently recognize the following subcategories: Chinese, Japanese, Hawaiian, Filipino, and Other Asian/Pacific Islanders. The last category alone includes over 39 different nationalities. Collectively, they speak over one hundred languages and dialects. Moreover, there can be great cultural, social, economic, and political differences within specific ethnic groups, as well as between dissimilar ethnic groups, for example, between fifth-generation Chinese Americans and new immigrants (Lee and Fong, 1990).

After decades of intermarriage, the Pacific Island populations are a mixture of racial backgrounds. Individuals often identify with the ethnic culture that is dominant in their household, and when this fact is not taken into consideration, demographic data that report race/ethnicity as one choice will not reflect accurate information for a population as racially and ethnically diverse as the Pacific Islanders. For example, the 1990 Census identified approximately 138,000 self-identified Hawaiians residing in Hawaii, while the state department of health's annual Health Surveillance Program estimated that by 1986 there were already nearly 205,000 residents of Hawaiian ancestry.

Epidemiology

Of the 242,146 total AIDS cases in the United States through September 1992, CDC reported that 1,525 (0.6%) were Asian Americans/Pacific Islanders. The Asian American/Pacific Islander male-to-female ratio of AIDS cases and deaths is approximately 11 to 1. In 1991 Asian Americans/Pacific Islanders had an annual AIDS case rate of 3.7 per 100,000 population (CDC, 1992d).

When exposure categories are examined, it is apparent that the HIV epidemic among Asian Americans/Pacific Islanders is still in the early stages. Of the AIDS cases in the Asian American/Pacific Islander community, 74 percent were contracted by men who have sex with men, compared with 58 percent for all races. Among the pediatric cases, 16 percent have been in children with hemophilia, and 37 percent of pediatric AIDS cases among Asian American/Pacific Islanders were due to transmission of HIV through blood transfusions or blood products. All of these categories are strikingly higher than the national averages and resemble data collected at the beginning of the epidemic in other racial groups. (See Table 6.)

Conversely, only 4 percent of all AIDS cases in adult/adolescent Asian Americans/Pacific Islanders have been due to injection drug use. Furthermore, only 47 percent of pediatric cases have been due to perinatal transmission from a mother at risk for HIV. These rates are much lower than the national averages. Again, these data are reminiscent of epidemiologic data obtained in the early years of the HIV/AIDS epidemic for other groups.

Knowledge, Attitudes, Beliefs, and Behaviors

National surveys of knowledge, attitudes, beliefs, and behaviors do not presently report data for Asian American/Pacific Islanders as a separate group.

Health Status

Impediments to gathering adequate data on the health status of the Asian American/Pacific Islander community include the small size of the population, its diversity, and the inability to make inferences at the national level about the community as a whole. State and local studies have been done, but they cannot be generalized to the whole Asian American/Pacific Islander community because of the diversity of the community and differences in their geographic distribution.

Two diseases in particular, however, have been identified as being of critical importance to health among Asian Americans/Pacific Islanders. According to the Public Health Service, the two infectious diseases that have followed immigrant Asian and Pacific Islander population subgroups to this country are tuberculosis and hepatitis B. Tuberculosis rates differ by country of origin; in some Asian American/Pacific Islander populations, the disease is seen at rates 40 times higher than the national average. Age is also a factor, with rates particularly high among those over age 45. Hepatitis B infection is also found at a much higher rate among Asian immigrants. The overall carrier rate in the United States is estimated to be 0.3 percent of the population; however, among immigrants from Southeast Asia the estimated rate is 4 percent (PHS, 1990).

Comprehensive health care, particularly in the areas of prenatal care, HIV testing, nutrition, and substance counseling, is desperately needed on many of the Pacific islands. Integration of services would allow HIV testing to be disguised among a number of health services, thereby decreasing the anxiety associated with going to an explicit HIV testing site. However, currently, there is little prospect of comprehensive health care, and the average island medical and mental health professional needs more information and education on HIV/AIDS.

TABLE 6: Adult/adolescent AIDS Cases by Sex, Exposure Category, and Race/ethnicity, Reported through September 1992, United States.

	Asian American/ Pacific Islander		Total[4]	
	Number	Percent	Number	Percent
ADULT/ADOLESCENT				
MALE				
Exposure category				
Men who have sex with men	1,112	(81)	136,912	(65)
Injection drug use	47	(3)	41,631	(20)
Men who have sex with men and inject drugs	34	(2)	15,203	(7)
Hemophilia/coagulation disorder	23	(2)	1,910	(1)
Heterosexual contact:	12	(1)	5,983	(3)
Sex with injection drug user	6		2,448	
Sex with person with hemophilia	-		12	
Born in Pattern II[1] country	3		2,003	
Sex with person born in Pattern II country	1		105	
Sex with transfusion recipient with HIV infection	-		94	
Sex with HIV-infected person, risk not specified	2		1,321	
Receipt of blood transfusion, blood components, or tissue[2]	59	(4)	2,956	(1)
Other/undetermined[3]	91	(7)	7,553	(4)
Subtotal	1,378	(100)	212,148	(100)
FEMALE				
Exposure category				
Injection drug use	18	(14)	12,844	(50)
Hemophilia/coagulation disorder	-	(#)	43	(0)
Heterosexual contact:	47	(37)	9,238	(36)
Sex with injection drug user	16		5,612	
Sex with bisexual male	15		789	
Sex with person with hemophilia	2		110	
Born in Pattern II country	-		841	
Sex with person born in Pattern II country	-		90	
Sex with transfusion recipient with HIV infection	3		196	
Sex with HIV-infected person, risk not specified	11		1,600	
Receipt of blood transfusion, blood components, or tissue	40	(31)	1,877	(7)
Other/undetermined	23	(18)	1,945	(7)
Subtotal	128	(100)	25,947	(100)

[1] "Heterosexual contact" cases include persons who report either specific heterosexual contact with a person with, or at increased risk for, HIV infection (e.g., an injection drug user), or persons presumed to have acquired HIV infection through heterosexual contact because they were born in countries with a distinctive pattern of transmission termed "Pattern II" by the World Health Organization (MMWR 1988;37:286-8,293-5). Pattern II transmission is observed in areas of sub-Saharan Africa and in some Caribbean countries. In these countries, most of the reported cases occur in heterosexuals and the male-to-female ratio is approximately 1:1. Injection drug use and homosexual transmission either do not occur or occur at a low level.

[2] Nineteen adults/adolescents and two children developed AIDS after receiving blood screened negative for HIV antibody. Five additional adults developed AIDS after receiving tissue or organs from HIV-infected donors. Two of the five received organs or tissue from a donor who was negative for HIV antibody at the time of donation.

[3] "Other" refers to seven health care workers who developed AIDS after occupational exposure to HIV-infected blood, as documented by evidence of seroconversion; and to two patients who developed AIDS after exposure to HIV within the health care setting, as documented by laboratory studies. "Undetermined" refers to patients whose mode of exposure to HIV is unknown. This includes patients under investigation; patients who died, were lost to follow-up, or refused an interview; and patients whose mode of exposure to HIV remains undetermined after investigation.

[4] Includes 551 persons whose race/ethnicity is unknown.

SOURCE: Adapted from CDC HIV/AIDS Surveillance, October 1992.

TABLE 6 continued: Pediatric AIDS Cases by Sex, Exposure Category, and Race/ethnicity, Reported through September 1992, United States.

	Asian American/ Pacific Islander		Total[4]	
	Number	Percent	Number	Percent
PEDIATRIC				
Exposure category				
Hemophilia/coagulation disorder	3	(16)	183	(5)
Mother with/at risk for HIV infection via:	9	(47)	3,480	(86)
Injection drug use	3		1,634	
Sex with injection drug user	2		704	
Sex with bisexual male	1		77	
Sex with person with hemophilia	-		18	
Born in Pattern II[1] country	-		271	
Sex with person born in Pattern II country	-		17	
Sex with transfusion recipient with HIV infection	-		17	
Sex with HIV-infected person, risk not specified	1		176	
Receipt of blood transfusion, blood components, or tissue	-		75	
Has HIV infection, risk not specified	2		491	
Receipt of blood transfusion, blood components, or tissue[2]	7	(37)	303	(7)
Other/undetermined[3]	-	(#)	85	(2)
Subtotal	19	(100)	4,051	(100)

NOTE: See technical notes and source from Table 6.

Programs

Programs for the prevention and care of HIV/AIDS among Asian Americans/Pacific Islanders have only recently been developed and funded. Currently, a number of organizations are working to meet the HIV/AIDS service needs of the Asian American/Pacific Islander community. On the national level, organizations such as the Asian American Health Forum, the Association of Asian/Pacific Community Health Organizations, and the National Asian/Pacific American Families Against Substance Abuse are working to raise awareness about the HIV/AIDS service needs of Asian American/Pacific Islander communities. Community-based organizations such as the Asian/Pacific AIDS Coalition in San Francisco, the Asian and Pacific Islander Coalition on HIV/AIDS in New York, and the Asian Pacific AIDS Education Project in Los Angeles are providing direct prevention and education services targeting specific Asian American/Pacific Islander subpopulations.

However, HIV/AIDS prevention and care programs that appropriately meet the needs of Asian Americans/Pacific Islanders are not available in many of the communities where the need for such services exist. This can be attributed to the tendency to dismiss the need for such targeted services based on the comparatively low number of AIDS cases among Asian Americans/Pacific Islanders, a general lack of awareness about the service needs of Asian Americans/Pacific Islanders, a lack of culturally appropriate services, and insufficient financial support.

Few publicly or privately funded AIDS programs target Asian Americans/Pacific Islanders for AIDS-related prevention and care services. In its effort to increase the involvement of national and regional racial and ethnic minority organizations in HIV information and education efforts, the Centers for Disease Control has funded one organization in the nation to provide HIV prevention activities to Asian Americans/Pacific Islanders. The Association of Asian/Pacific Community Health Organizations is funded by CDC to integrate HIV prevention activities with services of member community health centers and to develop a media campaign to change public perceptions about HIV/AIDS within Asian American/Pacific Islander communities.

It is important to note that, even where Asian Americans/Pacific Islanders are targeted by HIV/AIDS intervention efforts, the scope of the services provided are often insufficient to meet the needs adequately of diverse and often monolingual Asian American/Pacific Islander ethnic subgroups. Given the diversity among Asian American/Pacific Islander communities, unique challenges exist in the delivery of prevention, education, and other HIV-related services. Except in cases where there is a very large client population, access to bilingual/bicultural AIDS service providers or materials is minimal. Interpretation services to meet the language needs of Asian Americans/Pacific Islanders in the health care setting are severely limited. Consequently, fear of difficulties in communication remains a significant factor for many Asian Americans/Pacific Islanders when they consider whether or not to seek testing, counseling, and care.

In particular, persons who have only recently immigrated to the United States require special attention, both in terms of prevention messages and in access to health care. Legal uncertainties and complexities frequently deter undocumented immigrants from seeking appropriate care and services for which they qualify. Helping such individuals overcome their reluctance to utilize services to which they are entitled deserves urgent attention.

Community Concerns

In May 1991 the Commission conducted a hearing in San Francisco on the impact of the HIV epidemic among Asian Americans/Pacific Islanders. In addition, the Commission received written testimony from individuals and organizations. Among the concerns raised were:

- ***Alienation.*** A person living with HIV disease may face tremendous alienation within their own ethnic and cultural communities. The stigma can be compounded by the revelation that a person is homosexual or is an injection drug user.

- ***Clinical trials.*** For clinical trials and other research opportunities, specific and affirmative guidelines need to be developed for multilingual and multicultural access and for the recruitment of participants from the Asian American/Pacific Islander communities.

- ***Community diversity.*** A number of witnesses presenting testimony before the Commission emphasized the need for recognition of the diversity among Asian

Americans/Pacific Islanders in order to ensure the integrity of AIDS programs that target specific racial or ethnic minority populations. When Asian Americans/Pacific Islanders are aggregated in surveillance reports, it is impossible for communities to know exactly where their attention should be focused. Asian American AIDS service providers expressed a need to know the extent of the HIV/AIDS problem in their communities.

- ***Community empowerment.*** There is a great need to foster coalition building among Asian American/Pacific Islander organizations. Asian American/Pacific Islander organizations across the country need to get together and exchange information on a regular basis. Information exchange is a valuable tool for training health professionals and sensitizing service providers on important issues concerning Asian Americans/Pacific Islanders with regard to the AIDS epidemic.

- ***Community input.*** As with other communities, Asian Americans emphasized the need to improve efforts to include community members in HIV program planning and policy development. Specifically, witnesses pointed out the need to establish mechanisms that provide a forum for input from Asian Americans/Pacific Islanders, such as the establishment of advisory committees and the hiring of racial and ethnic minorities to staff federal, state, and local health agencies.

- ***Education.*** Witnesses voiced concern that money was being wasted on the translation of pamphlets and brochures originally developed for other audiences. Witnesses warned that the messages were often inappropriate for the Asian American/Pacific Islander audiences (for example, when a pamphlet mentions AIDS in African American and Hispanic/Latino populations but makes no mention of AIDS among Asian Americans/Pacific Islanders). Moreover, translation may be so inadequate that it renders the pamphlet incomprehensible. Furthermore, literal translations of words from one language to another loses the crucial and most meaningful nuances that transmit the correct interpretation of the messages.

- ***Funding.*** Frustration was voiced regarding the ability of the Asian American/Pacific Islander community to compete effectively for funding. Anecdotal accounts of AIDS cases and HIV-positivity were not specific enough to submit and support funding proposals. In addition, the concern was raised that because the numbers of AIDS cases among Asian Americans/Pacific Islanders are low HIV/AIDS proposals developed for Asian Americans/Pacific Islanders would be given a lower priority for funding.

- ***Immigration.*** As with other communities, Asian Americans/Pacific Islanders who spoke with the Commission strongly encouraged the elimination of HIV-seropositive status as a basis for immigration exclusion and the ending of mandatory HIV testing for immigrants and refugees.

- *Language.* Language is a significant barrier to accessing HIV education and health care in Asian American/Pacific Islander communities. For service providers, reaching significant numbers of Asian Americans/Pacific Islanders requires the capacity to provide services in a variety of languages and dialects. For many Asian Americans/Pacific Islanders, the already complex and burdensome task of securing appropriate HIV services is compounded by the inability to speak fluent English.

- *Model minority myth.* The common stereotype that Asian Americans are categorically high achievers who excel academically and economically and who suffer from relatively few health concerns obscures serious problems in the Asian American/Pacific Islander community, including poverty, substance use, and significant health concerns.

- *Outreach.* A major component of HIV/AIDS service delivery involves outreach to publicize services and to create trust between clients and service providers. Without these outreach efforts comprehensive HIV services cannot be delivered. In particular outreach efforts are essential in reaching newly arrived immigrants and refugees who may be monolingual.

Concerns regarding the U.S. Trust Territories in the Pacific included:

- *Community empowerment.* Existing community-based organizations can be empowered to involve the community. HIV is not regarded as a major health problem by most Pacific Islanders; however, other health concerns do surface, and eventually HIV/AIDS can be addressed within the context of these other concerns.

- *Confidentiality.* On the Pacific Islands, it is typical for one public health nurse to take care of the health needs of all the people on the island. Because they know everything and everybody, all public health nurses must be educated on the importance of confidentiality. Typical small communities on these islands have or will have major problems with confidentiality aspects of risk assessments (that is, HIV testing, AIDS reporting, counseling, and partner notification). For example, HIV testing is conducted on some islands once a week on the same day, at the same time. This is widely known, and anyone showing up at the clinic on that day at that time is therefore suspected of being HIV positive, and gossip travels fast.

- *Cultural competence.* Individuals who do not come from or are not known in the community are generally not trusted or believed. In these islands, academic degrees do not confer credibility and respect–familiarity within a community does. Position qualifications for health educators and outreach workers should be adjusted so that paraprofessionals can fill the positions and do an effective job of educating the community about HIV and AIDS, thus helping empower the community to take responsibility for its health problems.

- *Denial.* Many people on these islands firmly believe that AIDS is a disease that affects only white men. Island governments are facing the difficult dilemma of creating laws to protect people from diseases that may be brought to the islands by tourists, and at the same time maintaining the economic stability that tourism brings.

- *Funding.* Funding criteria for support of prevention efforts should extend beyond the number of AIDS cases reported. These islands are particularly vulnerable if HIV infection becomes established; prevention must take place before, not after, cases of AIDS are reported. One funding strategy could be to recognize areas that report sharp rises in STDs and teen pregnancy and automatically to target those areas for increased HIV prevention funding.

- *Transportation.* Many islands have only one test site, often located in the island's main city, which may be as far as 60 miles from some residents, who may have no means of transportation. Island-based organizations need considerable support for large travel budgets, a circumstance often not understood by funding agencies. When apparently inflated travel budgets are cut substantially by funding sources, the effectiveness of projects diminishes.

The American Indian and Alaskan Native Community

Community Description

Historical demographers estimate that at the time of the initial European exploration and settlement of North America, there were 12 to 15 million aboriginal "Indian" inhabitants of what is now the contiguous 48 states. By the end of the nineteenth century, the Native American population had been reduced to about 250,000. This demographic collapse was due largely to epidemics of infectious diseases, which raged from the beginning of contact with Europeans. Smallpox, tuberculosis, typhoid, cholera, typhus, and other diseases decimated the native "New World" population, who had no immunity to "Old World" pathogens. Only in the twentieth century has the population of Native Americans begun to recover; by the 1990 U.S. Census, 1.87 million people reported themselves as being of Native American descent.

Native North Americans were not and are not now one people, but many nations, each with its own language, traditions, and history. There are over five hundred Native American tribes and Alaskan Native villages in the United States, each of which has government-to-government relationships with the United States and determines its own citizenship requirements as a sovereign nation. In 1985 there were just under one million legally recognized tribal citizens.

According to the 1990 Census, over half of all Native Americans live in standard metropolitan statistical areas. Fewer than one-quarter live on reserved lands, and the rest live in rural areas. Oklahoma has the largest Native American population and California has the second largest. Oklahoma is not a reservation state, and California has only a few reservations and rancherias. Most of Oklahoma's Native American population was removed from other parts of the continent to what before 1907 was the Indian Territory. The vast majority of California's Native American population is urban and moved to the state voluntarily.

The damage caused by the disruption of traditional economies and cultures owing to disease, war, wholesale population removals, and targeted government campaigns is still evident today in many Native American communities. In spite of this, many Native American communities are making positive changes with a spirit of self-determination and a renewed sense of pride in traditional cultural values and experience.

Epidemiology

Although, as of the end of September 1992, Native Americans/Alaskan Natives accounted for fewer than 1 percent of AIDS cases reported in the United States, the incidence of AIDS increased faster among Native Americans/Alaskan Natives than among any other ethnic group from 1989 to 1990 (Metler, Conway, and Stehr-Green, 1991). As of the end of September 1992, CDC reported 416 diagnosed cases of AIDS in Native Americans, 14 percent of whom were women. (See Table 7.) Twelve cases of pediatric AIDS were also reported.

Male-to-male sexual transmission accounted for just over half the reported cases (55%), with injection drug use accounting for another 18 percent. AIDS cases were reported in every age group. AIDS in Native Americans has been reported in every Indian Health Service Area (Chase, 1992).

AIDS among Native American women is overwhelmingly due directly or indirectly to injection drug use; 59 percent of the female adult/adolescent Native American AIDS cases were exposed through injection drug use, and 14 percent became infected through sex with an injection drug user. All Native American/Alaskan Native pediatric AIDS cases for which the transmission risk was reported were due to perinatal transmission from a mother who either used injection drugs or had sex with an injection drug user; none were due to hemophilia-related blood products or to blood transfusions. It is also interesting to note that among the Native American gay/bisexual men with AIDS those who report also injecting drugs is very high (16%) compared to whites (7%), African Americans (7%), and Hispanics/Latinos (7%) (CDC, 1992e).

There is substantial evidence that actual AIDS cases among Native Americans are undercounted. Studies of death certificates and AIDS service organization records in Los Angeles and Seattle found that between two-thirds and three-fourths of Native Americans with AIDS were misrepresented as white or Hispanic (Lieb et al., 1989; Smyser, Helgerson, and Hess, 1992).

Two seroprevalence studies offer evidence of the possible extent of HIV infection among Native Americans. The Indian Health Service (IHS) and CDC have been studying blood samples taken from women attending prenatal clinics and from men and women being evaluated in an IHS-funded STD clinic since 1989. The researchers estimate that, based on their findings, there are approximately 2,730 Native Americans (range 1,210 to 4,250) who are infected with HIV but are asymptomatic. HIV infection in rural areas among Native American women in their third trimester of pregnancy was found at rates four to eight times higher than rates for childbearing women of all races in the same states. This calculation of the number of seropositive Native Americans may underestimate the true size of the problem because urban areas with high rates of HIV seroprevalence were underrepresented in the study. The Military Seroprevalence Study begun in October 1985 tests all applicants for military service for HIV antibodies. In that study, Native Americans have had a seroprevalence rate of 0.08 percent (CDC, 1991c).

Knowledge, Attitudes, Beliefs, and Behaviors

National surveys of knowledge, attitudes, beliefs, and behaviors do not presently report data on Native Americans as a group. Consequently, there is very little representative information on their knowledge about and attitudes toward HIV and AIDS. One survey that looked at the level of HIV knowledge in Northwestern American Indian communities (Hall et al., 1990) found that, although the communities in Oregon and Idaho uniformly had a good understanding of the three primary modes of HIV transmission (sexual, perinatal, and injection drug use), misconceptions also persisted. For example, 96 percent of those surveyed knew that the virus can be transmitted from one person to another during sexual intercourse; however, 52 to 55

TABLE 7: Adult/adolescent AIDS Cases by Sex, Exposure Category, and Race/ethnicity, Reported through September 1992, United States.

	American Indian/ Alaskan Native		Total[4]	
	Number	Percent	Number	Percent
ADULT/ADOLESCENT				
MALE				
Exposure category				
Men who have sex with men	222	(64)	136,912	(65)
Injection drug use	39	(11)	41,631	(20)
Men who have sex with men and inject drugs	58	(16)	15,203	(7)
Hemophilia/coagulation disorder	9	(3)	1,910	(1)
Heterosexual contact:	4	(1)	5,983	(3)
Sex with injection drug user	3		2,448	
Sex with person with hemophilia	-		12	
Born in Pattern II[1] country	-		2,003	
Sex with person born in Pattern II country	-		105	
Sex with transfusion recipient with HIV infection	-		94	
Sex with HIV-infected person, risk not specified	1		1,321	
Receipt of blood transfusion, blood components, or tissue[2]	2	(1)	2,958	(1)
Other/undetermined[3]	14	(4)	7,553	(4)
Subtotal	346	(100)	212,148	(100)
FEMALE				
Exposure category				
Injection drug use	34	(59)	12,844	(50)
Hemophilia/coagulation disorder	-	(#)	43	(0)
Heterosexual contact:	11	(19)	9,238	(36)
Sex with injection drug user	8		5,612	
Sex with bisexual male	2		789	
Sex with person with hemophilia	-		110	
Born in Pattern II country	-		841	
Sex with person born in Pattern II country	-		90	
Sex with transfusion recipient with HIV infection	-		196	
Sex with HIV-infected person, risk not specified	1		1,600	
Receipt of blood transfusion, blood components, or tissue	5	(9)	1,877	(7)
Other/undetermined	8	(14)	1,945	(7)
Subtotal	58	(100)	25,947	(100)

[1] "Heterosexual contact" cases include persons who report either specific heterosexual contact with a person with, or at increased risk for, HIV infection (e.g., an injection drug user), or persons presumed to have acquired HIV infection through heterosexual contact because they were born in countries with a distinctive pattern of transmission termed "Pattern II" by the World Health Organization (MMWR 1988;37:286-8,293-5). Pattern II transmission is observed in areas of sub-Saharan Africa and in some Caribbean countries. In these countries, most of the reported cases occur in heterosexuals and the male-to-female ratio is approximately 1:1. Injection drug use and homosexual transmission either do not occur or occur at a low level.

[2] Nineteen adults/adolescents and two children developed AIDS after receiving blood screened negative for HIV antibody. Five additional adults developed AIDS after receiving tissue or organs from HIV-infected donors. Two of the five received organs or tissue from a donor who was negative for HIV antibody at the time of donation.

[3] "Other" refers to seven health care workers who developed AIDS after occupational exposure to HIV-infected blood, as documented by evidence of seroconversion; and to two patients who developed AIDS after exposure to HIV within the health care setting, as documented by laboratory studies. "Undetermined" refers to patients whose mode of exposure to HIV is unknown. This includes patients under investigation; patients who died, were lost to follow-up, or refused an interview; and patients whose mode of exposure to HIV remains undetermined after investigation.

[4] Includes 551 persons whose race/ethnicity is unknown.

SOURCE: Adapted from CDC HIV/AIDS Surveillance, October 1992.

TABLE 7 continued: Pediatric AIDS Cases by Sex, Exposure Category, and Race/ethnicity, Reported through September 1992, United States.

	American Indian/ Alaskan Native		Total[4]	
	Number	Percent	Number	Percent
PEDIATRIC				
Exposure category				
Hemophilia/coagulation disorder	1	(8)	183	(5)
Mother with/at risk for HIV infection via:	11	(92)	3,480	(86)
Injection drug use	4		1,634	
Sex with injection drug user	1		704	
Sex with bisexual male	-		77	
Sex with person with hemophilia	-		18	
Born in Pattern II[1] country	-		271	
Sex with person born in Pattern II country	-		17	
Sex with transfusion recipient with HIV infection	-		17	
Sex with HIV-infected person, risk not specified	2		176	
Receipt of blood transfusion, blood components, or tissue	-		75	
Has HIV infection, risk not specified	4		491	
Receipt of blood transfusion, blood components, or tissue[2]	-	(#)	303	(7)
Other/undetermined[3]	-	(#)	85	(2)
Subtotal	12	(100)	4,051	(100)

NOTE: See technical notes and source from Table 7.

percent also thought that HIV could be acquired by eating food prepared by someone who is HIV infected and 57 to 63 percent thought HIV could be acquired by being coughed and sneezed on by someone who is HIV infected (Hall et al., 1990).

Health Status

The health status of Native Americans is lower according to almost every indicator than the U.S. population as a whole; life expectancy is 71.1 years as compared with 74.4 for the white population. However, data from 1985 to 1987 showed that 33 percent of all Native Americans die before the age of 45, compared with 11 percent for the white population in 1986. Substance abuse, primarily alcohol use, accounts for most of the top ten causes of early death, either directly or indirectly. Alcohol abuse, suicide, unintentional injuries, and interpersonal violence account for many deaths among young Native Americans (Nickens, 1991).

A study conducted between 1984 and 1988 shows rates of STDs such as gonorrhea, syphilis, and chlamydia are on average twice as high for Native Americans as for the U.S. population as a whole (Toomey, Oberschelp, and Greenspan, 1989). In some states, the rates are seven to ten times higher. Sexual activity starts early, as evidenced by teen pregnancy rates; 20 to 25 percent of Native American babies are born to mothers 18 years of age or younger (OTA, 1986). Injection drug use may be a more serious problem than most health professionals realize (Rowell, 1990). Tuberculosis rates are five times higher for Native Americans than for the U.S. population as a whole (IHS, 1991).

STD rates may be higher for Native Americans because of high rates of substance use, overall poor socioeconomic conditions, and lack of access to the level of health care enjoyed by other Americans. It has been only within the past year that any movement has occurred within the Indian Health Service to begin an aggressive campaign to prevent STDs and to intervene early in the course of the infection.

The increase in the number of cases of tuberculosis, especially multidrug-resistant TB, is particularly troubling for Native Americans. TB was a serious disease in the Native American population in the first half of this century, and many living now were exposed to TB in their youth, making them particularly vulnerable to the disease. Living conditions in some Native American communities are not much better in 1992 than they were in 1950. Substance abuse also increases the difficulty of ensuring adherence to treatment regimens among TB-infected patients.

The Indian Health Service is the provider of last resort for the minority of Native Americans who live on or near reservations. IHS funds primary clinics in some urban centers, but more intensive services are generally not available from IHS for the majority of the urban Indian population.

IHS provides care directly through its own hospitals and clinics and through hospitals operated by the tribes themselves. It also contracts for specialized care or other services. Access to care is limited both by IHS's annual appropriations by Congress and the uneven distribution of services among IHS areas. The cost of care for eligible Native Americans with HIV infection has put and will continue to put a severe burden on an already strained IHS budget.

For Native American people living in rural areas, the lack of nearby service providers is as much a barrier to access as it is for other rural Americans. This is especially true of Alaskan Native villagers whose only access to care may be the airplane. There are many days, however, when planes cannot fly because of weather or other environmental conditions. In the lower 48 states, some Native Americans with AIDS have reported having to drive 70 miles in each direction over poorly maintained roads to obtain basic health care services.

Programs

Unfortunately, the response of the Indian Health Service and tribal governments to the threat of HIV has been slow. HIV/AIDS programs of any sort are a relatively new development in Native American communities. The first programs were funded in 1987-88, although AIDS had been diagnosed in Native Americans before 1983. The principal sources of funding for HIV prevention activities for Native Americans have been primarily the CDC, the Office of Minority Health, state departments of health, and the U.S. Conference of Mayors.

The Indian Health Service AIDS program began in 1989 but has played only a minor role to date in funding HIV prevention and education projects for Native Americans. It has provided training for pretest and posttest HIV-antibody counselors in each area office and has given small prevention education grants to service units. With CDC, IHS is conducting a national seroprevalence survey of prenatal clinics, substance abuse programs, and STD clinics. In 1991 IHS set up a national drug depot for zidovudine (AZT), aerosolized pentamidine, and other AIDS-related drugs at the Carl Albert Hospital in Ada, Oklahoma, and established a system for making these drugs available to all eligible HIV-infected Native Americans through IHS or IHS-funded providers.

The various of types of Native American organizations working in the field, funded and unfunded, include national organizations, organizations based in individual states, and local and community-based organizations scattered throughout the country. Inter-ethnic coalitions between Native Americans and others have been very important in ensuring the inclusion of Native Americans in discussions and policy decision-making related to AIDS.

The majority of existing efforts among Native American communities consist of HIV prevention education programs. More often than not, these programs are targeted at the population as a whole and at youth. It is rare for Native American AIDS programs to target men who have sex with men or injection drug users specifically, although some such programs do exist.

The National Indian AIDS Media Consortium, based in Minneapolis, is a nationwide media education effort involving over 150 Native American newspapers, magazines, newsletters, and radio stations. The consortium has operated since early 1989, providing regular press packets and camera-ready ads or audio public service announcements to encourage regular reporting on HIV and related issues for the Native American audience in the United States and Canada.

The National Congress of American Indians (NCAI), the oldest national tribal organization in the United States, is a recipient of a subcontract with George Washington University under a grant from the Ford Foundation to work with state, local, and tribal governments on HIV-related policies. NCAI and the National Native American AIDS Prevention Center (NNAAPC) recently published a handbook for tribal leaders on the development of HIV policies.

Programs that provide case management and client advocacy services for Native Americans also exist in some areas. NNAAPC operates a national case management demonstration project in Oklahoma City–the Ahalaya Project–and on the Pascua Yaqui and Tohono O'odham reservations in southern Arizona with Health Resources and Services Administration funds for Special Projects of National Significance from the Ryan White CARE Act. CARE Act funds are supporting case management services at the American Indian AIDS Institute of San Francisco, the American Indian Community House in New York City, the Minneapolis Indian Health Board, and the San Diego Urban Indian Health Center.

Community Concerns

In February 1991 the Commission conducted a series of site visits to Arizona, New Mexico, Oklahoma, Minnesota, and South Dakota in order to better understand the challenges facing Native Americans as they struggle to confront the HIV/AIDS epidemic. In addition, the Commission heard from caregivers serving Eskimo and Aleut populations in Alaska. Among the many concerns raised by AIDS service providers, tribal leaders, community members, and persons living with AIDS were:

- ***Burnout.*** In the absence of communitywide awareness, a few dedicated individuals are providing the prevention education, direct service delivery, advocacy, and support, as well as education to tribal leaders and governmental bodies on the need to address the emerging epidemic among Native Americans. The efforts of such individuals have been critical to raising awareness regarding the HIV epidemic among Native Americans.

- *Community diversity.* Group-specific and culturally competent AIDS education activities are sorely needed. No one approach to education and prevention will work for all Native Americans. Each nation or community has culturally specific attitudes and beliefs, particularly with regard to sex and sexuality. This diversity in cultural and traditional beliefs require that prevention programs be designed and delivered with input from each nation or community. Native American AIDS service providers impressed upon the Commission that, in their experience, in order for AIDS education messages and materials to be effective for many Native Americans they must be brought to them by other members of their community. Recognition must also be given to the different needs of Native Americans living in isolated rural areas, such as Alaska, and those living in urban settings.

- *Confidentiality.* A consistent theme throughout the Commission's site visits was the issue of confidentiality. Individuals and tribal leaders voiced concern over the inability of the Indian Health Service to protect the confidentiality rights of patients. Evidence of breaches of confidentiality served to reinforce already prevalent fears of discovery and discrimination that may prevent individuals from seeking HIV education, care, and treatment. Similar concerns were raised regarding the lack of anonymous test sites in states such as Minnesota and South Dakota.

- *Demographic collapse.* The poor health status of Native Americans as a whole and their vulnerability to HIV owing to those risk factors already discussed makes HIV a threat to this population. From the point of view of Native Americans themselves, there is a perceived threat of another demographic collapse in the population if measures are not taken rapidly at all levels to prevent the spread of the virus.

- *Denial.* Recognition that the HIV epidemic is an issue for Native Americans is inhibited by denial within Native American communities as to the prevalence of homosexual and bisexual behavior as well as drug use.

- *Funding.* During several visits, the Commission heard of the need to have CDC fund tribal programs directly instead of through layers of state and Indian Health Service bureaucracy. The need for longer-term funding of programs was also made evident.

- *Health care providers.* Many individuals who spoke to the Commission expressed concern regarding the availability of health care providers knowledgeable about caring for people with HIV disease.

- *Invisibility.* Perhaps the single greatest barrier to HIV prevention and care among Native Americans is invisibility. This invisibility is a result of two factors: the low numbers of Native Americans in the overall U.S. population and the multiple layers of stereotypes about Native Americans inherited through popular culture. This two-tiered invisibility places Native American people at a disadvantage when fighting AIDS, to the extent that public resources are divided through a political system that rewards either numbers or visibility through effective organizing. Unfortunately, Native Americans are few in number and have been unable to capture public attention.

- *Services.* Throughout the Commission's visits in Native American communities, individuals and service providers complained of a lack of coordination among federal, state, and tribal governments in their efforts to deal with the HIV epidemic in Native American communities. Historically complicated relationships between the federal and state governments and the Native American nations has made effective HIV service delivery and health care financing difficult. Individuals described situations in which they were shuffled between agencies or, even worse, turned away because there was no clear definition of agency responsibility or patient eligibility.

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APPENDIX A

Witness List

The Commission thanks the following people who presented formal testimony at a hearing before the Commission during the past three years and whose testimony was helpful in furthering the Commission's understanding of HIV/AIDS issues confronting communities of color.

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Gen Iinuma, M.P.H.

Cory Jacobs
Collette Jacques, R.N.
Michael James
Janice Jireau
Robert Johnson, M.D.
Ronald Johnson
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Si Hoi Lam, M.D.
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Deborah Lee
Lori Lee
Rita Lepicier
Carol Levine
Sharon Lim-Hing
Nina Nicolette Lira

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German V. Maisonet, M.D.
Luis Maldonado
Miguelina Maldonado
Floyd J. Malveaux, M.D., Ph.D.
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Sam Marinez
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Frankie Mason
Henry Masters, III, M.D.
Adolfo Mata
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S. Denise Rouse, M.P.H.
Ron Rowell, M.P.H.
Johnny Rullan, M.D., M.P.H.

Jackie Sadler, M.P.H.
The Honorable Jose Saler-Zapata
Romeo Sanchez
Nancy Santiago, M.D.
Wifredo Santiago
Merina Sapolu
David Satcher, M.D., Ph.D.
The Honorable Kurt Schmoke
Peter Selwyn, M.D., M.P.H.
Yolanda Serrano
Walter Shervington, M.D.
Paul Shimazaki
Sonia Singleton
Ruth Slaughter
Mark Smith, M.D., M.B.A.
Brenda Smith, Esq.
Mario Solis-Marich
Marie St. Cyr, M.S.W.
The Honorable Louis Stokes
Irma Strantz, Dr.P.H.
Kianja Stroud
The Honorable Isabel Suliveres de Martinez

Alpha Thomas
Stephen B. Thomas, Ph.D.
Mimi Tiemble
Jose Toro, Ph.D.
Laura E. Torres

Elizabeth Valdez, M.D.
Nora Vargas, Esq.
Carmen Vasquez, M.S.Ed.
Anita Vaughn, M.D.
Manuel Vega
Raul Villalobos, M.D.
Sandra Vining-Bethea
Janet Voorhes, M.P.H.

Bob White
Phillip Wiley
Reggie Williams
Jane Wilson, M.S.
Phill Wilson
Dorothy Wong, M.B.A.
David Woodring
Wayne S. Wright

Velma Yemota
Mary Young, M.D.
Yvette

John Zamaro
Pedro Zamaro
Andrew Ziegler, M.H.S.A.
Carmen D. Zorilla, M.D.

APPENDIX B

Agendas

NATIONAL COMMISSION ON AIDS

<u>Agenda</u>

HIV Disease in African American Communities

Curran Conference Room
100 North Holiday Street
City Hall
Baltimore, Maryland

December 17-18, 1990

Monday, December 17, 1990

8:30 a.m. - 8:40 a.m.	Welcome:	June E. Osborn, M.D.
8:40 a.m. - 9:00 a.m.	Overview:	Harlon Dalton
9:00 a.m. - 10:30 a.m.	Understanding a Legacy of Mistrust	
	Presenter:	Mark Smith, M.D., M.B.A.
	Respondents:	Marie St. Cyr, M.S.W. Alpha Thomas Alyce Gullattee, M.D., F.A.P.A.
10:30 a.m. - 10:45 a.m.	Break	
10:45 a.m. - 12:15 p.m.	Organizing African American Communities	
	Presenter:	Wilbert Jordan, M.D., M.P.H.
	Respondents:	Sandra McDonald Sonia Singleton Elsie Cofield
12:15 p.m. - 1:30 p.m.	Lunch	

1:30 p.m. - 3:00 p.m.	Communities Working Together—Pitfalls and Promises of Coalition Building Presenter: Catlin Fullwood Respondents: Phill Wilson Keith Cylar, M.S.W.
3:00 p.m. - 3:15 p.m.	Break
3:15 p.m. - 4:45 p.m.	Determining What is Culturally Appropriate Presenter: Rashidah Hassan, RNCIC Respondents: Jacob Gayle, Ph.D. Reggie Williams
4:45 p.m. - 5:30 p.m.	Public Comments
6:00 p.m.	Reception: Hosted by the Honorable Kurt L. Schmoke, Mayor of Baltimore and Elias Dorsey, Acting Commissioner of Health

Tuesday, December 18, 1990

1:15 p.m. - 1:30 p.m.	Remarks: The Honorable Kurt L. Schmoke, Mayor of Baltimore

NATIONAL COMMISSION ON AIDS

Agenda

Arizona and New Mexico Site Visits
HIV Disease in Native American Communities

February 25-26, 1991

Monday, February 25, 1991

7:30 a.m.	Breakfast meeting with urban Native American leaders La Frontera Center Welcoming Remarks Acardio Gastelum, Chairman, Pascua-Yaqui Nation Andrew Lorrentine, Acting Director, Tohono O'odham Health Department Dr. Floyd H. Martinez, Executive Director, La Frontera Center
8:30 a.m.	Travel to New Pascua, Arizona

9:00 a.m.	Roundtable with members of the Pascua-Yaqui Nation, New Pascua
10:30 a.m.	Travel to Sells, Arizona
11:45 a.m.	Community lunch with members of the Tohono O'odham Nation, Courtyard of the Tohono O'odham Health Department, Highway 86, Sells
12:45 p.m.	Roundtable with members of the Tohono O'odham Nation, Tohono O'odham Health Department
2:15 p.m.	Drive through Sells en route to the Sells U.S. Public Health Service Indian Hospital, Highway 86, Sells
2:30 p.m.	Visit to the Sells U.S. Public Health Service Indian Hospital
3:15 p.m.	Drive to the Tucson Airport

Tuesday, February 26, 1991

7:30 a.m.	Breakfast with Melvin Harrison, Central Navajo AIDS Coalition
8:15 a.m.	Drive to Window Rock, Arizona, capital of the Navajo Nation
9:00 a.m.	Visit AIDS train-the-trainers session, Window Rock, Arizona
10:00 a.m.	Meet with tribal officials at the Navajo Nation President's Office Complex
11:00 a.m.	Drive to Gallup, New Mexico
11:40 a.m.	Visit to the Gallup Indian Medical Center Nizhoni Boulevard, Gallup
12:45 p.m.	Drive through Gallup en route to the Gallup Airport

NATIONAL COMMISSION ON AIDS

Agenda

Minnesota and South Dakota Site Visits

HIV Disease and the American Indian/Alaskan Native Communities

February 27-28, 1991

Wednesday, 27 February 1991

8:30 a.m.	Breakfast, The Cafe at the St. Paul Hotel, 350 Market Street St. Paul, Minnesota
	Joined by Norman Landsem, AIDS Coordinator, Bemidji Area Office, Indian Health Service
9:45 a.m.	Depart for the Center School, Minneapolis
10:00 a.m.	Center School, 2421 Bloomington Avenue South
	Sharon Day, Executive Director, Minnesota American Indian AIDS Task Force Lori Beaulieu, Training Coordinator, National Native American AIDS Prevention Center Carole LaFavor, person living with AIDS Representatives of Minnesota State-wide Indian Services Organizations
11:00 a.m.	Performance of "Ni Nokomis Zagayug" (My Grandmother's Love) by The Ogitchidag Gekinooamaagad Players
11:45 a.m.	Tour of the Minneapolis American Indian Center, 1530 Franklin Avenue East
12:30 p.m.	Lunch at the Minneapolis Indian Health Board Clinic, 1315 East 24th Street
	Joined by Greg Moses, Yukon Kuskokwin Health Corps, and Terrance Booth, Alaska Native Health Board
1:45 p.m.	Tour of the Minneapolis Indian Health Board Clinic
	Rene Whiterabbit, AIDS Project Coordinator Joan Myrick, AIDS Coordinator, American Indian Healthcare Association
2:30 p.m.	Depart for the Shakopee Mdewakanton Sioux Community
3:00 p.m.	Tour of the reservation and meeting with tribal officials, 2330 Sioux Trail, Prior Lake
	Leonard Prescott, Chair Sally Milroy, Program Administer

4:00 p.m.	Meeting with members of the Wisconsin Winnebago Health and Human Services Division, the Great Lakes Inter-Tribal Council, and the Minnesota Tribal AIDS Coordinators
5:30 p.m.	Depart for St. Paul-Minneapolis airport
7:35 p.m.	Flight to Rapid City, South Dakota

Thursday, 28 February 1991

8:00 a.m.	Depart for the Pine Ridge Reservation
10:00 a.m.	Meeting with South Dakota reservation representatives Charon Asetoyer, Native American Women's Health Education Resource Center Cecilia Fire Thunder, Director of Health Services, Pine Ridge Reservation Willy Bettelyoun, person living with AIDS Lorelei DeCora, R.N., Rosebud Reservation
11:00 a.m.	Tour of the reservation
12:00 p.m.	Depart for the Rapid City airport
2:00 p.m.	Arrive at the airport
2:50 p.m.	Flight to St. Paul-Minneapolis airport

NATIONAL COMMISSION ON AIDS

Participants

Minnesota and South Dakota Site Visits

HIV Disease and the American Indian/Alaskan Native Communities

February 27-28, 1991

Ms. Lori K. Beaulieu, Training Coordinator
The National Native American AIDS Prevention Center

Ms. Carole LaFavor

Mr. Robert Peacock, Chairman
Fond du Lac Reservation
Business Council

Indian Health Service

Ms. Kathleen Annette, M.D.
Bemidji Area Office

Mr. Norman Landsem
Bemidji Area Office

Minnesota State-wide Indian Services Organizations Representatives

Ms. Sharon Day
Executive Director
Minnesota American Indian AIDS Task Force

Mr. Roger Head, Director
Minnesota Indian Affairs Council

Ms. JoAnne Stately
Minnesota Indian Affairs Council

Mr. Darrell Wadena, Chair
Minnesota Chippewa Tribe

Native Alaska Representatives

Mr. Terrance Booth, Program Manager
Alaska Native Health Board

Mr. Greg Moses
Yukon Kuskokwin Health Corps

Minneapolis Indian Health Board

Ms. René Whiterabbit, AIDS Coordinator

American Indian Healthcare Association

Ms. Joan Myrick, AIDS Coordinator

Shakopee Mdewakanton Community

Ms. Sally Milroy, Program Administrator

Mr. Leonard Prescott, Chair

Wisconsin Winnebago Tribe

Dr. Vijay Prabhaker, Director
Department of Health and Human Services

Great Lakes Inter-Tribal Council

Ms. Star Ames-Nielsen, AIDS Coordinator

Minnesota Tribal AIDS Coordinators

Ms. Rachelle Danelle
Ponemah Clinic

Ms. Mike Snesrud, P.H.N.
Fond du Lac Reservation

Ms. Paula Woods, P.H.N.
White Earth Reservation

South Dakota Reservation Representatives

Ms. Charon Asetoyer, Director
Native American Womens'
Health Education Resource
Center

Mr. William Bettelyoun
Person living with AIDS

Ms. Lorelei DeCora, R.N.
Rosebud Reservation

Ms. Cecilia Fire Thunder,
Director
Health Services
Pine Ridge Reservation

NATIONAL COMMISSION ON AIDS

Agenda

Oklahoma Site Visits

HIV Disease and the Native American Communities

February 27-28, 1991

Wednesday, 27 February 1991

9:30 a.m.	Depart for the Comanche tribal complex
10:00 a.m.	Tour of the Comanche tribal complex in Lawton, Medicine Park Exit on Interstate 40
10:30 a.m.	Discussion with the members of the Inter-Tribal AIDS Coalition
12:00 p.m.	Depart for Oklahoma City
1:30 p.m.	Lunch in Oklahoma City at Applewood Restaurant, 4301 Southwest 3rd Street
	Joined by Pat Gideon, M.D., of the Oklahoma Area Office, Indian Health Service
2:45 p.m.	Depart for the Oklahoma City Indian Health Clinic
3:00 p.m.	Tour of the Oklahoma City Indian Health Clinic, 1214 North Hudson Street
6:00 p.m.	Dinner at the Hilton Inn Northwest
	Joined by Mr. Curtis L. Harris, AIDS Coordinator, American Indian Community House, New York City

Thursday, 28 February 1991

7:30 a.m.	Depart for the Sac & Fox tribal complex
9:00 a.m.	Meeting with the Elders of the Sac & Fox Tribe, Highway 99, south of Stroud
10:00 a.m.	Depart for Sapulpa
10:45 a.m.	Meeting with representatives of the Creek Nation Health Board, Sapulpa Indian Health Center, 1125 East Cleveland

12:15 p.m.	Depart for Tulsa
1:00 p.m.	Lunch in Tulsa at the Louisiane Restaurant, 1400 South Boston Street
	Joined by representatives of the Cherokee Nation of Oklahoma
2:45 p.m.	Depart for the airport

NATIONAL COMMISSION ON AIDS

Participants

Oklahoma Site Visits

HIV Disease and the Native American Communities

February 27-28, 1991

Ms. Gloria Bellymule, R.N.
Oklahoma City Indian Health Clinic

Mr. Curtis L. Harris, AIDS Coordinator
American Indian Community House, New York City

Intertribal AIDS Coalition

Ms. Emma Autaubo, EMS Coordinator
Caddo Tribe

Ms. Debra L. Birney, CHR Coordinator
Absentee Shawnee Tribe

Mr. Richard Chalopah
Kiowa Tribe Alcohol Program

Ms. Margaret Enright
Planned Parenthood

Mr. Alfred Franklin
Cheyenne-Arapaho Treatment Center

Ms. Frances Harrison, CHR Coordinator
Wichita Tribe

Ms. Ruth Jenks
Absentee Shawnee Tribe

Ms. Michelle Jensen
USPHS Indian Health Center

Ms. Marquita Kickapoo
Absentee Shawnee Tribe

Mr. Shae Kinnaman
CH/AIDS Educator

Ms. Marsha Lindsey
Comanche County Memorial Hospital

Mr. Rob Meyers
USPHS Indian Health Center

Ms. Yvonne Monetathchi

Ms. Sherrie Nowlin
Oklahoma Alliance Against Drugs

Ms. Doris Olivor, CHR

Ms. Marcella Panana
Cheyenne and Arapaho Tribes

Mr. Glenn Starr
Cheyenne Tribe

Ms. Jan Vassar
Sac & Fox Historian

Mr. Frank Wahpepaah
Sac & Fox Tribal Health Director

Ms. Flora Weryackwe
Ft. Sill Apache Tribe

Cherokee Nation of Oklahoma

Ms. Pamela Irons, Director
Health and Human Services
Cherokee Nation of Oklahoma

Col. Brenda Cummings, R.N.
Administrator, Indian Health Care Resource Center

Mr. Truman Geren, L.P.N.
AIDS Coordinator

Mr. Stephen Short, M.D.
W.W. Hastings Indian Hospital

Ms. Dixie Stewart, R.N., B.S.
AIDS Coordinator

Ms. Ellen Wolfe, P.H.N.
Claremont Hospital

Comanche Nation

Ms. Teresa Lopez, Director
Comanche Tribe Substance Abuse Program

Mr. Kenneth Saupity
Tribal Chairman

Ms. Bonnie Turner
Tribal Administer

Creek Nation of Oklahoma

Ms. Sherry Baker, R.N., Director
Public Health Nurses

Ms. Kathryn Bell

Mr. Thomas Berryhill, Member
Creek National Council

Ms. Shelly Crow, R.N., Chair
Creek Nation Health Board

Ms. Sally Foster, Administrator
Creek Nation Healthcare System

Mr. Ed Frye

Mr. Toni Hill
Tribal Town Leader

Mr. David Smith, D.O.
Chief, Medical Staff
Eufala Clinic

Ms. Kathy Stubbs, D.O.

Sac & Fox Nation

Mr. Gaylon R. Franklin, Sr.
Second Chief

Mr. Elmer Manatowa
Principal Chief

Indian Health Service

Mr. Pat Gideon, M.D.
Oklahoma Area Office

NATIONAL COMMISSION ON AIDS

Agenda

HIV Disease in Hispanic Communities

The Park Hyatt Hotel
Terrace Room
800 North Michigan Avenue
Chicago, Illinois

March 11-12, 1991

March 11, 1991

	Optional Site Visits
2:00 p.m.	Departure from the Park Hyatt Hotel 800 North Michigan Avenue, Chicago
2:15 p.m. - 3:00 p.m.	Visit Erie Family Health Center 1656 W. Chicago Avenue, Chicago Contact: David Ley (312) 666-3488
3:15 p.m. - 4:30 p.m.	Visit Cook County Hospital 1835 W. Harrison Street, Room 912, Chicago Contact: Dr. Marge Cohen (312) 633-5080
4:45 p.m. - 5:30 p.m.	Visit Pilsen/Little Village Mental Health Center 2635 W. 23rd Street, Chicago Contact: Luis Ortiz (312) 927-1228
6:00 p.m. - 8:00 p.m.	Reception Mexican Fine Arts Museum, 1852 West 19th Street, Chicago, Illinois

March 12, 1991

8:30 a.m.	Opening Remarks June E. Osborn, M.D., Chairman, National Commission on AIDS
8:40 a.m.	Framing the Problem Aida Giachello, Ph.D., Midwest Hispanic AIDS Coalition, Chicago, Illinois

9:00 a.m. Prevention

Illeana Herrell, Ph.D., Center for Prevention Services, Centers for Disease Control, Atlanta, Georgia
Hortensia Amaro, Ph.D., Boston University School of Public Health, Boston, Massachusetts
America Bracho, M.D., M.P.H., Latino Family Center, Detroit, Michigan
Adolfo Mata, Center for Prevention Services, Centers for Disease Control, Atlanta, Georgia

9:45 a.m. Break

10:00 a.m. Services

Nilsa Gutierrez, M.D., New York AIDS Institute, New York, New York
Emilio Carrillo, M.D., New York Health and Hospitals Corporation, New York, New York
Manual Fimbre, A.C.S.W., San Jose State University, San Jose, California
Paula Amaro

10:45 a.m. Migrant, Rural, and Undocumented Populations

Deliana Garcia, National Migrant Resource Program, Austin, Texas
Sam Martinez, Washington State Migrant Council, Sunnyside, Washington
Barbara Garcia, Salud Para la Gente, Watsonville, California

11:30 a.m. Policy and Leadership Issues

Helen Rodriguez-Trias, M.D, Brookdale, California
Alberto Mata, Ph.D., Division of Applied Research, National Institute on Drug Abuse
John Zamora, Texas Department of Health, Austin, Texas
Miguel Gomez, National Council of La Raza, Washington, D.C.
Miguelina Maldonado, Hispanic AIDS Forum, New York, New York

12:15 p.m. Summary Discussion

Ileana Herrell, Ph.D.
Nilsa Gutierrez, M.D.
Deliana Garcia
Helen Rodriguez-Trias, M.D.

12:45 p.m. Lunch

2:00 p.m. Commission Business

5:00 p.m. Adjourn

6:00 p.m. Reception

Tania's Restaurant, 2659 North Milwaukee Avenue, Chicago, Illinois

Affiliations listed for identification purposes only.

NATIONAL COMMISSION ON AIDS

Agenda

HIV Disease and Asian, Asian American, and Pacific Islander Communities

San Francisco, California

May 17, 1991

8:30 a.m. Opening Remarks: June E. Osborn, M.D., Chair

8:35 a.m. Remarks: Paul Kawata

8:45 a.m. Introduction: Historical Perspective

Gen Iinuma
Tessie Guillermo
Suki Ports

9:30 a.m. Moderator: Jane Po

Roundtable Discussion: Impact of HIV Disease Among Asians, Asian Americans and Pacific Islanders

Kiki Ching
Lei Chou
Billy Gill
Martin Hiraga
Sharon Lim-Hing
Sinh Nguyen
Robby Robison
Merina Sapolu
Paul Shimazaki
Velma Yemota

10:45 a.m. Break

11:00 a.m.	Moderator: Fernando Chang-Muy
	Roundtable Discussion: Provision of Services
	Wayne Antkowiak, Jaime Geaga, Dean Goishi, Kerrily Kitano, Lori Lee, John Manzon, Nga Nguyen, Tony Nguyen, Joanna Omi, Dorothy Wong
12:15 p.m.	Public Comments
12:45 p.m.	Lunch
2:00 p.m.	Commission Business
4:00 p.m.	Adjourn

APPENDIX C

Planning Committees

Hispanic Hearing Planning Committee

Rosemunt, Illinois 60018

February 14, 1991

America Bracho, M.D.
Medical Director
La Casa Family Services
713 Junction
Detroit, Michigan 48209

Aida Giachello, Ph.D.
Acting Director
Midwest Hispanic AIDS Coalition
College of Social Work
University of Illinois
Post Office Box 4348, M-C 309
Chicago, Illinois 60680

Miguel Gomez
Director, AIDS Center
National Council of La Raza
810 First Street, N.E.
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Washington, D.C. 20002

Nilsa Gutierrez, M.D.
Assistant Medical Director
AIDS Institute
New York Department of Health
5 Penn Plaza, 4th floor
New York, New York 10001

Ileana Herrel, Ph.D.
Assistant Director for Minority Health
Center for Prevention Services
Centers for Disease Control
Rd M.S. E-07, Rm 309
1600 Clifton
Atlanta, GA 30333

Raul Magaña, Ph.D.
52 Shooting Star Road
Urbine, California 92706

Miguelina Maldonado
Executive Director
Hispanic AIDS Forum
121 Avenue of the Americas
Suite 505
New York, New York 10013

George Rivera, Ph.D.
Catholic Hispanic AIDS Leadership Education (CHALE AIDS Project)
4535 Winona Court
Denver, Colorado 80212

Jessie Sanchez
1017 North Main Street
Suite 208
San Antonio, Texas 78212

John Zamora
Minority HIV Education Specialist
HIV Division
Bureau of HIV and STD Control
Texas Department of Health
1100 West 49th Street
Austin, Texas 78756

Asian American and Pacific Islander Hearing Planning Committee

San Francisco, California

April 10, 1991

Sam Akinaka
BAART
45 Franklin Street
3rd Floor
San Francisco, CA 94102

Ignatius Bau
Staff Attorney
Immigration and Refugee Rights Project
San Francisco Lawyers' Committee for Urban Affairs
301 Mission Street, Suite 400
San Francisco, CA 94105

Rene Durazzo
San Francisco AIDS Foundation
25 Van Ness Avenue
San Francisco, CA 94102

Michael Foo
GAPA Community HIV Project
2261 Market Street #447
San Francisco, CA 94114

Tessie Guillermo
Executive Director
Asian American Health Forum
116 New Montgomery Street #531
San Francisco, CA 94105

Steve Lew
Asian/Pacific AIDS Coalition
Dept. 513
P.O. Box 597004
San Francisco, CA 94159

Jim Naritomi
Asian American Communities Against AIDS
1840 Sutter Street Suite 200
San Francisco, CA 94115

Tony Nguyen
Community Health Outreach Worker
Center for Southeast Asian Refugee Resettlement
875 O'Farrell Street
San Francisco, CA 94109

Nicky Philips
Association of Asian Pacific Community Health Organizations
1212 Broadway #730
Oakland, CA 94612

Jane Po
Coordinator
SFAF Filipino AIDS Hotline
25 Van Ness Avenue
San Francisco, CA 94102

Alaine Raymundo
Filipinos for Affirmative Action
310 8th Street
Oakland, CA 94612

Robby Robison
Treatment Advocate
Early Advocacy and Care for HIV
625 O'Farrell Street
San Francisco, CA 94109

Dorothy Wong
Progam Director
Asian AIDS Project
300 Fourth Street #401
San Francisco, CA 94107

Douglas Yaranon
California AIDS Intervention
  Training Center
507 Divisadero Street, Suite B
San Francisco, CA 922-6135

Velma Yemota
Volunteer
GAPA Community HIV Project
2261 Market Street #447
San Francisco, CA 94114

APPENDIX D

Commission Documents

For any of the information about reports and proceedings
of the National Commission on AIDS please contact:

The National Commission on Acquired Immune Deficiency Syndrome
1730 K Street, N.W., Suite 815
Washington, D.C. 20006
(202) 254-5125
TDD (202) 254-3816

Records are kept of all Commission proceedings and are available for public inspection at the above address.

For copies of all reports please contact:

National AIDS Clearinghouse
P. O. Box 6003
Rockville, Maryland 20849-6003
1-800-458-5231
TDD 1-800-243-7012

Reports

First Interim Report to the President and the Congress: "Failure of U.S. Health Care System to Deal with HIV Epidemic." December 1989.

Working Group Summary Report on Federal, State, and Local Responsibilities. March 1990.

Second Interim Report to the President and the Congress: "Leadership, Legislation, and Regulation." April 1990.

Third Interim Report to the President and Congress: "Research, the Work Force, and the HIV Epidemic in Rural America." August 1990.

Annual Report to the President and the Congress. August 1990.

Fourth Interim Report to the President and the Congress: "HIV Disease in Correctional Facilities." March 1991.

Report of the Working Group on Social and Human Issues to the National Commission on AIDS. April 1991.

Fifth Interim Report to the President and the Congress: "The Twin Epidemics of Substance Use and HIV." August 1991.

Technical Report Prepared for the National Commission on AIDS. "Financing Health Care for Persons with HIV Disease: Policy Options." August 1991.

Second Annual Report to the President and the Congress: "America Living With AIDS." September 1991.

Sixth Interim Report to the President and the Congress: "The HIV/AIDS Epidemic in Puerto Rico." June 1992.

Seventh Interim Report to the President and the Congress: "Housing and the HIV/AIDS Epidemic, Recommendations for Action." July 1992.

Eight Interim Report to the President and the Congress: "Preventing HIV Transmission in Health Care Settings." July 1992.

Statements

Support for Passage of the Americans with Disabilities Act. September 6, 1989.

Support for Increase in AIDS Funding in the FY '90 Appropriations Bill. September 19, 1989.

Support for the Goal of Treatment on Demand for Drug Users. September 26, 1989.

Support for Continued Funding of Research on Effectiveness of Bleach Distribution. November 7, 1989.

Resolution on U.S. Visa and Immigration Policy. December 1989.

Endorsement of Principles and Objectives of Comprehensive AIDS Resources Emergency (CARE) Act of 1990. March 6, 1990.

Despite Debate Among Epidemiologist, HIV Epidemic Will Have Greater Impact in 1990s than 1980s. March 15, 1990.

Endorsement of Principles and Objectives of AIDS Prevention Act (H.R. 4470) and Medicaid AIDS and HIV Amendments Act of 1990 (H.R. 4080). May 11, 1990.

Endorsement of Principles and Objectives of the Ryan White CARE Act of 1990. March 6, 1991.

Statement on Immigration. July 1991.

Statement on the Meeting Between the National Commission on AIDS and the Secretary of Health and Human Services. June 25, 1992.

Statement by David E. Rogers, M.D., Vice Chairman, National Commission on AIDS, on the Resignation of Magic Johnson from the NBA. November 2, 1992.

Information on the Commission

Commission Fact Sheet

Individual Commissioner Biographies

Public Law 100-607 (Creation of the National Commission on AIDS)