

MYOPIC EXCLUSION

The Lack of Attention by Most Community Planning Groups to the HIV/AIDS Epidemic in Asian American, Native Hawaiian, and Pacific Islander Communities
 September 2009

I. BACKGROUND

Since 1994, the Centers for Disease Control and Prevention (CDC) has required all directly funded state and local jurisdictions to implement HIV Prevention Community Planning. These community planning processes have helped jurisdictions to focus their responses to HIV and have drawn public health attention to populations that had been previously sidelined. As a result of community planning, many health departments began subcontracting with local community based organizations (CBOs) to provide culturally specific HIV interventions and health education/ risk reduction strategies.

In 2003, CDC released the Revised Guidance for HIV Prevention Community Planning which restructured the community planning process and instructed jurisdictions to develop comprehensive HIV prevention plans that included 5 key products: an epidemiologic profile, a community services assessment (CSA), a prioritized list of target populations, a priority set of interventions for each population, and letter of concurrence/non-concurrence. Most community planning groups (CPGs) continued the practice of beginning their planning process with the development of the epidemiologic profile, a report that describes the impact of HIV and AIDS among populations through reported cases of HIV, AIDS, and other related health indicators such as sexually transmitted disease, tuberculosis, and hepatitis.

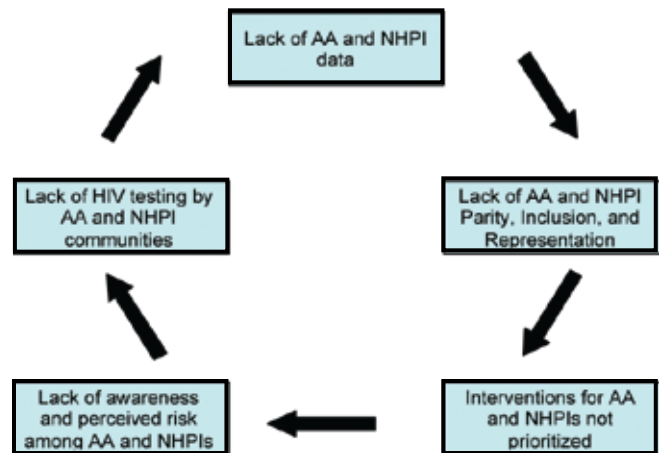
Given that the epidemiologic profile plays a central and often pivotal role in the CPG process, it is important to note that most epidemiologic profiles do not adequately include or depict data for Asian American, Native Hawaiian, and Pacific Islander (AA and NHPI) communities. Often, information for these communities

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- Community CPG Member,
 NorthEast Region

is lumped into an “Other” category or completely omitted. The result is a blindness to HIV’s emergence in AA and NHPI communities throughout the United States. This structural barrier often precluded any further possibility of discussion regarding the inclusion of AA and NHPI communities in the CPG planning process and ultimately as a prioritized population for funding.

The following diagram depicts how flawed epidemiologic profile data has a cascading effect on the CPG process.



The epidemiologic profile often dictates which populations a CPG will focus on in the CSA process, thus the lack of AA and NHPI data in the epidemiologic profile minimizes the likelihood that CPGs will conduct surveys, focus groups, key informant interviews, or other assessments that are targeted to AA and NHPI populations. Furthermore, the epidemiologic profile is used to inform CPG member recruitment and selection activities. Thus, the lack of data also contributes to a lack of AA and NHPI parity, inclusion, and representation in CPG membership.

Both the epidemiologic profile and the CSA are the key products used by CPGs to determine priority populations for state or city’s HIV prevention funding. Without data and without community members representing the needs of AA and NHPIs in the process, AA and NHPI populations are excluded from consideration during the prioritization process. Ultimately, this reduces the likelihood of the health department funding community based organizations to provide HIV prevention and testing services that specifically target AA and NHPIs.

Without specific HIV prevention strategies targeted to AA and NHPIs, many members of the community erroneously believe that they are not at risk for HIV. Thus, they do not seek out HIV testing. CDC has estimated that nearly one-third of AAs and NHPIs who are living with HIV/AIDS are unaware of their HIV status. This is the highest

percentage across all racial/ethnic groups. Their undiagnosed status is not captured in the surveillance data that are used to develop epidemiologic profiles, thus perpetuating the cycle of AA and NHPI exclusion.

Inclusion of AA and NHPI data in the epidemiologic profile serves as a crucial point of interruption for this cycle. This can be supported by other efforts throughout the CPG process to ensure the meaningful input, participation, and consideration of AAs and NHPIs. Unless these tragic flaws are addressed, communities will remain unresponsive to the HIV epidemic in AA and NHPI communities even as HIV/AIDS rates continue to rise.

II. METHOD

For this report, the authors conducted a review of comprehensive HIV prevention plans from 24 jurisdictions with the largest AA and NHPI populations. Documents were gathered from the websites of the planning jurisdictions, and in some cases by follow up with the jurisdictions.

The 24 jurisdictions included the following states and directly-funded cities: California, Colorado, District of Columbia, Florida, Georgia, Hawaii, Illinois, Los Angeles, Maryland, Massachusetts, Michigan, Minnesota, Nevada, New Jersey, New York, New York City, Ohio, Oregon, Pennsylvania, Philadelphia, San Francisco, Texas, Virginia, and Washington.

The review focused on:

- how jurisdictions described AA and NHPI communities in their epidemiologic profiles
- how jurisdictions described the HIV prevention needs and AA and NHPI communities
- how jurisdictions included AA and NHPI communities in their prioritized populations
- how AA and NHPIs participated in the CPG process

Planning documents came in two types: a comprehensive plan for HIV prevention spanning multiple years and mid-course updates to the multi-year plan. Most jurisdictions had published a comprehensive plan (62.5%). Three jurisdictions published a comprehensive plan as well as a plan update (12.5%). For six jurisdictions, only the plan update was available (25%).

Additionally, key informant interviews were conducted between July 2009 and September 2009 with individuals from seven jurisdictions. These key informant interviews helped to expand upon the information gathered in the review of planning documents. Four of these interviews were conducted with health department staff, and four interviews included AA and NHPI members of CPGs.

III. KEY FINDINGS

A previous study on Asians and Pacific Islanders and the CPG process revealed a lack of inclusion and involvement of these populations in CPGs across the US.¹ Since its publication, there have been jurisdictions who have made attempts to specifically involve and include Asians and Pacific Islanders on their respective CPGs. Overall, however, there are still significant gaps and shortcomings that echo past findings,

including: 1) the continued omission of AA and NHPI data, 2) inconsistency in reporting categories, 3) lack of access to disaggregated AA and NHPI data, 4) limited inclusion of AA and NHPI data in community services assessments, 5) lack of AA and NHPI CPG members, and 6) AA and NHPIs are not often included in priority populations.

In the sections that follow, the limitations of CPGs are described in greater detail. Selected quotes from key informants are provided to highlight the major concerns. The quotes also reflect the type of key informant (i.e., community CPG member, health department staff) and jurisdiction.

Continued Omission of AA and NHPI Data

A majority of the epidemiologic profiles reviewed did not adequately describe the AA and NHPI communities. Few included AA and NHPI population counts or population growth rates. Although some jurisdictions included socioeconomic data on poverty and education levels, most did not provide this data by racial/ethnic group. Census information about AA and NHPI communities was missing for 33.3% of the jurisdictions selected for review. Few plans included information regarding limited English proficiency, a key barrier that AA and NHPIs face in accessing HIV prevention services.

There really is no AA and NHPI data that we get or we've seen at the CPG.
(Community CPG Member, Northeastern Region)

HIV/AIDS data for AA and NHPI communities were often placed into an “Other” category with data from multiple racial/ethnic groups. Often, the “Other” category also included cases where the race/ethnicity was unknown for the specific data element. Several jurisdictions presented data for only three racial/ethnic groups (“White, Black, Hispanic”), completely omitting any mention of AA and NHPI data. For these jurisdictions, it was unclear whether or not the omission of AA and NHPI data indicated that there were zero AA and NHPI cases.

We don't have 0 (cases in AA and NHPI communities), but you wouldn't know how many we actually have because they've been excluded from our epi profile.
(Health Department Staff, MidWest Region)

Inconsistency in Reporting Categories

When AA and NHPI data was included, there was often no consistency of reporting AA and NHPI data within jurisdictions which prevented of comprehensive understanding of the epidemic's impact in these communities. For example, in one jurisdiction's Comprehensive HIV Prevention Plan, AA and NHPI communities were reported in at least five different ways: “Other” (as in White, Black, Hispanic, Other); “Asian (non-Hispanic)”; “Asian”; “Asian (non-Hispanic)” and “Hawaiian/Pacific Islander (non-Hispanic); “Asian/Pacific Islander”; and “Asian and Hawaiian/Pacific Islander.”

Lack of Access to Disaggregated AA and NHPI Data

Few jurisdictions provided data for AA and NHPI communities disaggregated by country of origin or ethnic subgroup (e.g. Chinese, Korean, Vietnamese, etc.). Yet, this level of data is crucial to creating awareness and understanding of how HIV is impacting AA and NHPI communities in a jurisdiction.

Data disaggregation for other racial/ethnic communities has yielded valuable data. For example, CDC analysis of AIDS diagnosis data for Hispanic populations has already found that transmission trends vary by country of origin. Some jurisdictions, such as Minnesota, have separated HIV and AIDS case reports for Black populations by those who are African-born and those who are African American. This has resulted in greater information about specific populations and their need for HIV prevention. In an era of shrinking budgets, access to this disaggregated data will help CPGs, CBOs, and health departments focus their efforts on the sub-groups that are at highest risk.

Limited Inclusion of AA and NHPI Data in Community Services Assessments

Only half (12) of the jurisdictions mentioned AA and NHPI communities in their CSAs. For example, San Francisco identified the need for Tagalog, Vietnamese, Cantonese, and Thai linguistic competencies in case management services. Other jurisdictions were less specific, but generically identified geographic and linguistic isolation for “Asian populations” and cultural stigma as barriers to HIV prevention efforts.

Most jurisdictions did not include specific data collection activities targeted to AA and NHPI communities. In cases where AA and NHPI community needs were identified, information tended to be gathered using convenience sampling methodology. A few jurisdictions identified community needs by including national information that may or may not pertain to specific AA and NHPI communities in the jurisdiction.

*What's the data like for APIs...
you wouldn't know how many
we actually have because
they've been excluded
from our epi profile.*

- Health Department Staff, MidWest Region

When combined with a lack of data in the epidemiologic profile, AA and NHPI communities are placed in a vulnerable position during the CPG prioritization process. The dearth of data closes the door for any possibility of considering AA and NHPI communities as a prioritized target population. AA and NHPI CPG members clearly see this connection:

When I had asked what's the data like for APIs, the standard language was “there are very little cases” and “we can't afford it.” Since then, we haven't had any discussions about APIs.

(Community CPG Member, NorthEast Region)

When we write our comprehensive state plan, APIs are not one of our target populations. And so the CPG doesn't intentionally go out and seek API representation on our focus groups or in conducting the CSAs.

(Health Department Staff, Western region)

Key informants also suggested that cultural learning and training could take place in CPGs and with health departments so that planning efforts would eventually become focused on the particular AA and NHPI communities where HIV prevention needs exist.

Lack of AA and NHPI CPG Members

According to aggregated CPG membership data, AA and NHPI communities represented 3% of the CPG participants across jurisdictions. So on a national level, it may seem that AA and NHPI communities are equitably involved in the CPG process. A closer look, however, reveals that a few CPGs (e.g. Hawaii, California, New York) have multiple AA and NHPI CPG members. Yet, almost half of CPGs across the US, including some states with significantly sized AA and NHPI populations, did not have even one member who identified as AA and/or NHPI.

Parity, inclusion, and representation (PIR) is a principle which guides jurisdictions so that CPGs include the views, perspectives and needs of communities who are infected, affected, or at-risk for HIV. Achieving PIR requires not only membership from AA and NHPI communities, but also a process that generates openness and participation. Particularly for AA and NHPI communities, CPGs must recognize that culture may pose barriers to participation.

“It's not that AANHPI don't have an opinion, it might be more difficult for them to have their opinions and voice put forward when there are other people who are not at all shy.”

(Health Department Staff, Western Region)

Institutional barriers also pose a challenge. Communities need to see themselves in a process in order to become part of it. Structural issues of participation such as meeting locations and times pose barriers to participating on the CPG for many communities; however for AA and NHPI communities, the lack of community level data and CPG cultural awareness are potentially the most significant barriers to achieving PIR. The presence of AA and NHPI CBOs in a jurisdiction often provides institutional support for participation on CPG processes. The lack of specific AA and NHPI organizations in one jurisdiction was noted as a barrier by the one AA and NHPI member of the CPG:

“APIs in the larger population level is 4%. I'm just one person out of 23 on the CPG which is just about 4%. So that's somewhat inclusive and somewhat representative. But, I've never been in a conversation where there is an API specific discussion.

(Community CPG Member, NorthEast Region)

My jurisdiction doesn't have many API specific providers. That's a larger institutional barrier. It doesn't help facilitate those conversations in terms of including APIs in the CPG process.

(Community CPG Member, NorthEast Region)

In some cases, AA and NHPI members were part of the CPG process because of other skills or expertise they contributed to the CPG process functionally. Yet their involvement precludes the membership of other AA and NHPI members who might have a more direct connection to AAs and NHPIs at risk for HIV and the CBOs that serve them.

I fill a specific niche and role in the CPG of a social-behavioral scientist in terms of interventions and the prioritization of interventions...But the role that I play in the CPG is functionally not that of an API person.”

(Community CPG Member, NorthEast Region)

The range of structural barriers effectively excluded AA and NHPI visibility and participation in the CPG process effectively. It is this nuanced reality, deeply embedded into the CPG process design that functionally stifles any current and future attempts to understand HIV's emergence in AA and NHPI populations.

AA and NHPIs Are Not A Priority

Of the 24 jurisdictions, only four jurisdictions (16.7%) included AA and NHPI communities in their list of prioritized target populations. These included:

- Georgia ranked “Transgenders and Asian/Pacific Islanders” as tenth out of ten prioritized populations
- Illinois identified “Asian/Pacific Islanders” as one of many sub-populations of their targeted and prioritized populations
- Minnesota listed “Asian/PI” as a sub-population for their High Risk Heterosexual priority population;
- San Francisco consistently identified “Asian/Pacific Islanders” as a prioritized sub-population.

In six other jurisdictions, particular AA and NHPI populations were implicitly included among priority populations or sub-populations, though not specified by name. For example:

- Massachusetts prioritized refugee and immigrant populations
- New York prioritized people of color in Tiers 1-3 of their prioritization scheme.

One key informant summarized this myopic lack of prioritization as follows:

People focus on the populations that are “most impacted” without looking at the factors that may facilitate HIV transmission by these “most impacted” communities to other communities.

(Community CPG Member, NorthEast Region)

Indeed, the increasing number of individuals in the U.S. census who identify as “multi-racial” is indicative of the increasing interaction between racial/ethnic communities.

IV. CONCLUSION/RECOMMENDATIONS

In response to these key findings, the following recommendations are offered:

1. **Increase resources to HIV surveillance programs** to assure the gathering and reporting of AA and NHPI community specific epidemiologic data. Such resources should be utilized to support disaggregation of data by country of origin for those jurisdictions with significant AA and NHPI populations.
2. **Require data reporting consistency** for all sources in epidemiologic profiles. This would mean that all input data such as HIV counseling and testing data, access to HIV care, STD, TB, and HIV case reporting use the same racial/ethnic sub groups for AA and NHPI populations, preferably in accordance with

OMB standards for data collection and reporting of racial/ethnic data. At minimum, jurisdictions should stop the practice of lumping data for AA and NHPI communities into an “Other” category.

3. **Require minimum membership** for AA and NHPI communities on CPGs. CPGs are encouraged to include AA and NHPI community members so that further understanding can be gained about the diversity of AA and NHPI cultures and communities in jurisdictions. This would also help to enhance understanding of the structural and social determinants contributing to HIV transmission in these communities.
4. **Increase policy flexibility** to allow CPGs and jurisdictions to address the impact of HIV among emerging populations, including AA and NHPI communities. While CPGs must ensure their priorities are focused primarily on those communities that have significant HIV incidence and prevalence, CPGs must also be on the lookout for warning signs (e.g. significant increases in HIV incidence and prevalence rates, population growth, evidence of significant risk-taking behaviors) that point to emerging epidemics.

Health departments and CPGs are encouraged to adopt these recommendations. Relevant action steps and examples can be found in *Breaking Through the Silence*, previously released by APIAHF and the National Alliance of State and Territorial AIDS Directors (available for download at www.apiahf.org or www.nastad.org)

CDC is encouraged to incorporate the above recommendations in the upcoming revision of the *Guidance for HIV Prevention Community Planning*. CDC is also encouraged to ensure that capacity building assistance to support health departments and CPGs in implementing these recommendations is available.

Finally, AA and NHPI community members must continue to actively engage in the community planning process despite the challenges mentioned in this document. A failure to do so would be truly myopic.

REFERENCES

- ¹ Bau, I (1998). Asian and Pacific Islander Americans and HIV Prevention Community Planning. *AIDS Education and Prevention*, (10A):77-93.

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