Asian and Pacific Islander
Community Consultation:

Access to HIV/AIDS Care Issues

February 2, 2004
Doubletree Hotel and Executive Meeting Center
1750 Rockville Pike
Rockville, MD
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Introduction

The HIV/AIDS epidemic in the United States (US) disproportionately impacts ethnic and racial minorities, the poor and other populations that are underserved by the health care system. Together, ethnic and racial minority populations make up close to thirty percent of the total population of the US. However, these populations experience a disparate burden of HIV disease. In 2002 for example, ethnic and racial minority populations accounted for over three-fifths (61.6%) of the estimated number of persons living with HIV/AIDS in the US. Despite the advances made in HIV clinical care and drug therapies, disparities in health outcomes and access to HIV treatment and care persist for ethnic and racial minorities living with HIV disease.

The Ryan White Comprehensive AIDS Resources Emergency (CARE) Act, originally enacted by Congress in 1990, and subsequently amended and reauthorized in 1996 and 2000, is due for reauthorization again in 2005. The CARE Act is administered by the United States Department of Health and Human Services (DHHS), Health Resources and Services Administration's (HRSA) HIV/AIDS Bureau (HAB). The purpose of the CARE Act is to improve the quality and availability of care for low income, uninsured and underinsured individuals and families affected by HIV disease, reduce the use of more costly inpatient care, increase access to care for underserved populations, and improve the quality of life for those affected by the HIV/AIDS epidemic. CARE Act funding is distributed through grants to states, local governments and private, nonprofit organizations and institutions for primary health care and support services that enhance access to and retention in care; healthcare provider training; and technical assistance to assist funded programs address implementation and emerging HIV care issues.

CARE Act funding also supports oral health treatment for individuals with HIV disease; development and evaluation of innovative HIV/AIDS service delivery models with potential for local and national replication, and time limited planning and capacity building grants to eligible public or private nonprofit entities, interested in developing, enhancing or expanding high quality HIV primary health care services in rural or urban un-served areas and communities of color.

On an annual basis the CARE Act programs reach over 500,000 persons. These programs are an important source of HIV care and support
sers for ethnic and racial minorities living with HIV disease. In 2001, more than three fifths of the persons served by CARE Act programs were ethnic and racial minorities.6

During 2003, in preparation for the upcoming 2005 reauthorization of the CARE Act, the HIV/AIDS Bureau engaged in extensive consultation with constituents, the CDC/HRSA Advisory Committee on HIV and STD Prevention and Treatment, national partners, frontline service providers, community members and people living with HIV/AIDS. This consultative process was designed to solicit broad feedback on current HIV/AIDS treatment and care issues and the future directions needed to improve and strengthen the Care Act. This process also included an examination of how well the Care Act is fulfilling its purpose of providing quality health care, treatment and crucial support services to low-income, uninsured, underinsured and underserved people living with HIV and AIDS.

Purpose of the Meeting

As part of its on-going efforts to assure input from many diverse communities across the country, the HIV/AIDS Bureau convened, four, one-day meetings of representatives of different ethnic and racial minority groups in late January and early February 2004. This report summarizes the meeting held on January 29, 2004, with a group of Asian American consumers and service providers working on the frontlines throughout the United States to address the epidemic in their communities.

The purpose of the meeting was to elicit feedback from participants on the resources that are currently available through the CARE Act in their communities, the resources that are still lacking, and their perspectives on what is necessary to improve access to quality HIV/AIDS care at the community level. The meeting was structured to examine the following:

- What is, and is not, working in the provision of HIV/AIDS care and treatment in their communities.
- The broader systems issues that impact access to HIV/AIDS care in their communities.
- The factors and special needs that must be taken into account to assure that Asian and Pacific Islander communities receive access to quality HIV/AIDS care and treatment.
- The unique characteristics of their communities, their healthcare needs, and the service delivery system(s) that need to be taken into account -- where the CARE Act fits within this broader framework.
• Strategies that the HIV/AIDS Bureau can undertake to reduce disparities in access to care through policy and guidance development, training, technical assistance, program development, program management, and in formulation of recommendations for reauthorization

**Participants**

The Asian and Pacific Islander Community Consultation Group convened on February 2, 2004, was a diverse group of ten (10) predominantly Asian men and women, representing people living with HIV disease, consumers of CARE Act services, and community-based service providers. The participants were from a cross section of cities and states including San Francisco, CA, Los Angeles, CA, Washington, DC, Chicago, IL, Boston, MA, New York, NY and Philadelphia, PA. They represented a mix of experience and expertise and included health educators, policy advocates, case managers, program managers and executive directors. Some of the participants had experience with the CARE Act through membership on Title I planning councils, Title II consortia or working in Title III and Title IV funded programs.

The participants represented a mix of national, regional and local Asian and Pacific Islander (A&PI) led AIDS service organizations, health clinics, and community based organizations. The populations served by these organizations include A&PI youth, women, men and families affected by HIV/AIDS and sub-populations such as, men who have sex with men, transgender persons, immigrants and refugees. They offer a wide range of services, such as primary medical care, outreach, HIV-antibody testing, pre- and post-test counseling, support groups, case management, and risk reduction programs, safer sex counseling, nutrition counseling, volunteer training, peer education, referrals and legal assistance, technical assistance, provider training and cultural competency training, policy research, advocacy and leadership development.
Trends of HIV/AIDS among Asians and Pacific Islanders

The Asian and Pacific Islander population in the United States (US) is diverse and growing rapidly. Although HIV/AIDS prevalence and incidence has remained relatively low in this population, lack of disaggregated data by national origin mask the differential impact of HIV/AIDS on the distinct sub-groups making up this population. The following sections provide a socio-demographic profile of Asians and Pacific Islanders in the US, highlighting issues related to access to care and the trends in HIV/AIDS in this population.

Demographic Profile

Asians and Pacific Islanders (A&PI) represent the fastest growing ethnic population in the US. Census data indicate that overall growth in the A&PI population from 1990 to 2000 was 69%. In March 2002, there were 12.5 million A&PI lived in the US and U.S.-associated Pacific Island jurisdictions, accounting for 4.4% of the total US population. The Asian and Pacific Islander population is distributed across the US. However, there are large concentrations of this population in certain regions, states and metropolitan areas. More than half of the A&PI population lived in the West (51%) and nearly one fifth lived in the South (19%). In addition about 12% of the A&PI population lived in the Midwest and 19% resided in the Northeast. Asians are spread albeit unevenly across the country.

In 2000, the ten states with the largest Asian populations were California (4.2 million), New York (1.2 million), Hawaii (0.7 million), Texas (0.6 million), New Jersey (0.5 million), Illinois (0.47 million), Washington (0.39 million), Florida (0.33 million), Virginia (0.30 million) and Massachusetts (0.23 million). Slightly more than half (51%) of the total Asian population resides in just three states: California (35%), New York (10%) and Hawaii (6%). A&PIs are predominately urban with 95% living in metropolitan areas compared to 78% of the white population. Among A&PIs living in metropolitan areas, 41% lived in central cities...
and 54% lived in areas outside of central cities. Of places with 100,000 or more population New York, NY (872,777), followed by Los Angeles, CA (407,444), had the largest populations of Asians.⁹

The Asian population is very diverse representing different nationalities and ethnic groups. These groups vary in language, culture and length of time living in the US. Chinese are the largest sub-group of accounting for more than one fifth of the total number of Asians in the US. Filipinos are the second largest sub-group (19.9%) followed by Asian Indians (16%). When combined these three sub-groups, make up 58% of respondents who reported a single a single Asian group in the 2000 Census. Koreans (10.3%), Vietnamese (10.3%) and Japanese are the next largest Asian sub-groups. The table below lists the twelve largest Asian sub-groups reported in Census 2000.¹⁰

<table>
<thead>
<tr>
<th>National Origin</th>
<th>Number</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Chinese (except Taiwanese)</td>
<td>2,734,841</td>
<td>22.3</td>
</tr>
<tr>
<td>Filipino</td>
<td>2,364,815</td>
<td>19.9</td>
</tr>
<tr>
<td>Asian Indian</td>
<td>1,899,599</td>
<td>16.0</td>
</tr>
<tr>
<td>Korean</td>
<td>1,228,427</td>
<td>10.3</td>
</tr>
<tr>
<td>Vietnamese</td>
<td>1,223,736</td>
<td>10.3</td>
</tr>
<tr>
<td>Japanese</td>
<td>1,148,932</td>
<td>9.7</td>
</tr>
<tr>
<td>Cambodian</td>
<td>206,052</td>
<td>1.7</td>
</tr>
<tr>
<td>Pakistani</td>
<td>204,309</td>
<td>1.7</td>
</tr>
<tr>
<td>Laoitian</td>
<td>198,203</td>
<td>1.7</td>
</tr>
<tr>
<td>Hmong</td>
<td>186,310</td>
<td>1.6</td>
</tr>
<tr>
<td>Thai</td>
<td>150,283</td>
<td>1.3</td>
</tr>
<tr>
<td>Taiwanese</td>
<td>144,795</td>
<td>1.2</td>
</tr>
<tr>
<td><strong>Total Asians</strong>*</td>
<td><strong>11,898,828</strong></td>
<td><strong>100.0%</strong></td>
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</tbody>
</table>

*Note: Total includes Asians alone or in combination with one or more other races or other Asian groups. The Asian population alone in 2000 was 10,242,998. Numbers do not add up to the total.

Native Hawaiians and other Pacific Islanders reflect diverse populations that include Polynesians, Micronesians and Melanesians, who are differing in language and culture. Native Hawaiians are the single largest sub-group accounting for nearly half (45.9%) of the total number of Pacific Islanders. The next largest Pacific Islander sub-groups are Samoans (15.2%), and Guamanians or Chamorros (10.6%).¹¹ In 2000, the ten states with the largest Pacific Islander populations in 2000 were Hawaii, California, Washington, Texas, New York, Florida, Utah,
Nevada, Oregon and Arizona. Together, these ten states accounted for 80% of the Pacific Islander population. However, two states, Hawaii and California alone, accounted for more than half (58%) of the Pacific Islander population. In 2000, of the places with populations of 100,000 or more, Honolulu, HI, had the largest Pacific Islander population (58,000). New York, NY (19,203), Los Angeles, CA (13,144) and San Diego, CA, (10,613), had the next largest Pacific Islander populations.

The Asian and Pacific Islander population in the US is also diverse in terms of socio-economic status. According to the Commonwealth Fund's 2001 Health Care Quality Survey, Asians overall have high educational levels. However, there are variations by national origin. While 48% of the total Asians in the US were college graduates, the proportions were highest among Asian Indians (71%) and lowest among Vietnamese (19%). The proportions of college graduates among the other major Asian groups were as follows: Filipinos (59%) Chinese (56%), Japanese (56%) and Koreans (44%). Overall the proportion of Asians with less than a high school education was very low (9%). However, 30% of Vietnamese had less than a high school education.

In 2001, 13% of Asians and Pacific Islanders were living below the poverty level (under 100% poverty). Vietnamese (31%) and Koreans (28%) had the highest proportions and Asian Indians (1%) and Filipinos (4%) had the lowest proportions living under 100% of the poverty level. Among Asians, Vietnamese also had the highest proportions with annual incomes below $20,000 (33% compared to 14% of all Asians). In contrast Filipinos (5%) had the lowest proportion in this income level. Asian Indians (36%) and Japanese (34%) had the highest proportions among those earning $75,000 or more annually, while Vietnamese had the lowest (7%) proportions in this income bracket. In terms of insurance coverage, overall 66% of Asians had coverage through their employers. However, Koreans (20%) had the lowest proportions and Japanese (77%) had the highest proportions of employer based health insurance coverage. About 15% of Asians overall were uninsured. In contrast more than half of Koreans (54%) and nearly one third of Vietnamese (32%) were uninsured.

Asians comprise about 26% of the foreign-born population in the US. Nearly half (45%) of the Asian-born population lived in one of three cities: Los Angeles, New York or San Francisco. About 7.0 million people in the US speak an Asian or Pacific Island language at home. Of this number, 5.4 million speak English "well" or "very well." About 40% of A&PIs do not speak English fluently. The most commonly spoken
Asian or Pacific island languages are Chinese (2.0 million speakers), Tagalog (1.2 million), Vietnamese (1.0 million) and Korean (894,000). It is important to have effective communication between patient and doctor to assure good health outcomes. However, Asians and Pacific Islanders experience the most difficulties among ethnic and racial groups in communicating with doctors. While some of these problems are related to language barriers, cultural differences also play a role since English-speaking Asians also experience difficulties. For example, results from the Commonwealth Survey indicate that less than one-half of Asian reported that they felt their physicians listen to everything they have to say (49%) or that they understand everything their doctor says (48%). More than two-thirds of whites reported the same for both questions (68% and 69%, respectively).

**HIV/AIDS among Asians and Pacific Islanders**

On a national level, A&PIs account for about 1% of the total HIV and AIDS cases in the US. This is less than their proportion of the total US population. A number of factors may affect national HIV surveillance data for A&PI populations such as, undercounting and misclassification of data, and small sample size. Many states do not collect HIV/AIDS surveillance data by A&PI ethnicity or do not provide these data separately. Two of the three states with the highest numbers of A&PIs in their population (California and Hawaii) do not require HIV reporting. New York implemented its reporting system in 1999. Therefore, the national data of HIV/AIDS among the A&PI population may not provide an accurate picture of the actual trends.

Through December 2002, a total of 6,556 AIDS cases were reported among A&PI adults/adolescents. Males account for 87% of the cumulative A&PI adult/adolescent cases. The overall AIDS rate among A&PIs was 4 per 100,000 in 2002, the lowest among ethnic/racial groups for which data is collected. In 2002, a total of 455 AIDS cases were reported among adult/adolescent A&PIs. Males accounted for 85% of the new AIDS cases. The cumulative number of adult/adolescent A&PI HIV cases reported through December 2002, from the 39 areas with confidential name-based HIV infection reporting, was 1,060. Males accounted for 75% of these cases. In 2002, a total of 278 new HIV cases were reported among A&PI adults/adults, from these 39 areas and males accounted for 75% of the cases. Among adult A&PIs the rate was 8.6 among males and 1.5 among females. Among A&PI children, the AIDS rate was 4.9 per 100,000.  

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The leading modes of exposure for A&PI males is male to male sexual contact, accounting for 55% of the AIDS cases and 52% of the HIV cases reported among A&PI males in 2002. Heterosexual is the leading exposure category among A&PI women accounting for 42% of the AIDS and 34% of the HIV cases reported in 2002. However, the category of risk/not reported or identified is of special concern since it is significantly high for A&PI women (48% of AIDS and 64% of HIV cases reported in 2002). This exposure category is also significant for A&PI men comprising 26% of the AIDS and 35% of the HIV cases reported in 2002.18

In 2002 there were an estimated 3,189 A&PI living with AIDS and an estimated 1,181 living with HIV/AIDS (30 areas with confidential HIV reporting). Moreover there were an estimated 93 deaths due to AIDS reported among A&PIs in 2002.19

There are differences in risk among sub-groups of the A&PI population. Since the national data is not disaggregated by sub-group or national origin for A&PIs as it is for Latinos, these differences can be seen by analyzing data from the states with the highest numbers of A&PIs. For example the A&PI sub-group accounting for the largest percentage of AIDS cases reported in California as of June 30, 1999, was Filipino, accounting for close to one-third (32.9%) of the cases. Other highly affected sub-groups were Chinese (13.1%), Japanese (11.3%) and Vietnamese (6.8%).20

A&PI populations experience a number of socio-economic, cultural and linguistic barriers to access to HIV/AIDS services. These access barriers are compounded by the diversity of the A&PI population in the US in terms of languages spoken, ethnicity, national origin, culture, immigrant status, socio-economic status, health care coverage and geographic distribution across the US. The combination of diversity and complexity of the multiple factors affecting access to care for A&PI sub-groups present formidable challenges to program planners and service providers in the design, implementation and delivery of culturally and linguistically appropriate HIV prevention and care services. The Asian and Pacific Islander Community Consultation Group identified specific issues and barriers to access to care faced by A&PIs living with HIV/AIDS in their communities. These issues are discussed in detail in the next sections of this report.
Meeting Proceedings

On February 2, 2004 HRSA's HIV/AIDS Bureau (HAB) convened the Asian and Pacific Islander Community Consultation Group meeting. The National Minority AIDS Council (NMAC), in partnership with HAB identified participants for the meeting and arranged the meeting, travel and lodging logistics. The meeting was held at the Doubletree Hotel and Executive Meeting Center, in Rockville, Maryland, from 9:00 AM to 4:00 PM. The full report on the meeting proceedings is in the appendix of this report.

Dr. Deborah Parham Hopson, Associate Administrator of the HIV/AIDS Bureau, welcomed the participants and then provided an overview of HAB's rationale and objectives for the meeting.

Ms. Idalia Sanchez, Acting Director of HAB's Office of Policy and Program Development (OPPD), welcomed the participants and then expanded on Dr. Parham Hopson's description of the purpose of the meeting.

Mr. Steven Young, Director of HAB's Division of Training and Technical Assistance, provided an overview of the Ryan White CARE Act.

All three speakers opened the floor to questions from the attendees following the opening presentations. A detailed description of the presentations and questions and answers may be found in the appendix of this report.
Mr. Kilkelly, a consultant who facilitated the meeting, introduced and handed out the tool "A Community Window...HIV/AIDS Care from My Point of View". This tool was used to structure and guide the discussions throughout the remainder of the day, on the focus question:

**What is necessary to achieve better access to quality HIV/AIDS care through the Ryan White Comprehensive AIDS Resources Emergency (CARE) Act at the community level?**

The discussion was divided into three segments that required participants to work individually, and then in small groups to address the focus question in the context of identification of:

- Community Strengths
- Community Challenges
- Barriers to, and Facilitators of, HIV/AIDS Care

Following each segment, the small groups presented the outcomes of their deliberations to the larger group and a broader discussion of the issues ensued. The facilitator stated that it was important to acknowledge the diversity of the communities represented (race/ethnicity, geography, etc.). He asked participants to define what they meant by "community" and to share that definition with the larger group when they reported out.
Key Findings

This section summarizes the key issues participants identified regarding community strengths and challenges, and the barriers to, and facilitators of, HIV/AIDS care in their communities.

Definition of Community
The different small groups defined community as follows:

- Sexual orientation and ethnicity - "What you claim and what claims you. For example, some Asian men who have sex with men (MSM) may not identify with the gay community and the gay community has not reached out to them, so they do not really identify with the gay community."
- A&PI community broadly and different ethnic groups within it - "While thinking about Asians in general, you also think about where you are from. As a Laotian, coming from a small minority group, I brought that perspective to the discussion."
- The broader A&PI political community
- The A&PI community in general (with considerations for geography and provider focus)

Community Strengths
The participants identified the following community strengths:

Socio-cultural Factors
Family
- Family is a priority
- Family-oriented culture; family ties and honor are very strong
- Communalism- focus on group needs and interests above the individual's
- Families are multigenerational, include extended family members as part of household
- Tend to cluster together and live in same neighborhoods and communities, to help one another
- Families willing to care for sick members
Diversity
• Not homogenous community
• Many distinct ethnic, racial, cultural and language groups

Ethnic Enclaves and Mutual Support
• Tend to cluster in central cities by ethnic sub-groups
• After immigrating, A&PIs tend to concentrate in ethnic neighborhoods, where local establishments and churches are specific to their sub-group affiliations.
• Provide mutual aid and support for all community members

Acculturation/Assimilation
• Take on mainstream values and acculturate to the degree necessary to move forward and gain access to jobs
• Retain their ethnic culture and can operate in both worlds

Respect for Authority Figures
• Respect for medical authority - respect what the doctor says and will follow orders
• Once in a system have strong respect for authority figures - for elders, teachers and other persons in positions of authority (providers)

Strong Work Ethic
• Very strong work ethic regardless of educational level.
• Hard work is a means to advance, take care of their families, and make a better life (immigrant experience)
• Take pride in their work

Value Education
• Focus on education as a means to achieve
• Even those with low educational attainment push their children and other family members to achieve through higher education
• Must "work twice as hard to get half as far"

Language Diversity
• No single A&PI language (60 recognized languages)
• Variations in literacy levels
Socio-political Factors

Cooperation and Collaboration

- Willingness to work in HIV, and overcome inter-group differences
- Alliances - willing to participate, some already established alliances across communities of color
- Mutual support - willingness to gather together as A&PIs, "could do a lot of crying together but have chosen to see the humor in the situation (able to laugh with each other) and do something about it (maybe at the expense of non-Asians)."

Growing Population and Political Participation

- Growth in organizations and in ability to get voices heard
- Population is growing many foreign-born, due to immigration
- Infrastructure is expanding to serve these populations.
- Community continues to grow and become more organized and active politically

Organizational Capacity

- Established and experienced multi-service agencies serving A&PIs
- Vision, value, and mission-oriented organizations

Discussion

The participants identified a number of socio-cultural factors that contribute to A&PIs communities' strengths. The importance of the family was underscored. Despite the diversity of A&PI cultures, one major over arching value is that of family. There is a strong emphasis placed on making the needs of the family as a whole the priority. Maintaining family ties and family honor is central. Individual needs are secondary and there is a strong emphasis on communalism (loyalty to the collective). Families are multigenerational and households include extended family members. A&PIs tend to reside in ethnic clusters in neighborhoods and communities to help one another. Families are also willing to care for sick members.

Participants noted that A&PI communities are not homogenous. Rather these communities are made up of many distinct ethnic, racial, cultural and language groups that tend to reside in ethnic enclaves, in central cities. These ethnic enclaves provide a vehicle for community cohesiveness, mutual support and the establishment of ethnic businesses, religious and civic organizations.
While traditional cultural values are preserved, acculturation is viewed as a vehicle to gain access to educational opportunities and resources for personal advancement through employment. A&PIs tend to operate within two cultures, balancing traditional ethnic values with new cultural norms that are necessary for success in business and the professional spheres.

Another important community strength identified by participants is the value of respect for authority, particularly medical authority. This respect facilitates compliance by patients in the health care system with medical instructions and orders. Deference to and respect for elders and others in positions of authority such as teachers and providers of care services is also an asset.

Participants agreed that the strong work ethic in A&PI communities is a key asset. Even A&PIs without higher education have very strong work ethic. They work hard to make advances in their social and economic status in order to take care of their families. The strong work ethic is closely related to the reasons why most A&PIs immigrate to begin with -- to make a better life for their families. A&PIs also take great personal pride in their work.

Closely related to the strong work ethic is the high value placed on educational achievement in A&PI communities. Education is a means to achievement of social and economic mobility. Even those parents with low educational attainment see the value of higher education and push their children and other family members to achieve. In essence, most A&PIs understand that they must "work twice as hard to get half as far".

The participants also identified several socio-political factors that contribute to community strengths. A&PIs willingness to cooperate and collaborate with other ethnic and racial minority groups to overcome barriers to access was raised as an important strength. This includes A&PI participation in alliances including some already established within communities of color. The participants also mentioned a willingness to work together as A&PIs and bridge inter-group differences as a key element. They noted that working in coalition is difficult and that there are many conflicts to resolve but ultimately they reach consensus. They observed that "we could do a lot of crying together but have chosen to see the humor in the situation (able to laugh with each other) and do something about it (maybe at the expense of non-Asians)."

The participants agreed that the growth in the A&PI population in and of itself was a strength that led to the establishment of A&PI specific organizations and greater acknowledgement by other groups and public
officials of their communities' unique needs. Organizational growth has also led to greater political organization and participation. The demands of the ever-increasing immigrant population in their communities has led to expansion and strengthening of organizational infrastructures. There are now a network of established and experienced A&PI led, vision, values and mission driven, civic and multi-service human service organizations addressing community needs.

Community Challenges
The participants identified the following factors as contributing to the challenges faced by their communities.

Socio-cultural

Language Barriers
- Diversity of languages spoken within A&PI communities
- Variations in literacy levels

Cultural Stigma
- HIV is taboo because of associated issues of sexuality and homophobia
- Dynamic of saving face by not telling, disclosing HIV status
- Stigma leads to low perception of risk and denial
- Fear of disclosure - shame will be brought on the family
- Immigrants attribute HIV to behaviors of other racial or ethnic groups

Lack of Perception of Risk
- Low perception of risk for HIV - do not seek HIV testing
- Little focus on preventive care, only seek care when feeling sick
- Large numbers of A&PIs in non-identified risk category - not knowing risk factors

Differences in Cultures and Levels of Acculturation
- Ethnic identification of second and third generations vs. newly arrived immigrants
- Limited research on acculturation and health beliefs
- Differences regarding class, sexual and ethnic identity within A&PI communities among recent immigrants
- Marginalization of certain A&PI sub-populations within A&PI communities
Mainstream Culture's Lack of Understanding of A&PI Cultures

- Motivations for behaviors can be very different between mainstream culture and across A&PI cultures.
- Lack of understanding leads to missed opportunities for HIV prevention and care

Model Minority Myth

- Non-Asians categorize A&PIs along with Caucasians due to similarities on socio-economic indicators
- Myth that A&PIs do not have the socio-economic problems ascribed to other minorities
- Masks variations in socio-economic status among A&PI ethnic sub-groups
- Leads to lack of targeting of prevention and care messages to A&PIs
- Contributes to invisibility of A&PI problems and needs

Socio-political


- Fewer services for documented and undocumented immigrants due to the chilling effect of immigration and welfare reform laws/policies
- Fear of deportation: policies that turn emergency rooms into deportation centers (Prop 107 in California)
- Deters undocumented immigrants from seeking health care
- Fear of INS by documented and undocumented immigrants
- Heightened xenophobia due to homeland security policies

Care Services System

Lack of Data

- Data is not disaggregated - broken down by subgroups
- A&PIs are lumped together in surveillance, research and service utilization data masking diversity and differences among sub-groups
- National data does not reflect geographic differences in distribution and severity of the epidemic

Late Entry to Care

- Due to low or no perception of risk by both providers and community members
- Lack of access to health care (especially for poor and undocumented populations)
Limited Resources for Staff Training, and Leadership Development

- Staff training, development and retention hampered by organizations' lack of time and resources
- Little opportunity to develop and grow organizational leadership

Invisibility: Low/No Representation

- Planning Councils
- Official data (US and overseas)
- Health departments' staff
- Care facilities' and CBOs' staff

Socio-political

Low/No Representation as Elected Officials

- Few A&PI elected and appointed officials nationally
- Few if any A&PI elected or appointed officials on state and local level

Lack of Advocacy

- At community level, A&PIs generally don't advocate for themselves (e.g., in healthcare setting do not talk with doctors). Working in CBOs - access issue
- At policy level there is little A&PI presence in legislative and policy advocacy and few A&PI elected officials to support community issues

Discussion

The participants discussed a number of challenges faced by A&PI communities due to socio-cultural factors. The diversity of the A&PI community in terms of national origin, cultural groups and languages spoken creates serious challenges to providing accessible services. The multiplicity of languages and ethnicities in these communities requires additional resources to assure cultural and linguistically appropriate services. This is further complicated by variations in the levels of education and literacy within and between A&PI ethnic groups.

Cultural stigma is a major challenge to HIV prevention efforts and increasing access to HIV care. HIV is a taboo subject due to cultural beliefs and taboos related to health and disease, sexuality and homophobia in many A&PI cultures. Discussion of such issues is viewed as bringing bad luck. There are also cultural beliefs stressing self-reliance and handling problems in private. Shame is an important element and is
used to strengthen the individual's sense of duty and obligation to the family. Saving face (not bringing shame to the individual and by extension to the family) is an underlying cultural norm that leads A&PIs to deny HIV risk, and heightens fear of disclosure of HIV positive serostatus. Fear of rejection and stigmatization by family members and the community may also lead to social isolation.

A&PI immigrants may also view certain behaviors related to HIV risk as attributable to mainstream culture or other ethnic/racial minority groups and therefore distance themselves from the problem. This dynamic leads to further denial of their risk for exposure to HIV and reinforces the misconception that they are at low risk. Lack of information and knowledge regarding HIV and AIDS exacerbates the problem.

The variations between and within specific A&PI groups in culture, immigration status and levels of acculturation and assimilation also pose problems in the development and implementation of HIV prevention and care services that are reflective and responsive to community needs. Participants noted that there are significant differences in the ethnic identification and degree of acculturation to mainstream cultural values between A&PIs that are newly arrived immigrants and second and third generation American born A&PIs. The lack of research on the acculturation process of these different ethnic and cultural groups and how it impacts culturally prescribed health beliefs also exacerbates the difficulties in the design and delivery of culturally responsive services.

Participants also identified differences in class, sexual orientation and ethnic identity as confounding factors that lead to the marginalization of some A&PI sub-groups within their own communities. One participant shared an example of the Burmese community in San Francisco. This sub-group is not assimilating into the broader culture because they are refugees and accustomed to receiving more support and assistance from governmental entities. Because of their expectation of assistance they are not functioning well within the larger A&PI community and remain isolated.

Another issue that was raised as a major community challenge is the lack of understanding of A&PI cultures by members of the mainstream community. Participants observed that behaviors are often motivated by underlying cultural values and beliefs. These cultural values and beliefs not only vary between the A&PI community and mainstream groups but also across different A&PI sub-groups. Lack of understanding leads to missed opportunities for HIV prevention and care. For example, one participant explained that it is very important to pass on the family name
in Asian cultures. In order to do this the family must have a son. This pressure may result in a gay Asian man not identifying as gay and hiding his sexual orientation from his family. This may also explain why many Asians do not self-identify with the gay community. The focus on the family, the family name and family honor may not be as strong in other ethnic or racial communities. Another example is the taboo regarding discussion of sexual matters and body parts. A&PI women may be uncomfortable discussing body parts (especially if the doctor is a male). This may lead to delayed care.

Another participant discussed how the view of Asian gay men or women as "exotic" foreign and exciting sexual objects by members of the mainstream culture, creates differential power imbalances in sexual relationships across cultures. These power imbalances may make it more difficult for gay Asian or Pacific Islander men for example to negotiate safer sex. A&PI gay men are also perceived to be at lower risk for HIV infection because surveillance data indicated lower infection rates among A&PIs. This makes them more desirable sexual partners for mainstream gay men and MSM.

The participants spent a considerable amount of time discussing how the perception of A&PIs as a "model minority" presents challenges in documenting community needs and making the case for targeted resources and services. In the aggregate, A&PIs share similar patterns on key socio-economic indicators as Caucasians. These similarities lead to the lumping of A&PIs with Caucasians and underestimating variations in socio-economic status between different A&PI sub-groups. As a community, A&PIs do not have the highly visible socio-economic problems that other racial/ethnic minority groups experience. Therefore the myth that A&PIs are a "model minority" is perpetuated. Socio-economic status also plays a role in perpetuating this myth. A&PIs are therefore not seen as needy (due to high financial status of some A& PI sub-groups). Some federal agencies (NIH, HRSA) do not even classify Asians as a minority group. Moreover, some Southeast Asians identify as Caucasians and may not be counted as Asians in official statistics.

The group emphasized that not all A&PIs enjoy the high socio-economic status (education, income, housing, etc.) that some do. For example, some immigrants such as Hmongs are less acculturated and do not have the same education level than other more prosperous Asian immigrants. Filipinos, Chinese, Asian Indians who have been in the country longer tend to be very successful. Their experience is very different from that of Asian refugees. Some refugees do have education but no money, others have neither education nor money. Household income can be deceptive as a measure of economic status. A&PIs may

The greater emphasis on Homeland Security and the rising xenophobia in the United States due to fear of terrorism has negative implications for Asians who have such high percentage of foreign-born persons within their communities.
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have very large household with many extended family members who work and contribute to the total household income.

One participant stated that Asians are never accepted as Americans by members of the mainstream culture. Due to their physical characteristics they are always viewed as different - Asians. That is why A&PIs stress educational attainment. It is seen as a means of gaining equality. People always assume Asians are from some place else. This is a very great detraction, for immigrants especially, because they are always dismissed.

Another participant observed that HRSA data indicates that Asians are overrepresented in some health related professions. While this may be true in terms of technical occupations, there are very few Asians in leadership positions in the health policy making arena on the federal, state or local levels. Language has always been a challenge for the A&PI community and affects the ability of Asians who may be technically proficient and highly educated to be selected for leadership positions because they speak with accents. It is not until the third or fourth generation that language ceases to be a barrier.

The participants agreed that the greater emphasis on homeland security and the rising xenophobia in the US due to fear of terrorism has negative implications for Asians who have such high percentages of foreign-born persons within their communities. Xenophobia and heightened homeland security is having a negative impact on Asians with Muslim surnames who are often viewed as suspect by INS officers and the police. Another example relates to refugees. One participant shared that 50,000 Hmong refugees have been approved to immigrate to the US, but have been in detention camps for 10 years. As refugees, they are settled all over the country. Then there is a secondary migration as they tend to settle in communities where other Hmong live. If someone becomes HIV+ they do not know where to get services because they have little contact with the larger community.

The participants also noted that fewer services are available for both documented and undocumented immigrants due to the chilling effect of immigration and welfare reform laws and policies. Fear of deportation is a very key factor in deterring immigrants from seeking services. In some states and cities more stringent enforcement of INS policies and immigration laws has turned emergency rooms into deportation centers (Prop 107 in California). Undocumented persons will not seek health care for fear of being deported.

There is also great fear of INS officers among documented and undocumented immigrants. For example in one state the police have been deputized as immigration service officers. The INS has also
become involved in court system and some undocumented immigrants are being identified by the INS officers when they report to court to answer charges of traffic infractions. They are often detained and then deported. Some countries of origin will not accept deported Asians back (e.g. if they have committed a crime). Many, therefore, live in limbo in INS detention centers. These INS policies and practices contribute to driving the HIV epidemic further underground in A&PI communities.

Pacific Islanders

The participants acknowledged that the Pacific Islander perspective was not well represented by this group because there were predominantly Asians at the meeting. The participants noted that Pacific Islanders are often not represented in forums like this one because of the unique challenges experienced in including this population, especially the extreme distances they must travel and the associated high costs of such travel. However, the participants identified some of the strengths and challenges of the Pacific Islander community. They recommended that HAB acknowledge that there was a lack of Pacific Islanders participating in the meeting, and the issues presented are not necessarily reflective of the voices of Pacific Islanders. The following issues were identified.

Community Strengths

Socio-cultural

• Value of family

Socio-political

Community Cohesiveness

Pacific Islanders are particularly cohesive because they are often underrepresented.

• They stand in for each other when they are not represented, speak for each other when other PI populations are not represented
• Have become more effective in advocating, particularly with the Federal government by forming the Pacific Island Jurisdictions AIDS Action Group (PIJAAG)
• Since there is no organizational infrastructure, community planning as it is known on the mainland is not viable in the Pacific Island jurisdictions - CDC developed a separate guidance (as a result of PIJAAG advocacy)
• In some areas (and on planning groups) they are the majority (e.g., in their own community)
Community Challenges

Geographic Location

- Must travel long distances for staff to get training, for clients to get care
- High travel costs
- Travel schedules are also limited (2 flights a week from some Islands makes meeting scheduling difficult)
- Logistics, communications, technological limitations, limitations on opportunities for information exchange (barriers to conference calls due to time differences, lack of access to phones or other technology limitations)
- Not represented in many Federal meetings due to distance and travel constraints

Geo-political

Mainland vs. Pacific Island Jurisdictions

- Colonial status seeps into culture (used to having Whites make all decisions)
- Treated as less than worthy of the same respect as mainlanders (e.g., dumping of infant formula on Pacific Islands)
- Not viewed as "real" Americans

High Cost of Living

- High poverty rates

Invisibility

- Model minority myth does not apply
- Fewer economic and educational opportunities where they live
- Do not have the same level of access as Asians or enjoy the same level of privileges as mainlanders

Care Services System

Poor Health Care Infrastructure

- Limited health care access
- For example, on many islands health care is limited to a nurse practitioner and many standard resources (x-rays, MRIs) are not available
Limited Confidentiality
• Since the PI community is so small and isolated, confidentiality will most likely not be maintained (concept of family/communalism sometimes becomes a detriment)
• People do not get tested for fear of disclosure of their HIV status and possible ostracism by community

Organizational Capacity
• No Community Based Organizations

Planning Processes Participation
• "Aloha" (respect and friendliness) willingness to get along and respect for authority (health department) creates barriers to advocacy that may require confrontation and contention.

Barriers to, and Facilitators of, HIV/AIDS Care
The participants identified the following factors as barriers to, and facilitators of, access to HIV/AIDS care in their communities:

<table>
<thead>
<tr>
<th>Socio-cultural Factors</th>
<th>Barriers</th>
<th>Facilitators</th>
</tr>
</thead>
</table>
| Language Barriers      | • Lack of culturally sensitive materials and service providers  
• Related to ethnicity, age, gender, class | • Needs to be Limited English Proficiency (LEP) language legislation [cannot have a family member translate].  
• Need translation/interpretation services  
• Need materials that, in addition to addressing language, address age, gender and across classes  
• Trained interpreter pools, funding for interpretation services, enforcement (Title 6 Civil Rights); translated of vital documents |
## Socio-cultural (continued)

<table>
<thead>
<tr>
<th>Barriers</th>
<th>Facilitators</th>
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</thead>
</table>
| **Language Barriers (continued)** | • Provide training to providers on OCR LEP guidelines and OMH CLAS standards  
• Enforce LEP and CLAS standards on state and local level  
• Social marketing to change cultural stigma of HIV/AIDS and to normalize health seeking behaviors  
• Funding for community-level interventions and research on how stigma impacts A&PIs  
• Education and skills building, regarding risk assessment and self perception  
• Group and individual level interventions (community and individual support)  
• Integrate HIV education into other systems where it is more accessible to the population (ESL, citizenship classes)  
• Need to address the needs of sub- populations  
• Support groups for A&PI MSM and separate ones for transgender A&PI |

### Cultural Stigma
- Around seeking services (counseling and testing) (e.g. Chicago study showing partners reacting negatively when their partner suggests testing, thought it was an indication that partners had been unfaithful, thought they were unfaithful, etc.)
- Stigma which results in A&PIs not seeking care (fear that family won’t accept them, homophobia)
- Stigma related to illness in general - won’t seek care because being sick is viewed as a "mark" that they don’t want to reveal.

### No or Low Perception of Risk
- Individuals not identifying their own risk

• Education and skills building, regarding risk assessment and self perception  
• Group and individual level interventions (community and individual support)  
• Integrate HIV education into other systems where it is more accessible to the population (ESL, citizenship classes)  
• Need to address the needs of sub- populations  
• Support groups for A&PI MSM and separate ones for transgender A&PI
### Socio-cultural (continued)

<table>
<thead>
<tr>
<th>Barriers</th>
<th>Facilitators (continued)</th>
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<tbody>
<tr>
<td><strong>Community Gate-keepers</strong></td>
<td></td>
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<tr>
<td>• In certain A&amp;PI communities there are different gatekeepers that are generally the first level of contact. These individuals may lack knowledge of HIV</td>
<td>• Educate gatekeepers about HIV and its impact on the community (AIDS 101) to dispel myths and stigma</td>
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### Socio-political Factors

<table>
<thead>
<tr>
<th>Barriers</th>
<th>Facilitators</th>
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<tbody>
<tr>
<td><strong>Immigration and Welfare Reform Restrictions</strong></td>
<td></td>
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<tr>
<td>• Government policies (homeland security; welfare; anti-immigrant)</td>
<td>• Vote to oppose anti-immigrant provisions</td>
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<tr>
<td></td>
<td>• Education of Legal Services Corporation (LSC) and law enforcement</td>
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<tr>
<td></td>
<td>• Advocacy and community organizing (government needs to address the human and social costs of these programs, communities need to make the connection between their civil rights and what the health impacts of them are)</td>
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</table>

### Care Services System

<table>
<thead>
<tr>
<th>Barriers</th>
<th>Facilitators</th>
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</thead>
<tbody>
<tr>
<td><strong>Lack of Health Knowledge</strong></td>
<td></td>
</tr>
<tr>
<td>• Health knowledge for both A&amp;PI clients and providers (body parts, how to access care)</td>
<td>• Culturally competent health education for A&amp;PI clients and providers</td>
</tr>
<tr>
<td>• Lack of knowledge of health care system</td>
<td>• Also need patient navigators to help clients interact with providers and health care system</td>
</tr>
<tr>
<td><strong>Lack of Cultural Competence</strong></td>
<td></td>
</tr>
<tr>
<td>• Organizations that claim to serve A&amp;PIs lack knowledge of specific needs of different sub-groups within A&amp;PI community</td>
<td>• Training and technical assistance in cultural competency</td>
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<td></td>
<td>• Educate providers on HRSA’s cultural competency guidelines and OMH CLAS standards</td>
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**Care Services System (continued)**

<table>
<thead>
<tr>
<th>Barriers</th>
<th>Facilitators</th>
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<tbody>
<tr>
<td><strong>Differences in Health Beliefs (provider-client)</strong></td>
<td>• Culturally competent education for health care providers (medical students, doctors, nurses, social workers, etc.) regarding cultural differences in health beliefs and implications for care</td>
</tr>
<tr>
<td>• A&amp;PI sub-group differences in community norms/beliefs of HIV, health care</td>
<td>• Social marketing (identify tools and practices specific to the population, using community and community media,</td>
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<td></td>
<td>• Making community sensitive to the needs related to HIV, input from the community, identify most critical need (use RARE)</td>
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<tr>
<td><strong>Lack of Appropriate Health Services</strong></td>
<td>• Funding (needs assessment of HIV-infected and high-risk populations)</td>
</tr>
<tr>
<td><strong>Lack of Integrated System</strong></td>
<td>• Educate funders and providers</td>
</tr>
<tr>
<td></td>
<td>• Advocate to encourage integrated service models of care</td>
</tr>
<tr>
<td><strong>Public Health Model</strong></td>
<td>• Holistic models of care provide comprehensive care that focus on the person as a whole</td>
</tr>
<tr>
<td>• Cookie-cutter approaches to different ethnic/racial populations are ineffective (e.g. belief that what works for Latino community, should work for A&amp;PIs)</td>
<td>• Also needs to be more research into the role of traditional medicine/complementary therapies and what role they plays in the A&amp;PI community</td>
</tr>
<tr>
<td>• Western medicine model does not always work for A&amp;PIs (focus on symptoms - often people can’t describe what ails them in English)</td>
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</table>
### Planning Processes

<table>
<thead>
<tr>
<th>Barriers</th>
<th>Facilitators</th>
</tr>
</thead>
<tbody>
<tr>
<td>Lack Representation</td>
<td>• Mandatory slots for A&amp;PIs on planning bodies</td>
</tr>
<tr>
<td>• Of A&amp;PIs on CPGs, RWCA HIV</td>
<td>• Mentoring and cultivating A&amp;PIs to participate</td>
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<tr>
<td>planning councils and consortia</td>
<td>• Tailored technical assistance to support long term sustainability</td>
</tr>
<tr>
<td>• Of A&amp;PI sub-populations and</td>
<td>• (different institutional levels so a single TA approach will not be appropriate</td>
</tr>
<tr>
<td>marginalized groups in</td>
<td>• Self-defined standards</td>
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<tr>
<td>decision-making bodies</td>
<td>• Meaningful engagement/research of those with marginalized needs (RARE)</td>
</tr>
<tr>
<td></td>
<td>• Need to target those communities with severest need</td>
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<td></td>
<td>• Some organizations have capacity to serve specific sub-populations based on the</td>
</tr>
<tr>
<td></td>
<td>capacity of the staff employed.</td>
</tr>
<tr>
<td></td>
<td>• Provide resources to sustain programs, train, support and retain staff</td>
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### Organizational Capacity

<table>
<thead>
<tr>
<th>Barriers</th>
<th>Facilitators</th>
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<tbody>
<tr>
<td>Variations in A&amp;PI Organizational Capacity</td>
<td>• Educate funders and providers, regarding understanding of A&amp;PI service and data collection/ research issues and needs</td>
</tr>
<tr>
<td>• Demands of multi-ethnic A&amp;PI</td>
<td>• Advocate for and encourage funding allocation to A&amp;PI organizations and services</td>
</tr>
<tr>
<td>sub-populations - lack knowledge of specific needs of different communities within A&amp;PI community</td>
<td></td>
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<tr>
<td>• Staffing to meet cultural and</td>
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<tr>
<td>language needs of multi-ethnic A&amp;PI populations</td>
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### Funding

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<tbody>
<tr>
<td>Lack of Funding for A&amp;PI Specific Programs</td>
<td>• Educate funders and providers, regarding understanding of A&amp;PI service and data collection/research issues and needs</td>
</tr>
<tr>
<td></td>
<td>• Advocate for and encourage funding allocation to A&amp;PI organizations and services</td>
</tr>
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</table>
Barriers to, and Facilitators of, HIV/AIDS Care for Pacific Islanders

The A&PI group noted that the barriers and facilitators identified for the Asian community do not specifically represent the Asian Pacific community, since there were no representatives in the meeting. However, some issues identified for Asians may be reflective of their needs as well.

Discussion

Socio-cultural Factors

Language Barriers

The diversity of languages spoken by A&PIs and the lack of sufficient bilingual staff to communicate with clients in their own language were identified as major barriers to access to care. A related issue is the lack of culturally sensitive materials. Aside from ethnic languages, barriers to communication are also posed by issues related to differences in ethnicity, age, gender and class. Participants identified a number of facilitators to address language barriers including Limited English Proficiency (LEP) legislation to assure that patients receive translations services from trained translators and interpreters. They emphasized that the provider practice of using family members, especially children, to translate must be stopped since this undermines the clients' right to privacy and confidentiality.

Participants also identified a need to provide resources for translation and interpreter services. HIV education materials need to be developed and/or translated into the language that clients speak by skilled translators, familiar with both language and cultural nuances. Such translations should also take age, gender and class status into account. Funding for trained interpreter pools, interpretation services and enforcement of Title 6 of the Civil Rights Act is also needed.

The participants observed that most providers and for that matter program officers overseeing funded programs are unfamiliar with the Office of Civil Rights (OCR) LEP guidelines and the Office of Minority Health's culturally and linguistically appropriate services (CLAS) in health care standards. They therefore recommended training for both providers and program officers on the OCR's LEP guidelines and OMH's CLAS standards. They also recommended federal monitoring implementation of these guidelines and standards on a state and local level.
In response to HAB staff questions regarding translation of materials, participants stated that Census data is available on language skill level. This data could be used to make determination about what languages should be selected for translations. Selection could be done on the basis of the predominant language spoken at home. However there may be a need to translate materials not only into the languages most frequently spoken but also on the basis of those language groups with the largest population growth. They also noted that some languages are spoken but not written. To reach groups in such cases, personal outreach by individuals who speak their language and use of community media (radio, television, local commentators) would be most effective. "Better to pay for person instead of paper."

The participants also stated that staff are needed who can be sent out to meet the needs of isolated minorities. Every single location does not need to have resources in every language (since A&PI populations tend to concentrate geographically by ethnic group). They suggested the use of non-traditional methods such as deploying staff from a regional pool of HIV providers to address the needs of small ethnic A&PI subpopulations in isolated areas. They also emphasized the need for providers to deepen their knowledge of the ethnic A&PI communities they serve. Based on greater cultural knowledge and understanding, providers might employ strategies employed to reach certain ethnic A&PI communities during some holidays or festivals where there are large gatherings of community members (the East Coast Lao community gathers at a Temple in a particular county of Virginia every year for New Years).

**Cultural Stigma**

Stigma, related to HIV, illness in general, and taboo behaviors, was identified as a major impediment to access to care. Stigma may result in A&PIs not seeking care due to fear (fear that family won't accept them, homophobia). In many A&PI cultures there is also stigma associated with illness in general and many people won't seek care because being sick is viewed as a "mark" that they don't want to reveal. The participants recommended a targeted, culturally appropriate stigma reduction campaign to change cultural stigma related to HIV/AIDS and to normalize health seeking behaviors. One participant stated that there is a need for spokespeople with high visibility who are well respected that can command the attention of A&PIs. Considering the cultural values related to deference to authorities and particularly doctors and older persons, such national figures of the stature of former Surgeon General Koop would be helpful. When HHS sent out the mass mailing on HIV, it came from a highly respected person (Dr. Koop) and had significant
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impact. It is important to have that level of respectability (in a non Asian speaking about HIV).

Participants discussed the impact of stigma on A&PI women. They noted that if an A&PI woman is HIV positive, family, friends and community members will question whether she is sleeping around. They also observed that even people in the HIV field might not know who to go to for support. They recommended increases in funding for community-level interventions targeted to A&PIs and research on how stigma impacts A&PIs.

Perceptions of No or Low Risk

A&PIs perceptions of no or low risk for HIV infection is another factor that creates barriers to access. As previously discussed, stigma, fear of disclosure of HIV status, and denial, as well as lack of education on HIV transmission, lead many individuals in the A&PI communities to believe they are at low risk for HIV. This affects the frequency of HIV testing in A&PI communities since people who perceive themselves to be at little or no risk will see little benefit in seeking testing services. The participants recommended a number of strategies to address this, including education and skills building regarding risk assessment and self-perception, group and individual level interventions (community and individual support), and integration of HIV education into other systems where it is more accessible to the population (ESL, citizenship classes). They also noted that the services need to be tailored to meet the specific needs of different A&PI ethnic sub-groups, and sub-populations. They recommended, for example, additional funding for support groups for A&PI MSM and separate ones for transgender A&PIs.

They also noted that programs that seek to increase community support are also needed to mitigate the negative effects of stigma on HIV positive individuals. Since A&PIs are very family and community oriented, community level support is needed to effect behavior change on the individual level.

Community Gatekeepers

In certain A&PI communities, there are different gatekeepers that are generally the first level of contact for people needing help. These individuals may lack knowledge of HIV. However, they may be the most important links to populations at highest risk. To help to dispel myths and stigma associated with HIV, the participants recommended education of gatekeepers about HIV and it's impact on the community.
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(AIDS 101). Examples of such gate keepers are specialized religious groups such as the Korean Churches and community doctors.

Socio-political Factors

Immigration and Welfare Reform Restrictions

The participants identified major barriers to access to care occasioned by restrictive and unresponsive immigration, homeland security and welfare reform measures and policies. They noted that following September 11th, anti-immigrant sentiment has increased. This is generating more restrictive policies that adversely impact benefits and access to care for many minority communities who have large proportions of foreign-born immigrants and refugees. A fuller discussion of this issue was presented in the community challenges section. The participants recognized that greater involvement is needed by A&PI communities in the political process to oppose anti-immigrant measures (voting). Advocacy and community organizing is also needed. They commented that the government needs to address the human and social costs of these repressive programs. Moreover, A&PI communities need to make the connection between their civil rights and the health impacts of the current policies.

Care Services System

Participants identified a number of barriers to access within the care services system itself.

Lack of Health Knowledge

There is a general lack of knowledge in the A&PI community about health and anatomy. This is related to cultural taboos regarding discussion of sexuality and issues of modesty and shame. The lack of knowledge is not confined to community members but also extends to health care providers. Participants also noted that many A&PI community members lack knowledge about the existing health care system and how to navigate it. They recommended the provision of culturally competent health education for A&PI clients and providers. They also identified the need for peers or staff to serve as patient navigators to assist clients in their interactions with providers and the health care system.

Lack of Cultural Competence

Participants noted a general lack of cultural competence in the health care delivery system. They observed that organizations that claim to serve A&PIs lack knowledge of specific needs of different sub-groups within A&PI community. Training and technical assistance in cultural
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Competent health care and human services delivery was recommended. They also recommended that CARE Act providers become educated providers on HRSA’s cultural competency guidelines and the OMH’s CLAS standards.

Differences in Health Beliefs

Related to the lack of cultural competency of providers is the cultural divide between most providers and A&PI clients related to health beliefs. There are diverse and common culturally prescribed beliefs and norms held by different A&PI sub-groups regarding HIV, health and health care. Lack of understanding of these beliefs and norms may lead to miscommunications between providers and patients that can affect the quality of care. The participants, therefore, recommended culturally competent education for health care providers (medical students, doctors, nurses, social workers, etc.) regarding cultural differences in health beliefs and the implications for care.

In addition, they noted that social marketing in A&PI communities is needed and providers need training and technical assistance to identify tools and practices specific to the diverse populations, and on how to best use community leaders and community media to promote positive HIV and health related messages and impact cultural norms. Participants also discussed the utility of approaches like HHS’ Rapid Assessment, Response, and Evaluation (RARE) Project in making A&PI communities more sensitive to the needs related to HIV, and in obtaining input from the community, to identify most critical issues and needs. They commented that RARE allows research on specific sub-populations to really get sense of community needs and may be a viable alternative for A&PI communities for planning and service development in light of the limitations of HIV surveillance data.

Lack of Appropriate Health Services

The participants indicated that there is an overall lack of appropriate health services in A&PI communities and recommended additional funding for needs assessment to determine the specific needs of, and service gaps related to, HIV-infected and high-risk A&PI populations.

Lack of Integrated System

Participants noted that integrated models of service work well among A&PI communities and identified the need for funding to develop and implement such models. They also identified a need to educate providers and funders on such models and encourage their adoption within the current system of care.
They explained that the elements of an integrated model of care will differ depending on the unique needs of a particular sub-population. Program development must be based on a thorough needs assessment. However, the overarching framework is based on wellness models that integrate physical, spiritual and psycho-social needs of clients. Such models require augmenting primary care with other components (mental health, substance abuse, supportive housing etc.). They noted that because of the small size of A&PI populations in some areas, the systems may need to be developed at the regional level. Implementing these approaches would require a lot of work, but with creativity there could be various levels of integration.

Public Health Model
The participants agreed that the current public health model itself is a barrier to access to care because it utilizes cookie-cutter approaches to serve different ethnic/racial populations. Such approaches are ineffective (e.g. the belief that what works for Latino community, should work for A&PIs). Moreover, approaches based on the western medicine model do not always work for A&PIs. For example, focusing on identification and description of symptoms when people often cannot describe what ails them in English is an ineffective approach. The participants recommended the adoption of more holistic models of care that provide comprehensive services based on the needs of the person as a whole. They also noted that more research needs to be done on the role that traditional medicine and complementary therapies plays in the A&PI community. They agreed that the public health model doesn’t really work for A&PIs. A&PIs, particularly new immigrants and refugees, may not identify with the Western system of medicine. Moreover, they may lack knowledge of what services are available and whether they need them. This can affect their knowledge of their rights and limit their decision-making (for example, opting out of perinatal testing).

Lack of Disaggregated Data on A&PI Sub-populations
The lack of data on A&PI sub-populations and its implications for service planning and delivery were discussed at length in the previous sections. Participants reiterated that this lack of disaggregated data is a barrier to effective care planning and delivery. They recommended training and education for state and local health departments around the Office of Management and Budget’s (OMB) and CDC’s data collection guidelines. They also recommended that the federal government require state and local health departments to follow the OMB guidelines on collection of disaggregated data.
Planning Processes
Lack of Representation
The participants agreed that the lack of A&PIs on a number of state and local planning bodies related to HIV prevention and care services (CPGs, Title I Planning Councils, Title II Consortia, etc.) created barriers to responsive and effective planning of services for these underserved and often marginalized populations. They recommended the institution by government agencies of requirement of mandatory slots for A&PI community representatives. They also called for resources to support training, mentoring and support of A&PIs to participate in such planning bodies.

Organizational Capacity
The participants agreed that sound A&PI organizational capacity and infrastructure are needed to deliver quality care services to A&PIs living with HIV. They observed there are wide range of A&PI community based organizations in many A&PI communities reflecting different levels of development and capacity. Additional resources are needed to strengthen these organizations' infrastructures and capacities to meet the service demands of multi-ethnic A&PI sub-populations. Moreover, considering the variations in organizational size, resources, capacity and infrastructures, tailored technical assistance is needed. A single TA approach will not be appropriate. For example, the TA and capacity building needs of a large health clinic that has been serving an A&PI community for twenty years are very different from those of a newly established HIV testing program.

Participants also identified the need for additional resources for A&PI organizations to expand their staffing to meet cultural and language needs of the multi-ethnic A&PI populations they serve. They noted that some organizations center their services to particular A&PI sub-groups based on the availability of a staff member who speaks their language and understands their culture. If the employee resigns, then the services for that group end. A&PI organizations need resources to support staff training and create incentives to retain and support staff. One participant shared the following example to illustrate this point. A program may have a Hindi outreach component because they have a Hindi-speaking person on staff person. If that single staff person leaves the organization, the entire program for that population suffers.
Funding

Lack of Funding for A&PI Specific Programs

Participants agreed that resources for A&PI specific care services are very limited. This lack of funding limits expansion and enhancement of care services to emerging populations and existing high need clients. They recommended strategies to educate funders and providers on the unique needs of A&PI communities and sub-groups; to assist them to understand how the current data collection systems mask A&PI community needs; and to encourage them to support culturally responsive and competent research, data collection and targeted funding for A&PI organizations.
Endnotes


2 Centers for Disease Control and Prevention (CDC), HIV/AIDS Surveillance Report 2002; 14: [p.18].


12 Ibid, pp.4-5.


18 CDC, Ibid.

19 CDC, Ibid,[17-20]