BREAKING THROUGH THE SILENCE:

KEY ISSUES AND RECOMMENDATIONS TO ADDRESS HIV/AIDS AMONG ASIAN AMERICANS, NATIVE HAWAIIANS, AND PACIFIC ISLANDERS IN THE UNITED STATES

APIAHF

NASTAD™
NATIONAL ALLIANCE OF STATE & TERRITORIAL AIDS DIRECTORS

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I. Executive Summary

Introduction

Asian Americans, Native Hawaiians, and Pacific Islanders constitute diverse communities that include over 50 different ethnic subgroups that speak over 100 languages and dialects. The United States (U.S.) Census estimates that these populations together have grown to almost 13 million.[1] This growth has been reflected not just in size, but also in diversity and geographic distribution. Specific Asian American, Native Hawaiian, and Pacific Islander ethnic subgroups have experienced significant growth rates that are much higher in comparison to other groups, notably in areas such as the Midwest and the Southeast. In recent years, several states outside of the West and East Coasts have had significant increases in Asian American, Native Hawaiian, and Pacific Islander populations.

In the U.S., the HIV/AIDS epidemic among Asian Americans, Native Hawaiians, and Pacific Islanders has kept pace with these communities' population growth. According to the U.S. Centers for Disease Control and Prevention (CDC), these communities are emerging as an at-risk group for HIV/AIDS with an estimated 7,739 cumulative AIDS cases diagnosed since the beginning of the epidemic. In 2005, an estimated 549 new AIDS cases were diagnosed among Asian Americans, Native Hawaiians, and Pacific Islanders. This represents a 47 percent increase in annual incidence compared to the 373 new Asian American, Native Hawaiian, and Pacific Islander AIDS cases diagnosed in 2000, the largest percentage increase among all racial/ethnic groups.[2]

As HIV incidence rises in Asian American, Native Hawaiian, and Pacific Islander communities, many health departments, community based organizations, and communities remain ill prepared to respond to the increasing HIV prevention needs of these communities. There are significant barriers that challenge HIV prevention efforts targeted directly and indirectly to these communities.

...breaking through
the silence
surrounding HIV
in Asian American,
Native Hawaiian, and
Pacific Islander communities...

"Breaking Through the Silence" is taken directly from interviews conducted with health deapartment staff, community based organization staff, and other stakeholders during the development of this document. *"Breaking Through the Silence"* refers to the silence surrounding HIV in Asian American, Native Hawaiian, and Pacific Islander communities. It also refers to the silence created and reinforced by public health systems that remain largely unaware of HIV prevention needs in Asian American, Native Hawaiian, and Pacific Islander communities.

Purpose

This policy document is focused on breaking the silence around HIV in Asian American, Native Hawaiian, and Pacific Islander communities through public health leadership and response. *"Breaking through the Silence"* aims to serve as a policy tool for health departments, community based organiza-

tions, community partners (e.g. community planning groups, advisory boards, task forces, etc.) as well as policy makers interested in the health of Asian American, Native Hawaiian, and Pacific Islander communities. Readers are encouraged to use the document as a resource to begin implementation of the recommendations offered or to support the continuation and enhancement of existing policies and efforts that are in alignment with the recommendations.

"Breaking Through the Silence" was informed by an extensive literature review; key informant interviews with a cross section of health departments, Asian American, Native Hawaiian, and Pacific Islander organizations, and researchers; and a survey of state AIDS programs.

Summary of Key Issues and Recommendations

"Breaking Through the Silence" identifies four key issues that challenge public health responses to the emerging epidemic among Asian American, Native Hawaiian, and Pacific Islander communities. Four recommendations to address these issues are offered along with challenges and health department examples.

Key Issues	Recommendations
There is an urgent need for health departments to consistently collect and report data disaggregated by Asian American, Native Hawaiian, and Pacific Islander race and ethnic subgroups.	Strengthen data collection and reporting efforts, consistent with the 1997 Office of Management and Budget "Revised Standards for Maintaining, Collecting, and Reporting Federal Data on Race and Ethnicity," to describe HIV's impact in specific Asian American, Native Hawaiian, and Pacific Islander communities and ethnic subgroups.
Many health departments and community planning groups are challenged in determining and/or remaining aware of the current HIV prevention needs and issues in Asian American, Native Hawaiian, and Pacific Islander communities.	Increase health department and community planning group awareness of Asian American, Native Hawaiian, and Pacific Islander communities and their HIV prevention needs.
Asian America, Native Hawaiian, and Pacific Islander communities are usually not prioritized for public health response to HIV.	Consider opportunities to increase prioritization of Asian American, Native Hawaiian, and Pacific Islander communities, especially in jurisdictions where data indicates established or emerging communities at risk for HIV infection.
Many health departments and community based organizations do not have the adequate capacity to respond to HIV in Asian American, Native Hawaiian, and Pacific Islander Communities.	Increase the capacity of health departments and community based organizations to address the HIV prevention needs of Asian American, Native Hawaiian, and Pacific Islander communities through increased access to resources and capacity building assistance.

"Breaking Through the Silence" is focused on health department responses and leadership to address HIV in Asian American, Native Hawaiian, and Pacific Islander communities, yet the responsibility for moving forward does not rest solely on health departments. The responsibility is shared with Asian American, Native Hawaiian, and Pacific Islander community based organizations, community leaders, and policymakers.

As the agencies that oversee the majority of HIV prevention funding and efforts for their respective jurisdiction, health departments play a pivotal role in planning and leading HIV prevention efforts. Often, these efforts are prioritized based on which communities have the highest incidence and prevalence. While this is important, health departments must also take into account data beyond HIV prevalence and incidence in order to identify opportunities to invest in high-risk communities where the epidemic is rapidly emerging in order to truly engage in HIV prevention.

II. Introduction

APIAHF Background

Founded in 1986, the Asian & Pacific Islander American Health Forum (APIAHF) is a national minority organization that seeks to improve the health status of Asian Americans, Native Hawaiians, and Pacific Islanders through data development and research, policy development and advocacy, information collection and dissemination, and capacity-building assistance. APIAHF's mission is to enable Asian Americans, Native Hawaiians, and Pacific Islanders to attain the highest possible level of health and well-being.

NASTAD Background

Founded in 1992, the National Alliance of State and Territorial AIDS Directors (NASTAD) is a nonprofit national association of state health department HIV/AIDS program directors who have programmatic responsibility for administering HIV/AIDS and viral hepatitis health care, prevention, education, and supportive services programs funded by state and federal governments. NASTAD's mission is to strengthen state and territory-based leadership, expertise, and advocacy and bring them to bear in reducing the incidence of HIV infection, and in providing care and support to all who live with HIV/AIDS.

Process

Through this document, APIAHF and NASTAD have collaborated to identify and respond to the continued challenges that state and local health departments face in responding to the HIV prevention needs of Asian American, Native Hawaiian, and Pacific Islander (AANHPI) communities.

In the initial stages of planning, APIAHF and NASTAD convened an 11 member advisory committee, with representatives from both health departments and community based organizations (CBOs).

To identify key themes and issues, APIAHF and NASTAD staff conducted a total of 21 key informant interviews. These interviewees were randomly selected via a tiered prioritization process from over 70 volunteers representing AANHPI CBOs, health departments, research institutions, federal agencies, and other community stakeholders. An independent policy consultant was hired to transcribe and analyze 21 key informant interviews. Additionally, 20 jurisdictions responded to a "2007 Online Survey" that was sent by NASTAD to health department HIV prevention programs in order to further inform the development of this document.

Based on the interviews and surveys, key issues and recommendations were identified and drafted. These were in turn reviewed by members of the advisory committee, key informants, and other community stakeholders. APIAHF, NASTAD, and Policy Resource Group staff co-authored the document.

About Terminology Used In This Document

The term "Asian American, Native Hawaiian, and Pacific Islander (AANHPI)" is used here to describe a diverse set of communities that have been grouped together by governmental and social-based classifications. There are over 50 distinct ethnic subgroups that fall under the term "Asian American, Native Hawaiian, and Pacific Islander" who speak more than 100 different languages and dialects.[1]

In 1997, the Office of Management and Budget (OMB) issued "Revisions to the Standards for the Classification of Federal Data on Race and Ethnicity." These standards divide Asian Americans, Native Hawaiians, and Pacific Islanders into two distinct categories: "Asian" and "Native Hawaiian and Other Pacific Islanders."

Based on OMB definitions, the term "Asian" includes persons having origins in any of the original peoples of the Far East, Southeast Asia, or the Indian subcontinent (for example: India, China, Philippines, Korea, Japan, Vietnam, Burma, Pakistan, etc.). The term "Native Hawaiian and Other Pacific Islander" (NHOPI) includes people having origins in any of the original peoples of Hawaii, Guam, Samoa, or other Pacific Islands.[3]

For the purposes of this document, the authors seek to remain inclusive of and responsive to the diversity of the Asian American, Native Hawaiian, and Pacific Islander communities.

Thus, the authors use the term "Asian Americans, Native Hawaiians, and Pacific Islanders" to include all individuals who trace their origins to the countries and diasporic communities of the Asian and Pacific regions of the world, (e.g. the authors include "West Asian" and "Middle Eastern" in our definition of AANHPI even though these groups are classified as "White" in the U.S. Census).

There are over 50 distinct ethnic subgroups...

The authors purposely eliminate the word "other" from the OMB and Census category of "Native Hawaiian and Other Pacific Islander," choosing instead to use the term "Native Hawaiian and Pacific Islander."

OMB standards define two categories for ethnicity: "Hispanic or Latino" and "Not Hispanic or Latino." For the purposes of this document, however, the authors use the term ethnic subgroup to refer to large groups of people classed together according to common national, tribal, religious, linguistic, or cultural origin or background (e.g. Chamorro, Chinese, Japanese, Samoan, Vietnamese, etc.)

Please note that wording used by key informant interviews in their quote may differ from this framework. For example, several key informants use the term "Asian & Pacific Islander (A&PI)" instead of AANHPI.

III. Asian American, Native Hawaiian, and Pacific Islander Communities in the U.S.

> *"I would say one of the unique challenges is the target population itself, its diversity, in the sense that you have your acculturated Asian and Pacific Islander community: 2nd and 3rd generation A&PIs who are pretty much acculturated to western philosophy and western way of life; but then you also have the emerging and immigrant communities who have a different way of approaching health access. So I think that is a particular issue that needs to be focused on."*
> (CBO representative, Western state)

In order to understand current challenges and assets related to HIV prevention in Asian American, Native Hawaiian, and Pacific Islander (AANHPI) communities, it is important to reflect on the history and current demographics of these communities. Doing so reveals a diverse set of communities who have varying experiences with migration, acculturation, discrimination and socioeconomic status.

Population and Growth

As of March 2002, there were over 12.5 million AANHPIs living in the U.S.[4,5] AANHPIs represent 4.4 percent of the total U.S. population and are the fastest growing racial group in the United States. Between 1990 and 2000, the Asian American population grew by as much as 72 percent; the Native Hawaiian and Pacific Islander population grew by as much as 140 percent. Several AANHPI ethnic subgroups have had significant growth rates during this time period. For example, the Bangladeshi population increased by as much as 385 percent, the Pakistani population increased by as much as 151 percent, the Asian Indian population increased by as much as 133 percent, and the Samoan population increased by as much as 112 percent.[1]

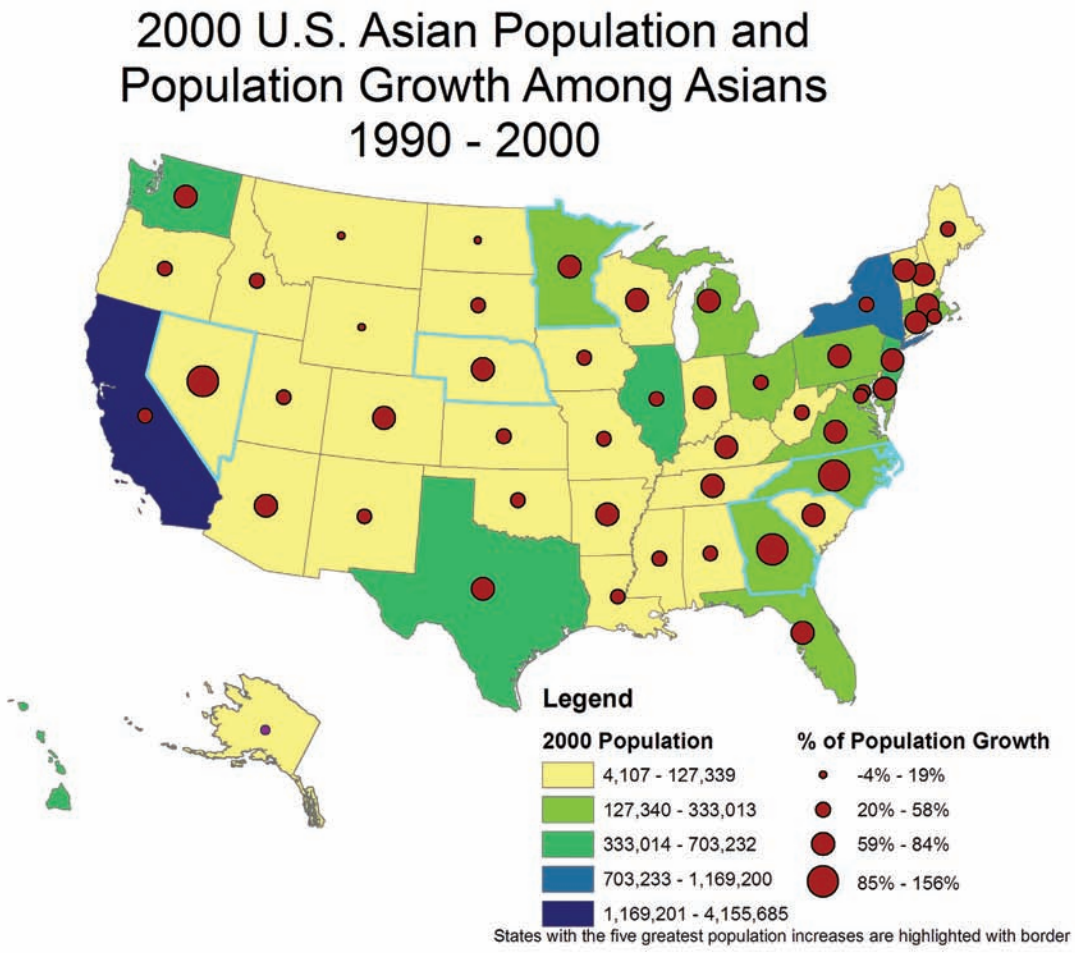
Historically, AANHPI populations have been concentrated in metropolitan areas within a handful of states. Over half of the individuals who identify as Asian live in California, New York, and Hawaii.[4] Over half of the individuals who identify as Native Hawaiian and Pacific Islander live in Hawaii and California.[5] These states are not necessarily the same states that experienced the highest AANHPI growth rates between 1990 and 2000. The following tables show that AANHPIs are establishing new patterns of migration and settlement across the United States, especially in states such as Nevada, North Carolina, Georgia, Arkansas, Massachusetts, and Connecticut.[1]

"I would say one of the unique challenges is the target population itself, its diversity...."

Asian American Populations in Select States Between 1990 and 2000

Highest Number of Asian Americans	
California	4,155,685
New York	1,169,200
Hawaii	703,232
Texas	644,193
New Jersey	524,356
Illinois	473,649
Washington	395,741
Florida	333,013
Virginia	304,559
Massachusetts	264,814

Highest Growth Rates of Asian American Populations	
Nevada	219%
North Carolina	173%
Georgia	171%
Arizona	130%
Nebraska	124%
Tennessee	123%
Florida	122%
Kentucky	118%
Delaware	113%
Colorado	111%



Note: Original source of data for tables and map is the U.S. Census Bureau (2000), available online at http://factfinder.census.gov

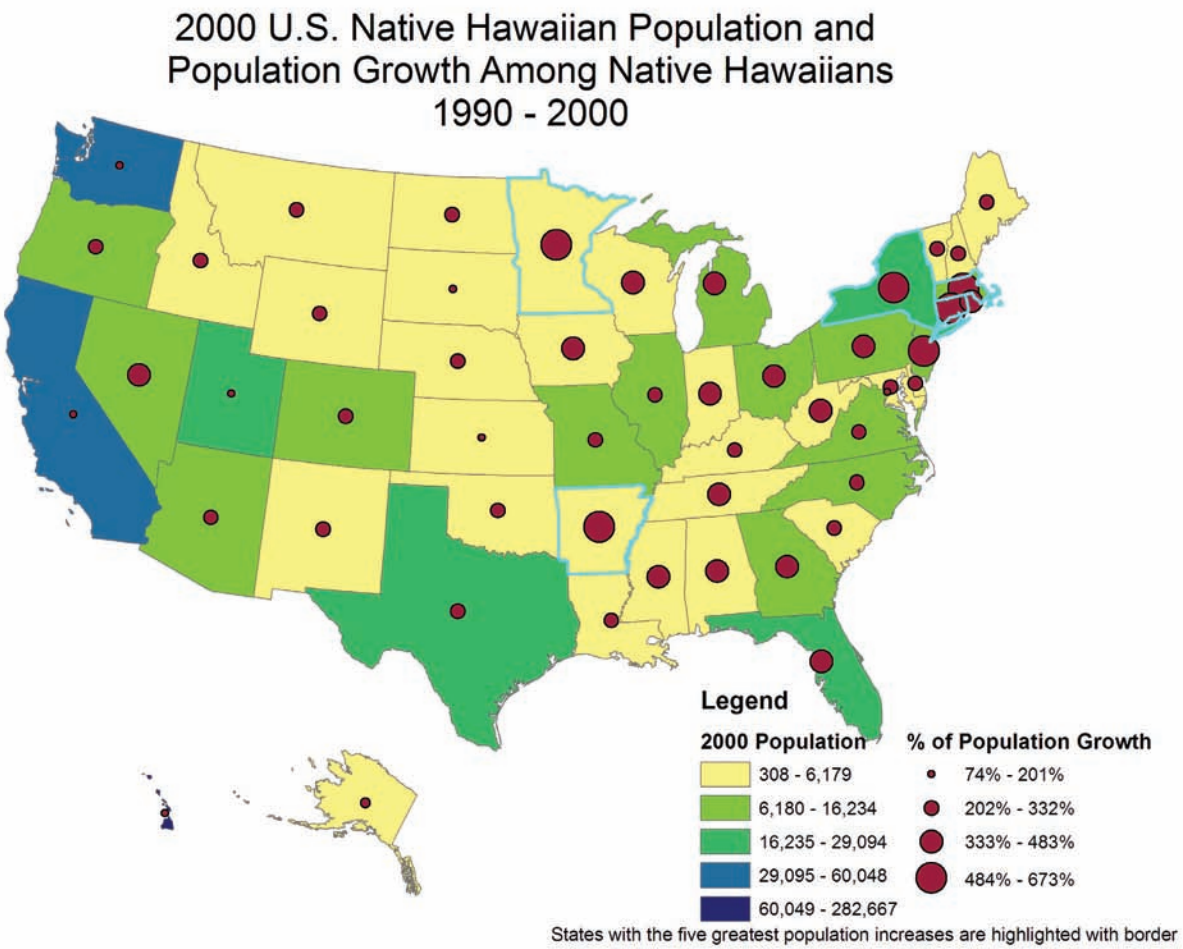
Native Hawaiian and Pacific Islander Populations in Select States Between 1990 and 2000

Highest Number of Native Hawaiians and Pacific Islanders

Hawaii	282,667
California	221,458
Washington	42,761
Texas	29,094
New York	28,612
Florida	23,998
Utah	21,367
Nevada	16,234
Oregon	16,019
Arizona	13,415

Highest Growth Rates of Native Hawaiians and Pacific Islanders

Arkansas	673%
Massachusetts	594%
Connecticut	557%
New York	542%
Minnesota	528%
New Jersey	498%
Rhode Island	483%
Mississippi	464%
Nevada	461%
Florida	440%



Note: Original source of data for tables and map is the U.S. Census Bureau (2000), available online at http://factfinder.census.gov

Experiences of Asian American, Native Hawaiian, and Pacific Islander Communities in the U.S.

The first Asian Americans in the U.S. can be traced back to 1763 when Filipino sailors settled in the Louisiana Bayou.[6] Since then, some Asian Americans have experienced incidents of anti-Asian violence, incarceration, racism, and discrimination. The history of Native Hawaiians and Pacific Islanders differs from Asian Americans due to the political, economic and social contexts of how the U.S. acquired Hawaii, Guam, the Commonwealth of the Northern Mariana Islands, and American Samoa, as well as the unique historical relationship with the Republic of the Marshall Islands, the Federated States of Micronesia and the Republic of Palau.

While local, state, and federal agencies have made some attempts to reach out to AANHPI communities, these agencies sometimes exist within political systems and communities that still harbor anti-AANHPI policies and attitudes. When combine with AANHPI cultural norms that often stigmatize HIV/AIDS and that do not encourage health seeking behaviors, these histories and experience can negatively impact efforts to provide HIV testing, prevention, and care services to AANHPI communities.

Native Hawaiians and Pacific Islanders

The diversity of the indigenous people of Hawaii and the Pacific is linguistic, cultural and political. Colonialism, cultural assimilation, and a legacy of resistance have greatly shaped Native Hawaiian and Pacific Islander experiences in regards to civil rights, land rights, migration patterns, social movements, and access to health, human and educational services.

The state of Hawaii and the six U.S. affiliated Pacific Island jurisdictions have similar yet different histories with the U.S. Hawaii was annexed by the U.S. in 1898 and later was admitted as a state in 1959.[7] Guam became a U.S. territory in 1898 after the Spanish American war, after 333 years of colonization by the Spanish, and was relinquished to the U.S. after the Spanish-American war.[8] In 1899, the U.S. signed a convention with Great Britain and Germany to turn American Samoa into a U.S. territory.[8]

Following World War II, the remaining four jurisdictions became part of the U.S.-administered United Nations Trust Territory of the Pacific Islands. Over the next four decades, each jurisdiction evolved into its current affiliation with the U.S. In 1976, the Commonwealth of the Northern Mariana Islands initiated a convenant to establish it as a U.S. commonwealth. This status was finalized under Presidential Proclamation in 1986.[8] The Republic of the Marshall Islands and the Federated States of Micronesia became sovereign states, also known as freely associated states, in 1986, followed by the Republic of Palau in 1994.[9, 10, 11] Although the latter three jurisdictions are sovereign states, they continue bilateral relationships with the U.S. under Compacts of Free Association which include funding from the U.S. Departments of the Interior, Education, and Health and Human Services.[12]

With these histories as indigenous people, Native Hawaiians and Pacific Islanders from the six U.S. affiliated jurisdictions share similar goals of self-determination and land rights with other Native American and Alaskan Native communities. Pacific Islanders from the territories of Guam, Commonwealth of the Northern Mariana Islands and American Samoa are considered U.S. citizens and Pacific Islanders from the freely associated states have unrestricted access to the U.S. to live, work and study. Pacific

Islanders from other nations such as Tonga, Tahiti, and Fiji are considered immigrants to the U.S. Lastly, there are significant multi-generational Asian populations in the Pacific Island jurisdictions, especially Guam, Palau, and the Commonwealth of the Northern Mariana Islands, due to migration and immigration from nearby Asian countries.

Asian Americans

The first wave of Asian migration occurred in the mid 1800s when contract workers from China, Japan, the Philippines, and Korea migrated to the U.S. These immigrants provided labor in the agriculture, mining, and construction industries. In particular, there was significant immigration from Asia and the Philippines to Hawaii to provide labor on sugarcane plantations, leading to modern day Hawaii's current demographics.[7] Large numbers of Chinese came to the United States as contract workers for gold mines and railroad development.[13] After the completion of the Transcontinental Railroad, many of the Chinese men were fired and forced to walk back to San Francisco.[14] There, they were seen as a threat to the economic labor force and faced an increasing anti-Chinese movement marked by riots, murders, and biased legislation. When Congress passed the Chinese Exclusion Act of 1882, this marked the first time in U.S. history that a specific ethnic group was barred from immigration and naturalization. Additional legislation was enacted in 1917 which denied naturalization to Asian Indians and excluded immigration of almost all Asian laborers.[15]

> *"When you talk about Tuskegee for African Americans, we have the relocation of Japanese Americans. I'm not sure how well we truly understand the impact and what's playing out because of that in our communities now."* (CBO representative, Western state)

Barriers to naturalization were not the only policies that impeded Asian American civil rights and liberties. On December 7, 1941, after the bombing of Pearl Harbor, President Franklin D. Roosevelt issued Executive Order 9066, which led to the internment of at least 110,000 Japanese Americans for no other reason than their race. Most were contributing members of their communities but were forced to abandon an estimated $200 million dollars in real estate, commercial, and personal property.[16] Forty-seven years later in 1988, President Reagan signed the Civil Rights Act of 1988 which offered a Presidential apology and symbolic reparation of $20,000 to survivors of the Japanese internment camps.[17]

It was not until 1952 that Asian immigrants born outside the U.S. were allowed to become naturalized citizens, and this naturalization was limited to 2,000 individuals per year, with an additional 2,000 allotted to the Philippines. Lyndon B. Johnson signed The Immigration Act of 1965 and raised the quota for Asian nations to 20,000 which was the same level as for European nations. However, the 20,000 limit was developed without consideration to the level of demand or size of the origin country resulting in long waiting lists for many Asian immigrants.[18]

The passage of the Immigration Act of 1965 marked a significant paradigm shift in immigration policies. Previous policies were focused on excluding specific groups based on national origin. These were replaced with a system of quotas as well as preferences based on reunifying families. This set the stage for increased immigration from Asian countries. Initially, many of the Asians who immigrated through this Act were professionals and political refugees. As people qualified for permanent residency and

U.S. citizenship, they utilized the Act's "family reunification" preferences to bring over other members of their family.

The Refugee Act of 1980 set policy for immigration via refugee resettlement and asylum. These were major sources of population growth for Vietnamese and other Southeast Asians from the mid 1970s and 1980s.

Policy support for immigrating communities has shifted in recent years, echoing the pre-1965 era. A number of bills have recently been debated in Congress that would make it a felony to provide humanitarian assistance to an undocumented person or their family,[18] to eliminate checks and measures that ensure due-process consideration of U.S. citizenship for long-term lawful permanent residents,[19] and to effect guest worker immigration plans that limit participation in the North American Free Trade Agreement (NAFTA) and Central America-Dominican Republic-United States Free Trade Agreement (CAFTA-DR) countries. This would effectively eliminate the opportunity for 1.5 million undocumented immigrants from Asia and the Pacific region seeking to legalize their status.[20] Although many of these bills did not pass in Congress, the debates have contributed to a growing tension among immigrants in AANHPI communities.

The Connection Between Historical Context, Socioeconomics, and Health

AANHPIs constitute a heterogeneous population whose diversity is marked by significant differences in language, culture, values, levels of acculturation, and histories. Although some Asian American families have lived in the U.S. for several generations, initially immigrating as students or professionals, others may have arrived more recently as refugees seeking to escape persecution or violence in their countries of origin. Native Hawaiians and Pacific Islanders from the six U.S. affiliated jurisdictions possess histories similar to other indigenous communities in the U.S.

These historical differences contribute to significant variations in socioeconomic status. By examining socioeconomic data related to per capita income, health insurance coverage, and education, the significant differences among AANHPI communities are underscored. Attention to these differences is critical when making prioritization decisions and when planning HIV prevention and care services.

In the U.S., more than one out of five Chinese, Bangladeshi, Samoan, and Guamanian adults have not finished high school.

Per Capita Income

Despite the established history of AANHPIs in the U.S. and continued population growth, several challenges impact access to prevention and health services by AANHPI communities. Collectively, AANHPIs have a lower per capita income and higher rates of poverty compared to the general population. This is particularly true for certain AANHPI subgroups.[21] Based on total numbers, the five largest Asian ethnic subgroups living in poverty were Chinese, Vietnamese, Asian Indian, Korean, and Filipino. The three largest Native Hawaiian and Pacific Islander ethnic subgroups living in poverty were Native Hawaiians, Samoans, and Chamorros. One out of every three Hmong, one out every five Samoans, one out every seven Chamorros, and one out of every seven Native Hawaiians live in poverty as compared to one out of every 12 Whites who live in poverty.[22]

Lack of Health Insurance Coverage

An important factor that affects an individual's ability to access health services is insurance coverage.[23] Health insurance coverage varies significantly across AANHPI ethnicities. Over two million AANHPIs do not have health care coverage. At least 17.7 percent of all Asian Americans and 21.8 percent of Native Hawaiians and Pacific Islanders are uninsured, as compared to 11.2 percent of non-Hispanic Whites,[24] and 52 percent of Korean Americans and 32 percent of Vietnamese Americans aged 18-64 are uninsured.[25]

Education

In turn, studies focused on the correlation between education and health have shown that adults who do not graduate from high school are twice as likely to be uninsured compared to adults with high school diplomas.[1] In the U.S., more than one out of five Chinese, Bangladeshi, Samoan, and Guamanian adults have not finished high school. Nearly half or more of Hmong, Cambodian, and Laotian adults have not completed high school. Ten AANHPI ethnic groups have below average rates of completing high school, and three groups have the lowest rates among the major racial and ethnic groups.[26]

Stigma

Stigma and cultural barriers challenge efforts to mount strong HIV prevention responses in AANHPI communities. Stigma exists in multiple layers as there is stigma against HIV, people living with HIV/AIDS, same-sex behavior, homosexuality identity, and intravaneous drug use. These layers of stigma contribute to a lack of HIV risk recognition, lack of access to services, and lack of ownership of HIV as a community issue.

> *"Our communities tell us that they want to know who has HIV so that they can stay away from them."* (Health department representative, Hawaiian and Pacific region)

> *"Shame is an important barrier. We have clients who are afraid to come to us because they don't want people to see them going to the AIDS organization."* (CBO representative, Hawaiian and Pacific region)

"Sometimes when we give presentations to A&PI organizations, we are not allowed to discuss how HIV is transmitted through sex. We can only talk about HIV as a health issue." (Health department representative, Midwest state)

Additional Asian American, Native Hawaiian, and Pacific Islander Community Challenges

Differing experiences with immigration and acculturation, value systems that emphasize community insularity, resistance to health promoting and disease preventing behaviors, and various cultural practices must all be taken into account to provide culturally competent services to AANHPI populations.[27] Several cultural norms affect AANHPI communities' abilities to access HIV prevention and care services. AANHPIs living with HIV/AIDS often experience tension between respecting family and community values and accessing specialized systems of HIV/AIDS care.[28]

"There is a level of mistrust, especially for A&PI immigrant communities, to seek out Western treatment and services." (CBO representative, Western state)

"The challenge in many immigrant communities is that we tend to think that the immigrant community is monolithic, when there are second generation immigrants, operating within that immigrant community. And there are those who are just recent immigrants who bring with them social norms from their countries of origin where there is a national policy of denial of HIV/AIDS. When you are running against that kind of reality where your community does not talk at all about these issues, you're not only dealing with the government's lack of attention but also a deafening silence within our community." (CBO representative, Eastern state)

*"There is a level of **mistrust,** especially for A&PI immigrant communities..."*

IV. Impact of HIV/AIDS on Asian Americans, Native Hawaiians, and Pacific Islanders in the U.S.

Globally, there are an estimated 39.5 million adults and children living with HIV. In Asia and the Pacific, there are an estimated 8.3 million adults and children living with HIV.[29] In the United States, AANHPIs are emerging as an at-risk group,[30] challenged by increasing rates of HIV and an extreme lack of services targeted to these communities and subpopulations. In the U.S.:

- As of December 2005, an estimated 7,739 AIDS cases have been diagnosed among AANHPIs since the beginning of the epidemic.[2]

- 4,356 AANHPIs are living with AIDS as of December 2005. This represents a 54 percent increase – the *largest percentage increase* for any racial/ethnic group – from 2001 when there were 2,825 AANHPIs living with AIDS.[2]

- When measuring change in HIV diagnosis rates between 2001 and 2004, the estimated annual percentage change was 8.1 for AANHPI males and 14.3 for AANHPI females. These were the *only statistically significant increases* among any racial/ethnic group.[30]

- In 2005, an estimated 549 new AIDS cases were diagnosed among AANHPIs. This represents a 47 percent increase compared to the 373 new AANHPI AIDS cases diagnosed in 2000, *the largest percentage increase among all racial/ethnic groups*.[2]

Asian American, Native Hawaiian, and Pacific Islander Transmission Modes

Men account for a large majority of the cumulative AIDS cases among AANHPIs, however, the epidemic has had a growing impact on women. Of the cumulative HIV/AIDS cases, AANHPI males account for 86 percent of reported cases and females account for 14 percent of reported cases. Among the cases diagnosed in 2005, however, males account for 82 percent of reported cases and females account for 18 percent of reported cases.[2]

For AANHPI male adult and adolescents, the primary transmission mode is male-to-male sexual contact (55 percent of cases in 2005).[2] For AANHPI female adult and adolescents, the primary transmission category is heterosexual contact. For both men and women, the second largest reported mode of transmission is 'other/risk factor not reported or identified.' This reflects the high level of stigma associated with HIV which complicates reporting about risk factors.

"We've done a number of focus groups and talked with our clients. The ongoing feedback that we get is that HIV doesn't exist in our community. If it does, it's not talked about. So if HIV is related to sex or drugs or prostitution or what many of our communities consider taboo or morally wrong, that's not talked about either. And so there's the deafening silence that goes along with that and contributes to a feeling that HIV is not in our community. It's intentionally not wanting to see it." (CBO representative, Western state)

Asian American, Native Hawaiian, and Pacific Islander Men Who Have Sex With Men

One population of AANHPIs who have significant unmet need for HIV prevention are men who have sex with men (MSM). AANHPI MSM engage in unprotected sex as well as use substances that can impair their risk-taking judgment.[32, 33, 34] Many health departments, community planning groups (CPGs), and CBOs are not focused on addressing the specific prevention needs of this high risk group, despite evidence indicating significant need for culturally appropriate HIV prevention services.

- A study of 495 A&PI MSM ages 18–29 years old found that 25 percent had never taken an HIV test due to perceived low risk, fear of the results, and/or fear of needles. Of the 13 individuals who were diagnosed HIV positive in this sample (2.6 percent seropositive rate), eight were not aware that they were infected and five believed themselves to be at low risk.[35]

- A study of 192 A&PI gay men found that experiences of anti-immigrant discrimination were associated with higher levels of unprotected anal intercourse with secondary partners.[36]

- A study of 496 A&PI MSM ages 18–29 revealed that 28 percent had evidence of past Hepatitis B Virus (HBV) infection, 8.2 percent were chronically infected, and 47 percent were susceptible to infection. This is significant in that HBV can be transmitted via similar routes as HIV (e.g. blood, sexual fluids, etc.).[37]

"Despite data that indicate quite the contrary, some people still mistakenly believe that HIV doesn't exist in our community..."

Asian American, Native Hawaiian, and Pacific Islander Youth

AANHPI youth are often at higher risk for HIV and other sexually transmitted diseases (STDs) than might be expected. Research in the U.S. has focused mostly on young AANHPI MSM and demonstrates that this group in particular is at high risk for HIV infection. Additional research is needed on other A&PI youth subgroups.

- In a study of young AANHPI MSM, 47 percent of participants reported unprotected anal intercourse within the past six months. [38]

- A study of young MSM in 13 cities show that AANHPIs (26%) were engaged in unprotected sex at rates comparable with whites (25%) and Latinos (24%). [39]

Asian American, Native Hawaiian, and Pacific Islander Women

AANHPI women are often underrepresented in HIV planning bodies and underserved by HIV prevention programs. HIV prevention research in the U.S. on AANHPI women is relatively limited. Existing studies tend to focus on college-aged women as well as women in the massage and sex work industry.[40] Additional research on other AANHPI women subgroups is needed as there is evidence that AANHPI women are at high risk for HIV infection.[41, 42]

- AANHPI women have limited access to HIV/AIDS related services and are often discouraged from seeking preventive and proactive healthcare. They are rarely asked about their HIV risk and sexual health by their health providers.[40]

- An AANHPI woman's sexual health is often connected to her partner's cooperation in discussing sexual history and her safer sex needs.[43]

- In a study of Asian American women aged 18-34, 16 percent of respondents reported having experienced "pressure to have sex without their consent.[44]

Asian American, Native Hawaiian, and Pacific Islander Transgender Individuals

AANHPI transgender individuals often face challenges related to transphobia, lack of access to culturally competent health care, and lack of socioeconomic resources. Transgender populations are often marginalized and lumped in with either MSM or women, instead of receiving their own specific funding and focus from prevention/interventions. HIV prevalence rates and risk behaviors are high for AANHPI transgender communities.

- In a study of transgender women of color, 13 percent of the AANHPIs were living with HIV. [45]

- In a related study of 110 AANHPI transgender women, 20 percent reported unprotected receptive anal intercourse during the past 30 days. [46]

- In the same study, 46 percent reported having sex with a male partner while under the influence of substances during the past 30 days.[46]

"We have a huge marginalized population of transgenders (with) very specific needs. We are not addressing many of their issues. We are very fortunate to still be able to serve those who are of unstable immigration status. There (is a) proposed bill in the U.S. Congress where even what we're doing now may be considered illegal, and this will probably draw across a lot of the immigrant communities. But it's of major concern to us because we are serving a very large marginalized population." (CBO representative, Eastern state)

Asian American, Native Hawaiian, and Pacific Islander Immigrants

There is evidence that AANHPI immigrants are at high risk for HIV infection. Of the AANHPIs who received an AIDS diagnosis from 1985-2002, over 61 percent were born outside of the U.S. [47] In New York City, 72 percent of cumulative AIDS cases among A&PIs have been among the foreign-born.[48] These numbers are alarming, considering that immigrants may have limited English proficiency, and thus HIV prevention and care efforts that are only provided in English may not be reaching this significant population.

"The A&PI community's experiences with immigration can set the context for relationships with state and local government. When you consider the historical exclusion, the history with Japanese internment camps, and previous experiences with governments that were more or less authoritarian, it's easy to understand the mistrust that some A&PIs have." (Researcher, Western state)

There is evidence that AANHPI immigrants are at **high risk** for HIV infection.

V. Key Issues

Health departments and communities often face four key issues as they strive to break the silence around HIV in AANHPI communities. These issues compound and can prevent effective community mobilization against emerging HIV epidemics in AANHPI populations and subpopulations. Currently:

1. There is an urgent need for health departments to consistently collect and report data disaggregated by Asian American, Native Hawaiian, and Pacific Islander race and ethnic subgroups.

2. Many health departments and community planning groups are challenged in determing and/or remaining aware of the current HIV prevention needs and issues in Asian American, Native Hawaiian, and Pacific Islander communities.

3. Asian American, Native Hawaiian, and Pacific Islander communities are usually not prioritized for public health response to HIV.

4. Many health departments and community based organizations do not have adequate capacity to respond to HIV in Asian American, Native Hawaiian, and Pacific Islander communities.

> **Bottom Line:** Collectively, we often do not have sufficient data to prioritize the needs of the diverse AANHPI communities and ethnic subgroups. As such, resources and policies are turned away from these communities, resulting in inadequate HIV information, prevention and intervention efforts. Without action by health departments and communities, the silence in AANHPI communities will continue to fuel the HIV epidemic.

Issue 1: There is an urgent need for health departments to consistently collect and report data disaggregated by Asian American, Native Hawaiian, and Pacific Islander race and ethnic subgroups.

> *"Our surveillance is divided among White, Black, and other/unknown. A&PI's go under other/unknown. But unknown also includes a mixture of individuals missing data for the sex or the ethnicity. So I cannot even tell by looking at our surveillance how much of the data in the 'other/unknown' category is Asian Pacific Islanders."* (Health department representative, Southern state)

It has been said that 'numbers are everything' in HIV prevention and care; yet, for AANHPI communities, the numbers are largely meaningless. Historically, AANHPI specific epidemiologic data have often been lumped together in an 'other' category or lumped together with other racial/ethnic groups. These practices occur despite the OMB 1997 Revised Standards on Collecting, Maintaining and Presenting Federal Data on Race and Ethnicity which should in turn inform practices for state level data.

In the 2007 Online Survey (n=20) conducted to inform the development of this document (refer to Section II: Introduction), 70 percent of responding jurisdictions indicated that they remain aware of the impact of HIV in AANHPI communities through the use of national or local surveillance data. Yet, 50 percent indicated that AANHPI HIV/AIDS data is lumped into an "Other" category with other racial/ethnic groups in surveillance reports.[49] Thus, it may be challenging for health departments to be truly aware of the specific impact that HIV is having on at-risk AANHPI communities and particular ethnic subgroups within their jurisdictions.

> *"Even in low incidence communities there are high incidence pockets. We need to adapt our data collection and reporting needs to better respond to these high-risk subgroups."* (Researcher, Western state)

Low HIV incidence in AANHPI communities complicates this policy issue, yet the fact remains that due to the lumping of epidemiologic data and paucity of behavioral risk factor data for specific AANHPI ethnic subgroups, health departments and their community partners (e.g. CPGs) do not fully know the impact of HIV in AANHPI communities and therefore cannot mount a public health response.[50] While HIV/AIDS numbers may be low in relation to other racial/ethnic communities, AANHPI organizations and advocates believe that data disaggregation is needed in order to see the true picture and inform prioritization efforts for specific AANHPI communities and ethnic subgroups.[51]

- Between 2001 and 2004, AANHPI were found to be the only racial group with statistically significant percentage increases in annual HIV/AIDS diagnosis rates.[31]

- Attention to AANHPI immigrants is critical to understanding HIV's impact. Nearly two thirds of AANHPIs living with AIDS were born outside of the U.S. Because their risk factor profiles more closely follow the pattern of the U.S. epidemic versus the epidemic on the Asian continent, it is likely that these individuals were infected after immigrating to the U.S.[47]

Disaggregating health data for AANHPI communities involves separating AANHPI HIV/AIDS data from Native American, Latino, African-American, and Caucasian data. It also means expressing these data by specific AANHPI ethnicity.

> *"For years we struggled with the Health Department to make sure that data would be disaggregated. And they kept telling us that there would not be a lot of numbers and that's going to hurt us. But you have to acknowledge that there are A&PIs getting infected. I wish they would also take the other step of disaggregating the A&PI numbers further. I know it's not going to be a lot, but at least that gives us an idea of who we need to be focusing on."* (CBO representative, Eastern state)

Issue 2: Many health departments and community planning groups are challenged in determining and/or remaining aware of the current HIV prevention needs and issues in Asian American, Native Hawaiian, and Pacific Islander communities.

> *"There needs to be a concerted, collective effort to address knowledge and beliefs around HIV.... I still think that in certain communities they don't think that HIV/AIDS happens, they don't think drug addiction happens, they don't think domestic violence happens. It's not just HIV; it's all these host of things."* (CBO representative, Eastern state)

The paucity of AANHPI specific epidemiologic and behavioral risk factor data means that health department and planning partners often lack adequate information to fully understand the HIV prevention needs and issues in AANHPI communities. HIV policies and interventions initiated in this vacuum are merely guesses as to what these very diverse communities actually need to respond to HIV.

It is irresponsible to consider AANHPIs as a monolithic 'community,' when there are multiple languages, cultures and historical relationships with the United States, differences in English proficiency, *compounded by* risk factors that are shared with all other race/ethnic groups in the U.S. *Therefore,*

- It is erroneous to assume that HIV impacts all AANHPI communities equally and in the same manner.
- It is critical to collect detailed demographic information for distinct AANHPI ethnic subgroups especially as these groups may have varying modes of HIV infection.[46]

> *"Among the different ethnicities (the) cultural piece changes too and the beliefs are clearly different from community to community."* (CBO representative, Hawaiian and Pacific region)

While many other communities have awareness of basic HIV information, this remains an HIV prevention need for AANHPI communities especially for specific AANHPI ethnic subgroups. In a study of HIV knowledge and attitudes among Asian immigrant religious institutions in New York City, researchers found serious misconceptions about HIV transmission and ways of preventing transmission.

> *"The lack of data on HIV/AIDS in A&PI communities contributes to a public misperception that A&PIs can't get infected."* (Health department representative, Midwest state)

Cultural issues and stigma compound the need for specific, targeted interventions for ethnic subgroups in AANHPI communities. Without resources for these interventions, HIV will continue to emerge in silence.

> *"Sixty-five percent of A&PIs living in this area don't speak English as a primary language. And I forgot the percentage that really doesn't speak English at all. It is possible to live in Philadelphia and not speak a word of English."* (A&PI CBO representative, East Coast state)

Limited English Proficiency (LEP) in this brief is defined as individuals who do not speak English "very well." LEP can adversely affect a person's ability to access and utilize HIV prevention, care, and treatment services. Data from the U.S. Census indicates that LEP is a significant challenge for many AANHPIs.

- There are over four million AANHPIs who have LEP. This constitutes about one-third of the AANHPI population.
- Asians are four times more likely to have LEP compared to the general population (36 percent vs. eight percent).
- Native Hawaiians and Pacific Islanders are six times more likely to have LEP compared to Whites and one-and-a-half times more likely compared to the general population.[1]

Other indicators of HIV prevention barriers are language spoken at home and linguistic isolation. The US Census defines "linguistic isolation" as households in which there is no one over the age of 13 years who speaks English "very well."[52] Compared to Whites, Asians are twenty five times more likely to be living in linguistically isolated households. Native Hawaiians and Pacific Islanders are six times more likely to be living in linguistically isolated households compared to Whites.[1]

Even as health departments consider offering language specific services, or conducting language specific assessments, the policy climate itself is not favorable to enabling access to and by AANHPI communities. In 2006, there were a number of bills debated in Congress to restrict federal funding for interpreters, translated materials, and for language assistance programs. The legal obligation to provide meaningful access regardless of English language ability, however, still stands. It is likely that most health departments do not know the composition and needs (language or otherwise) of AANHPI communities in their jurisdictions.

CPG membership often can make up for the lack of community level data for planning purposes; however, in the case of AANHPIs, there is widespread under-representation on CPGs. In 2006, the most recent year for which CPG membership data is available, 52 persons out of the 3014 CPG members nationwide identified as AANHPI. AANHPI CPG members are spread across 21 out of 53 jurisdictions for which data is available. Thirty two jurisdictions reported having zero AANHPI CPG members, including four jurisdictions that correspond to top 10 states with the highest AANHPI populations.[49]

Several factors may contribute to the lack of AANHPI participation on CPGs. AANHPIs are not often prioritized by community planning groups for HIV prevention services, thus it follows that they would not be prioritized for membership recruitment and retention. Further, without their community issues on the table, the burden of participation for AANHPIs would be disproportionate and insurmountable. Those AANHPIs that are currently CPG members have cited challenges related to lack of AANHPI HIV/AIDS data, tokenism (i.e. the feeling of being the sole representative included in a process to satisfy a diversity quota without true intent to address the needs and issues of the populations they represent), feeling uncomfortable with representing the entire AANHPI diaspora, discomfort with public speaking, and lack of familiarity with parliamentary procedures.

Issue 3: Asian American, Native Hawaiian, and Pacific Islander communities are usually not prioritized for public health response to HIV.

> *"Often when they say minority, they really mean Black."* (Health department representative, Southern state)

Without good information and community representation, health departments and planning partners do not know the needs of AANHPI communities. Without good representation and knowledge of needs, there is no discernable and culturally appropriate public health response to stem the emergence of HIV in AANHPI communities and ethnic subgroups. HIV in AANHPI communities is not prioritized for funding or interventions, so community level or health department capacity is so low that mounting a public health response to HIV in AANHPI communities is virtually impossible.

At the federal level, lack of prioritization for AANHPI efforts means that few AANHPI related organizations receive funding for HIV prevention activities. Of the 141 CBOs funded by CDC under Program Announcement 04064, only four CBOs specifically target AANHPI communities.

Similarly, at the state level, health department initiatives to fund CBOs for services to AANHPI communities are quite low. Based on a survey of state HIV/AIDS prevention programs, three jurisdictions (15 percent) who responded indicated that they held one or fewer subcontracts with community based organizations to *specifically* target AANHPI communities for HIV prevention services. In the same survey, three jurisdictions (15 percent) indicated that they held one or fewer subcontracts with community based organizations that were directed *in part* to target AANHPI communities for HIV prevention services (e.g. organizations funded to reach "communities of color"). Indeed, not much has changed since a 1998 review of state HIV prevention comprehensive plans revealed that only one jurisdiction (not including the six U.S. affiliated Pacific Island jurisdictions) specifically designated AANHPIs as a priority population.[49]

> *"There are still no A&PI specific prevention campaigns. Our community still needs basic facts on HIV/AIDS."* (CBO representative, Western state)

> *"For A&PI communities, we need to go back to the basics. HIV 101 may not be sexy, but it's critical."* (Researcher, Eastern state)

"Often when they say minority they really mean Black"

Issue 4: Many health departments and community based organizations do not have adequate capacity to respond to HIV in Asian American, Native Hawaiian, and Pacific Islander communities.

Many health departments and CBOs currently do not have the cultural and linguistic competence to address AANHPI HIV prevention needs. Resource constraints and the lack of prioritization for AANHPI communities compound the lack of capacity and existing cultural barriers. Low capacity to address AANHPI HIV prevention needs is evidenced by the lack of AANHPIs in health departments and on CPGs as well as by capacity issues facing CBOs working in the AANHPI communities.

With the exception of the six U.S. affiliated Pacific Island jurisdictions, there are few AANHPIs in key AIDS leadership positions within state and local health departments. This can and has contributed to a decreased emphasis at the national and state levels to build health department capacity related to HIV prevention in AANHPI communities and to address issues of AIDS policy related to AANHPI communities.

Despite strong AANHPI leadership in the health departments, the six affiliated Pacific Island jurisdictions face other significant challanges. While there have been 267 reported cumulative cases of HIV/AIDS in American Samoa, Commonwealth of the Northern Mariana Islands, Federated States of Micronesia, Guam, Republic of Palau, and Republic of the Marshall Islands, the cost of public health programming is disproportionately high due to unique circumstances in these jurisdictions.

Additionally, the six U.S. affiliated Pacific Island jurisdictions experience many struggles in their attempts to assess the extent of the HIV/AIDS epidemic. Most notably, HIV testing remains a constant challenge due to island geography of the jurisdictions (for example, the Federated States of Micronesia is comprised of 607 islands spread out across over 1500 miles), airline restrictions on shipping test specimens, limited flight schedules (in some jurisdictions, only one plane lands in the airport per day), and lack of laboratory infrastructure to analyze HIV test specimens and confirm positive tests (some jurisdictions must ship their HIV tests to Hawaii for analysis). Similarly, the six jurisdictions receive minimal funding that does not sufficiently support fully comprehensive HIV prevention activities.

AANHPI communities in jurisdictions across the U.S. and the six U.S. affiliated Pacific Islande jurisidictions have established solid social service, political, civic, and community infrastructures. Some health departments have been successful in recruiting key gatekeepers and stakeholders from these communities to inform various health promotion programs, including HIV. Unfortunately, however, most health departments have minimal relationships with AANHPI communities.

In the 2007 Online Survey (n=20) conducted to inform the development of this document (refer to Section II: Introduction), 45 percent of respondents indicated that the health department does not currently provide culturally and linguistically competent HIV/AIDS prevention and care services that are specifically targeted to AANHPI communities.[48] Thus, it appears that the responsibility for provision of these efforts often falls upon AANHPI CBOs and CBOs that serve minority populations. These efforts are accomplished primarily in lieu of health department or public financial support. Thus, these activities are not sustainable due to a paucity of resources.

"We're still facing the lack of qualified and committed personnel. As much as we like to say that we're trying to cultivate leadership, we're always challenged by the lack of funds to pay for a full time staff member. We can't compete in the market place. We can't offer competitive salaries. The most that we can retain a person is three to five years, if they even reach three years. So when they leave, its hard to replace them." (CBO representative, Eastern state)

Of those AANHPI CBOs that do offer HIV services, only a handful receive direct CDC funding. AANHPI CBOs also face challenges in accessing indirect CDC funding through state and local health departments due to the lack of prioritization of AANHPI populations in the CPG and health department planning processes. For most AANHPI CBOs, it is too difficult to provide HIV prevention services without these resources, and several AANHPI AIDS service organizations and programs have closed down as a result.

"HIV is not a priority for many A&PI community based organizations (because) it's difficult for them to compete for funding." (CBO representative, Western state)

"Prevention programs are too bound by our funding streams. Only certain communities and interventions get prioritized or funded." (CBO representative, Hawaiian and Pacific region)

Despite the challenges that these community based organizations face in securing funding to provide HIV prevention services to AANHPI communites, the need to fund these services continue to increase in correspondence with the growing impact of HIV/AIDS in AANHPI communities. Health departments do not bear the sole responsibility to fund these efforts, but they are in a unique position to support data collection and reporting, support increased awareness, increase priority, and support capacity and cultural competence within their juridictions.

...the need to fund these services continues to increase...

VI. Recommendations

For each of the four key issues previously mentioned, a corresponding recommendation is offered. Given that health departments possess differing capacities to act upon these recommendations, they are presented with a broad range of action steps and potential challenges. These are followed by "examples that work" which illustrate how some health departments have successfully implemented specific action steps or overcome challenges.

Note: Given this document's primary target audience of health department staff, the examples that work in this section focus on the activities of health departments. This is by no means intended to diminish the numerous efforts and interventions that have been undertaken by AANHPI CBOs. For more information about examples that work from AANHPI CBOs, refer to http://www.apiahf.org.

Recommendation One

Strengthen data collection and reporting efforts, consistent with the 1997 Office of Management and Budget "Revised Standards for Maintaining, Collecting, and Reporting Federal Data on Race and Ethnicity," to describe HIV's impact in specific Asian American, Native Hawaiian, and Pacific Islander communities and ethnic subgroups.

Health departments need to focus on two methods to strengthen data so that HIV's impact can be known in specific AANHPI ethnic communities. First, they need to consistently disaggregate data by AANHPI ethnic community in their surveillance reports and epidemiologic profiles. Second, they must work with specific AANHPI communities to identify and collect additional information to describe HIV risk factors.

Health departments need to collect and consistently report data on separate and distinct AANHPI ethnic groups. This is especially important in jurisdictions with large AANHPI populations such as California, New York, Hawaii, Texas, New Jersey, Illinois, Washington, Florida, Virginia, Massachusetts, Utah, Nevada, Oregon, and Arizona.

Action steps to achieve disaggregated data:

- Discontinue use of the "Other" category when reporting data by race/ethnicity.
- Collect and report HIV/AIDS surveillance data by Asian race and NHPI race.
- Collect and report HIV/AIDS surveillance data disaggregated by AANHPI ethnic subgroups.

- Convene consultations between health department prevention staff, HIV surveillance staff, epidemiology staff, CPG members, and CBOs to assess current AANHPI HIV/AIDS data collection and reporting practices.

- Create data gathering protocols that allow clients to self-identify race/ethnic subgroups.

Health departments can strengthen epidemiologic profiles by using a variety of information sources that relate to health indicators of AANHPI communities in their jurisdictions. Data can include information on immigration and acculturation, movement or migration, attitudes towards public health interventions and community services, and behavioral risk factor analyses.

Action steps to strengthen epidemiologic profiles of AANHPI communities:

- Collaborate with AANHPI CBOs and/or AANHPI community partners to identify HIV/AIDS data collection and reporting needs, to learn more about high risk subgroups, and to identify additional factors for inclusion in epidemiologic profiles.

- Incorporate AANHPI census population counts and population growth figures when describing jurisdiction demographics.

- Incorporate additional socioeconomic data in the integrated epi-profiles such as limited English proficiency, educational level, and level of insurance coverage to provide a more complete description of the AANHPI communities in their jurisdictions.

- Include surrogate data on sexually transmitted diseases, including hepatitis B virus and hepatitis C virus, for AANHPI communities.

- Conduct behavioral risk assessments, needs and service assessments with AANHPI high risk subgroups in your jurisdiction.

Potential Challenges

Lack of Resources

Health departments face resource constraints which determine whether and how innovations can be implemented. In this light, it may appear that epidemiologic data disaggregation will "cost more than it is worth." The costs are not just in surveillance staff time, but in reporting forms changes and provider education; depending upon the significance of the changes to capture AANHPI specific data such as immigration status, LEP, and risk factor information. This information, however, is also useful to more fully describing other racial/ethnic communities as well.

While cost will be incurred to implement the recommended change, health departments will find that in the long run, a public health savings will occur because programs and planning groups will be able to focus attention on the locus of HIV emergence. With specific AANHPI community and subpopulation data, health departments will be equipped to better utilize their increasingly stretched HIV prevention resources and will be able to more effectively measure the impact of HIV prevention efforts.

Small Cell Sizes

In some states with low AANHPI population counts and low AANHPI HIV/AIDS numbers, there may be concerns related to reporting data that inadvertently identifies or implies a person's HIV/AIDS status. In these situations, it may be useful to set cell size suppression rules. For example, instead of detailing in surveillance reports that there were two diagnosed cases of HIV among Asian males who are 65 or older, some jurisdictions report that there were "less than five cases" in this category. This designation is a better alternative compared to lumping AANHPI data with other racial/ethnic groups into an "other category" or simply leaving out AANHPI data all together. For categories where there are no AANHPI cases, it is appropriate to use a "0."

> *"Even if there are zero cases among Asian & Pacific Islanders, it's better for us to see a zero in the reports than to be completely left out."*(CBO representative, Midwest state)

Availability of U.S. Census Data Disaggregated by AANHPI Ethnic Subgroup

Current socioeconomic status (SES) and other data is not available by subgroup in the U.S. Census. For example, SES estimates for Asians are only available at the state level and only in aggregate form. Subgroup estimates are only available at the national level, but not for every group. State data centers, however, may have access to other data that can supplement Census data.

Examples that Work

Hawaii: Data Disaggregation

Hawaii is in a unique position regarding its populations of Asians, Native Hawaiians, and Pacific Islanders, who comprise approximately 60% of the state population. Together, AANHPIs are the majority population group in Hawaii. HIV/AIDS data prepared by the STD/AIDS Prevention Branch of Hawaii Department of Health has historically been reported by disaggregated racial categories relating to AANHPIs population groups: "Asian/Hawaiian/PI," "Asian," "Hawaiian/Pacific Islander" and "Total API." In Hawaii's most recent (2005) "Integrated Epidemiologic Profile of HIV/AIDS in Hawaii," data categories reflect its diverse populations: "Asian and Pacific Islander Ethnic Groups," "Hawaiians and Part Hawaiians," and "Filipinos." There are other examples of state data sources that present HIV, AIDS, STD, hepatitis and other related data by AANHPI ethnic subgroups.

This data is utilized by community-based organizations, public agencies, the Hawaii Community Planning Group and other entities for planning, program implementation, evaluation and other purposes.

Availability of disaggregated data that is presented in distinctive AANHPI ethnic subgroups not only assists public and private agencies in doing more effective and efficient program planning, but also raises awareness among agency staff of the diverse population groups for which they are providing services in Hawaii.

Massachusetts: Focus on Immigrant and Refugee Populations

Recognizing the growing immigrant and refugee populations within the state, the Massachusetts Department of Public Health, HIV/AIDS Bureau worked in partnership with several CBOs in the jurisdiction to assess the epidemic in more detail. Review of surveillance data revealed that immigrants and refugee populations accounted for 18 percent of people living with HIV/AIDS and their proportional representation has been increasing over time. Information about the impact of HIV/AIDS among immigrant and refugee populations is presented in a data fact sheet that is part of the jurisdiction's epidemiologic profile, including:

- World region and country of origin
- Regional distribution
- Gender
- Race and ethnicity
- Exposure mode
- People diagnosed with HIV infection and AIDS within two months
- Mortality with HIV/AIDS

Recommendation Two

Increase health department and community planning group awareness of Asian American, Native Hawaiian, and Pacific Islander communities and their HIV prevention needs.

Enhancing data collection and reporting efforts are not sufficient in and of themselves to mount a public health response. Health department staff and CPG members must also take the opportunity to read and utilize this data to increase their awareness of AANHPI communities in the jurisdiction and HIV's impact on those communities.

Action steps to increase awareness about AANHPI communities:

- Review U.S. Census data to have awareness about established and emerging AANHPI communities within the jurisdiction.
- Conduct a presentation on AANHPI communities in honor of AANHPI awareness activities in May.
- Increase health department staff and CPG cultural sensitivity and competence (see also Recommendation 4).
- Increase health department staff and CPG knowledge about the cultural barriers, language barriers, and stigma that impede AANHPI community access to HIV prevention and care services.
- Develop and strengthen relationships with AANHPI CBOs and civic leaders.
- Increase AANHPI representation on decision making bodies.

Furthermore, an awareness of the continued and evolving HIV prevention needs of AANHPI communities, particularly those at high risk for HIV infection, is important. This needs assessment is vital to inform decisions and policies carried out by the health department and the CPG.

Action steps to increase awareness about the HIV prevention needs of AANHPI communities:

- Create ongoing opportunities for health department staff and contractors to engage AANHPI community partners through community forums, the CPG, planning councils and consortia.
- Collaborate with AANHPI CPG members, CBOs, community gatekeepers, and/or AANHPI student groups to conduct surveys, focus groups, and/or key informant interviews to assess AANHPI HIV prevention needs.

- Conduct a resource inventory to assess current HIV prevention efforts specifically targeted to AANHPI communities.

- Enhance the CPG's Community Services Assessment via inclusion of findings from above assessments.

- Sponsor and coordinate events and activities in recognition of "National Asian & Pacific Islander HIV/AIDS Awareness Day"

- Offer a cultural sensitivity training to increase health department staff awareness of the predominant and emerging AANHPI communities that are part of their jurisdiction.

- Increase CPG recruitment and retention efforts of AANHPI community members and provide other opportunities for community input into the CPG process.

Potential Challenges

Low AANHPI Participation on CPGs

Without AANHPI membership on CPGs, health department and CPG partners may feel that efforts to learn more about the AANHPI communities in their jurisdiction are a 'waste of time.' In other words, an increase in awareness among these entities is useless unless they are linked with opportunities for AANHPI communities to be prioritized and ultimately receive support for HIV prevention efforts.

Difficulty Recruiting AANHPI CPG Members

HIV incidence among AANHPIs is low compared with other populations, and it may appear that the A&PI communities themselves do not prioritize HIV as an issue (as evidenced, perhaps, by the lack of CPG participation). Capacity building assistance is available to health departments and CPGs to recruit and retain AANHPI CPG members. Capacity building assistance is also available to help identify alternative methods of accessing AANHPI community input and involvement to inform community planning efforts. For more information about available capacity building assicance resources, please refer to the "Acknowledgment" section of this document.

Low Community Response to Assessment Efforts

Surveys, focus groups, and community forums conducted in AANHPI communities may face low response rates due to issues of mistrust, HIV/AIDS stigma, and other barriers. This can be especially true if there have not been previous efforts to outreach to AANHPI communities. Thus, it is crucial that AANHPI community members and leaders are involved in the development and implementation of the assessment efforts. These individuals can help to broker key relationships with community gatekeepers, develop culturally sensitive assessment tools and methodologies, and identify optimal locations to conduct assessment activities.

Examples that Work

Santa Clara County CPG: California Focus Groups Led by CPG Members

In Santa Clara County, one out of every four residents is AANHPI. The health department and CPG recognized the need for more AANHPI data to inform the CPG prioritization process but were challenged by limited resources and limited health department staffing. Thus, several CPG members took the initiative to work with the health department and CBA providers to design and conduct a series of focus groups and key informant interviews.

Minnesota: Health Department Sponsored Awareness Day Activities

Since the beginning of the epidemic, there have been 84 cases of HIV/AIDS among AANHPIs in Minnesota. This represents about one percent of cumulative cases for the state. In collaboration with ten CBOs, the Minnesota Department of Health - Office of Minority and Multicultural Health and the STD and HIV section co-sponsored it's first "National A&PI HIV/AIDS Awareness Day" event in 2006, including guest speakers, performances, and free food. The health department has also developed an awareness day web page, organized a calendar of statewide awareness day events, created a fact sheet, and offered tips for organizations interested in hosting their own local events. Building on the success of the previous year, the Minnesota Department of Health co-sponsored similar activities in 2007: http://www.health.state.mn.us/divs/idepc/diseases/hiv/worldaidsday/napihaad.html.

New York State Prevention Planning Group: Cultural Awareness Presentations

Over the past few years, the New York State Prevention Planning Group (PPG) hosted a series of presentations by ethnically representative members of various communities of color, including the AANHPI communities, at their full member meetings. Using a common framework provided by the PPG, the AANHPI representatives presented the historical underpinnings, cultural norms, demographic trends, and other external factors that have shape AANHPI communities. They also discussed the lessons learned and proposed steps to address issues identified in their presentation. Together with three other presentations by member of the African American, Latino, and Native American communities, the presentation series formed the basis of a summary report entitled "Voices from Communities of Color: A Tapestry of HIV Prevention" which underscored the PPG's appreciation of the roles of cultural and socioeconomic factors in HIV prevention strategies, intervention, and access to HIV/AIDS-related services. It also demonstrated the PPG's commitment to emphasize the central role of cultural competence in planning and prioritizing its future prevention efforts.

Recommendation Three

Consider opportunities to increase prioritization of Asian American, Native Hawaiian, and Pacific Islander communities, especially in jurisdictions where data indicates established or emerging communities at risk for HIV infection.

As health departments strengthen data collection, they will find it easier to determine HIV's impact in AANHPI communities, and can prioritize particular communities for public health mobilization. While numbers may be lower compared with other populations, health departments should have the ability to allocate resources for culturally appropriate HIV prevention efforts in particular AANHPI communities.

Action steps to prioritize AANHPI communities for HIV program and services funding:

- Engage the CPG and AANHPI communities to strengthen assessment of HIV preventions needs, current resources available, and analysis of gaps of Asian and Pacific Islander communities.
- Adjust CPG prioritization process to include factors that relate to emerging communities engaging in high risk behaviors.
- Establish a "minimum investment" prioritization and resource allocation strategy that would address the HIV prevention needs of AANHPI communities.

Prioritization of AANHPI communities for HIV prevention services also means increasing linguistic and culturally appropriate public information and interventions for AANHPI communities and ethnic subgroups at greatest risk for HIV. When disaggregated epidemiologic and behavioral data for AANHPI communities is available, health departments and CPGs are able to direct resources more efficiently and effectively. For example, radio broadcasts in specific AANHPI languages may be more effective than translated brochures at getting HIV prevention messages out in certain communities.

Action steps to increase linguistic and culturally appropriate public information and intervention services for AANHPI communities:

- Collaborate with national organizations serving AANHPI communities to identify current resources, materials and clearinghouses to share information and save on cost. When not available, purchase available HIV prevention materials translated into local AANHPI languages and make these materials available to health department funded CBOs.
- Collaborate with local AANHPI CBOs and communities to develop public information and social marketing campaigns for specific AANHPI subgroups at high risk for HIV infection. The campaigns should be expressed in English and select AANHPI languages. Fund community based social marketing efforts.

- Increase funding for multilingual, culturally-competent AANHPI HIV prevention programs.

- Fund interpretation and translation services based on Limited English Proficiency data from the U.S. Census and make these services available to all health department funded CBOs.

- Partner with other health programs to increase culturally and linguistically appropriate health services, such as family health, STD services, substance abuse and mental health services.

Potential Challenges

Lack of Asian American, Native Hawaiian, and Pacific Islander Data

"The numbers are everything." This refrain was shared repeatedly during key informant interviews to express the importance that HIV related data play in the prioritization process. Without good data, health departments and CPGs will not see the importance of prioritizing specific AANHPI communities and subpopulations for HIV prevention resources. Further, as with all resource associated planning bodies, CPGs recognize the difficulty of reprioritization with little or no additional resource. AANHPI communities and their partners will face the challenge of making a case for resources in the face of low HIV incidence data and flat HIV prevention funding.

Examples that Work

Massachusetts: Prioritization Process That Includes Emerging Populations

Like many other health departments who have faced serious funding cuts, the Massachussetts Department of Public Health, HIV/AIDS Bureau has worked to balance HIV prevention needs of heavily impacted populations while recognizing the need to address the HIV prevention needs of emerging populations. The health department undertakes significant formative assessment of emerging populations, sponsoring needs assessments, intervention development, and conferences specifically focused on refugee and immigrant populations. The health department also reviews seropositivity rates of the emerging population, client usage data, and other social and behavioral proxy indicators. This information is then shared with the CPG who shares the responsibility of setting prevention priorities with the health department. Both the CPG prioritization process and the health department's Request for Responses (RFR) process encourages organizations to serve emerging populations as part of their priority populations.

"The numbers are everything."

Los Angeles: Prioritization of Smaller Populations

For their 2004-2008 Comprehensive HIV Prevention Plan, the Los Angeles County HIV Prevention Planning Committee (PPC) endorsed seven behavioral risk groups during the priority setting process. The PPC took the initiative to additionally prioritize American Indians/Alaskan Natives and incarcerated populations. Although the PPC felt that priority populations needed to be defined by behavioral risk, they also wanted to ensure that small populations, such as American Indians/Alaskan Natives and incarcerated populations, did not fall through potential cracks as resources were allocated. Thus, the PPC additionally recommended that one percent of all HIV prevention funds be directed to support HIV Education/RISK Reduction and HIV counseling and testing programs that exclusively target American Indians/Alaskan Natives and that 1.5 percent of HE/RR funds target the incarcerated population.

Orange County, CA: Translation of HIV Materials into Vietnamese

AANHPIs account for about 15 percent of the population in Orange County, CA. The County of Orange Health Care Agency, in general, seeks to provide materials in languages appropriate to populations served. To accomplish this goal, the Health Care Agency has created a department that specifically works on cultural competency. Additionally, U.S. Census data and client demographic data are utilized to identify languages for prioritized translation. Based on this data, several HIV prevention documents were translated into Vietnamese (see http://www.ochealthinfo.com/public/hiv/local.htm).

The process for translation begins with a document that is created in English. This document is sent to a separate quality management department that is responsible for translation. Vietnamese staff in the HIV program reviews the translated document for linguistic and cultural competence. One challenge related to translation into Vietnamese is that grammar and vocabulary may differ based on age and level of acculturation. Thus, program staff review client data to identify the specific demographics that are most likely to access the document and adjust the translated material accordingly.

U.S. Affiliated Pacific Island Jurisdictions

Despite limited funding, limited staffing, and other significant challenges, health departments in the six U.S. affiliated Pacific Island jurisdictions have taken significant steps to ensure linguistic and culturally appropriate public information and intervention services for the communities they work with.

- In American Samoa, cannery workers (with standard wages of $3.30 per hour) were identified as a population engaging in high-risk behaviors. The Department of Health offered $5.00 incentives to encourage their participation in behavioral risk surveys.

- In the Commonwealth of the Northern Mariana Islands, the health department has collaborated with the Napu Life Foundation (the only AIDS service organization in the jurisdiction) to jointly conduct outreach and HIV counseling, testing and referral in non-traditional settings.

- In the Federated States of Micronesia, the health department staff in Chuuk worked closely with the Traditional Chief and the Special Assistant to the Governor to obtain permission to conduct HIV prevention and outreach activities in Pattew, an outer island reachable only by a 24-hour small boat ride over rough seas.

- In Guam, the Department of Public Health collaborated with the Guam HIV/AIDS Network (GUAHAN) Project and other organizations to develop the Prutehi Hao (Protect Yourself) social marketing campaign.

- In Palau, the Ministry of Health established a Health Resource Center for HIV & Sexually Transmitted Infections onsite at the Palau Community College in order to better reach young adults.

- In the Republic of the Marshall Islands, health department staff conducted behavioral risk surveillance surveys with pregnant women, high risk youth, and commercial sex workers to inform delivery of linguistic and culturally appropriate HIV prevention efforts.

Recommendation Four

Increase the capacity of health departments and community based organizations to address the HIV prevention needs of Asian American, Native Hawaiian, and Pacific Islander communities through increased staffing as well as increased access to resources and capacity building assistance.

Building capacity for health departments and CBOs to respond to HIV in Asian American, Native Hawaiian, and Pacific Islander communities involves organizational and resource development, cultural and linguistic capacity building, and leadership development. Health departments need to build internal staff capacity to work with AANHPI communities. This can be accomplished through cultural diversity trainings, and through specific efforts to recruit and retain staff who have personal and/or professional experience with AANHPI communities.

Action steps to increase health department capacity to work with Asian American, Native Hawaiian, and Pacific Islander communities:

- Develop AANHPI staff recruitment and retention strategies, focusing particularly on leadership, program and policy positions in the HIV program. Utilize AANHPI staff throughout health department as advisors to recruitment and retention efforts.

- Assess health department staff and contractor cultural competency and capacities to serve AANHPI communities. Work with AANHPI staff and community partners to establish competency indicators. Conduct targeted cultural competency training based on these indicators.

- Develop and strengthen health department relationships with AANHPI civic leaders, AANHPI CBOs, and other community stakeholders by establishing an AANHPI task force or commitee to increase awareness and inform health department planning efforts.

Health departments need to build internal staff capacity to work with AANHPI communities

- Collaborate with AANHPI CBOs that provide health services to AANHPI communities in your jurisdiction.

- Dialogue with other divisions and departments within the health department. It's possible that other disease programs (e.g. hepatitis B, tuberculosis, chronic disease, etc.) may have knowledge of and relationships with AANHPI CBOs and AANHPI gatekeepers that can be leveraged for HIV prevention efforts.

- Request capacity building assistance (CBA) from CDC funded CBA providers to support health department capacity on issues (e.g. cultural competence, data collection and reporting for AANHPI communities, conducting community services assessments among AANHPI communities).

- Assess and develop cultural and linguistic competence based on the U.S. Department of Health and Human Services Office of Minority Health National Standards on Culturally and Linguistically Appropriate Services (CLAS).

Action steps to build the capacity of CBOs and AANHPI specific CBOs to provide HIV prevention services to targeted populations in AANHPI communities:

- Strengthen communications by advising AANHPI CBOs of potential funding, training, and collaboration opportunities.

- Host an AANHPI CBO summit to discuss capacity issues and organizational challenges which pose barriers to reaching populations. Consider partnering with neighboring states or cities for the summit. Develop CBO training efforts based on outcomes of the summit. Increase funding for CBO efforts.

- Ensure that CBOs funded to serve people of color communities include AANHPI activities and interventions in their comprehensive programming. Assure that these CBOs are providing culturally and linguistically competent services to AANHPI communities.

- Connect health department funded CBOs with CDC-funded CBA providers. Support capacity building assistance efforts by submitting CBA requests on behalf of these organizations through CDC CBA Request Informaiton System (CRIS).

Potential Challenges

Funding and Resources
Health departments and CBOs face significant funding and resource constraints. Their lack of capacity to address the HIV prevention needs of AANHPI communities is often related to a broader lack of capacity to respond to the full spectrum of health issues and needs among AANHPIs. Building capacities to work with AANHPI communities and building cultural and linguistic capacities means expending currently limited or non-existent resources. Instead of waiting for new resources to conduct competency trainings, however, health departments can work with AANHPI community organizations and leaders to help raise awareness and build community norms that support HIV prevention efforts – particularly those who represent AANHPI communities and subpopulations at greatest risk for HIV.

To expand capacities of CBOs will require financial and organizational resources that are not currently available to many jurisdictions. Health departments can team up with AANHPI CBOs to identify other resources (foundation, federal, state, private) to address capacity needs. Again, strong data will help make the case for funding.

Examples that Work

Southern Nevada Health District: Supporting Health Department Staff Capacity

Between 1990 and 2000, the state of Nevada experienced the highest growth rate among Asians compared to other states. In particular, the Southern Nevada Health District (which includes Henderson and Las Vegas) took the opportunity to proactively hire an Asian staffperson. Although this person's responsibilities do not focus specifically on AANHPI communities, the staffperson holds the important responsibility of leading the community planning group process. The health department has supported this individual's leadership development and capacity building by connecting this staffperson with CDC funded CBA providers who work with AANHPI communities. Moreover, the staffperson is allowed to use work hours to attend trainings sponsored by the CBA providers.

Again,
strong data
will help
make the case
for funding.

VII. Moving Forward

Breaking Through the Silence is focused on health department responses and leadership to address HIV in AANHPI communities; yet the responsibility for moving forward does not rest solely on health departments, as it is shared with AANHPI community based organizations and community leaders. Buy-in and support from the AANHPI communities is essential to address cultural insularity, challenges with immigration and acculturation, and HIV stigma.

AANHPI communities have already begun efforts to confront these barriers to effective HIV prevention and care. Concurrent health department attention, action, and support is critical in order to effectively reduce the impact of HIV among AANHPIs. This is especially critical given that HIV prevention efforts are most successful when the at-risk community is actively involved in the development, implementation, and evaluation of these efforts. Health departments must assess how they can strengthen their relationships with AANHPI communities within their jurisdiction.

There are responsibilities that health departments must take the lead on:

- Health departments should provide community based organizations, community planning groups, and community stakeholders with clear and specific epidemiologic and surveillance data regarding the impact of HIV/AIDS in AANHPI communities.

- Health departments should increase their own awareness and responsiveness regarding the emerging impact of the HIV epidemic on AANHPI communities and the particular subgroups within that are at highest risk for HIV infection.

- Health departments should recognize and address their own capacity or lack thereof to respond to the emerging epidemic in AANHPI communities. Health departments alone are not responsible for building the capacity of community based organizations to work with AANHPI at risk populations, but they play a pivotal role in providing capacity building assistance, leadership and resources, especially to health department subcontractors.

Health departments and community planning groups share the responsibility of setting HIV prevention priorities for their respective jurisdictions. In most prioritization processes, decisions are based on factors and indicators that fuel the HIV epidemic. In order to truly "prevent" HIV infections, health departments and community planning groups must also take into account data beyond HIV prevalence and incidence in order to identify opportunities to invest in high-risk communities where the epidemic is ripe for explosion.

To break the deafening silence around HIV in AANHPI communities, health departments must work with AANHPI CBOs and community leaders to move forward on all of the above fronts. We cannot afford to forget the lesson learned from over 25 years of the HIV/AIDS pandemic:

"Silence equals death."

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In particular, APIAHF and NASTAD would like to applaud the work of health departments and CBOs who have already undertaken some of the recommendations suggested in this document. We encourage these jurisdictions to continue their efforts and also offer peer support to other jurisdictions hoping to strengthen HIV prevention for AANHPI communities.

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Technical Assistance and Capacity Building

With a continuing commitment to address the key issues identified in "Breaking Through the Silence," APIAHF and NASTAD encourage health departments and community based organizations to access technical assistance and capacity building in moving forward with the suggested recommendations.

Through funding from the Centers for Disease Control and Prevention (CDC), NASTAD staff work with with state and local AIDS directors and health department staff to support peer-exchange and networking. NASTAD also helps broker agreements with CDC on issues related to health department implementation of HIV prevention cooperative agreements from CDC and works with other national organizations to foster collaboration and coordination at the local level.

Similarly, APIAHF is currently funded by CDC to provide capacity building to health departments, community based organizations, and community planning groups on issues related to organizational infrastructure and strengthening community planning, especially focused on Asian American, Native Hawaiian, and Pacific Islander communities.

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