Asian and Pacific Islander
Ending the Epidemic
Advisory Group
Implementation Strategies

For Presentation to the New York State AIDS Advisory Council
Ending the Epidemic Subcommittee
July 15th, 2020
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Introduction:

The Asian and Pacific Islander (API) Ending the Epidemic (ETE) Advisory group have developed implementation strategies in support of the New York State ETE Blueprint to maintain safe, effective, and culturally accepting solutions to health inequities and improve viral suppression rates.

Racial and ethnic minorities have been disproportionately affected by HIV/AIDS since the beginning of the epidemic. There are many ethnicities within the population labeled API, including Chinese, Filipinos, Koreans, Hawaiians, Japanese, and Vietnamese, among others, making it difficult to address the scope of HIV/AIDS problem within each group, as most systems of classification do not allow subculture identification.¹ While HIV and HIV-prevention research are continuously advancing, little research focuses on API populations. New infections of HIV among API populations have decreased only 3% within NYS.

To address this disparity, it is necessary to develop a clear understanding of the structural or institutional barriers that cause it, including the way API populations are presented in the data; and to determine if we are reaching this often-underrepresented population that lacks access to care. Stigma must also be addressed, as it remains a barrier to testing and engagement in the care continuum, hindering identification of people at risk for HIV infection or living with HIV who remain undiagnosed. There is a pressing need for culturally sensitive strategies to build trust among API, especially among immigrant populations with limited English proficiency; fostering ongoing trust in health care is key to retention in care after initial linkage.

Historical Context

Remarks Written and Delivered by Therese Rodriguez, at the NYSDOH AIDS Institute AIDS Advisory Council Meeting, July 15, 2020

“Other” in my language meant an outsider or a nobody.
In the 1980s Asian and Native American Indian civil rights and gay rights activists, called the government’s attention to those dying of HIV/AIDS in their communities. These activists needed resources to confront homophobia and HIV stigma. But AIDS surveillance data lumped Asians and Native Americans in the category “Other.”

These activists went to Washington to meet with officials of the HHS and the CDC. Given their particular traumatic histories, without political influence and representation, they were filled with hopeful skepticism. Instead, a surprising turn of events. Drs. Gary Noble, then of CDC, and James O. Mason, then the Assistant Secretary of HHS called off their other meetings of the day and moved the bureaucracy to add two columns to the census count—one A&PIs and another for Native American Indians. At that historic moment activists made a moving pact, to speak for each other whenever one is not in the room or at the table. These sympathetic bureaucrats may well have changed the course of the epidemic in our communities.

Faced with another barrier the coalition had to threaten NYSDOH with a discriminatory lawsuit in order to be included in the category “minority” now called “communities of color. Although “Other” has been replaced by A&PI, the sense of inclusion remains extremely tenuous. When in a “communities of color” slide presentation we are insignificant and we still have to queue up to a microphone and demand that epidemiologists produce charts that show the impact of HIV on small populations, we get very frustrated. As did the American Indian woman, at the last EtE Summit. She aptly protested the disrespect of the First People of this land.

“Other No More” is part of history but is also an existential battle cry for all. It is about aborting the corrosive effect of “other” on our sense of equity and justice for the first people to of this land, and its foreign born. The first Asians set foot in the United States in late 1500s. It was not until late 1840s and the mid-1850s that Asians came in the tens of thousands. By early 1900s Asians in the U.S. were in the hundreds of thousands and by the 1990 U.S. Census count, there are more than seven million A&PIs. This segment of the population is projected to grow to over 20 million by year 2020.

Following the end of Civil War, deliberate exclusionary acts against Asians began. The Naturalization Law of 1790, which grants “free white persons” rights to naturalization, was amended to include persons of African nativity, and … descent. Asians were excluded, even Japanese-Americans who came at the end of the eighteenth century and were already in Hawaii or in the United States. Excluded from becoming citizens, Asians were prohibited to enter the United States, until 1952.

The Chinese Exclusion Act of 1882, supported by powerful labor unions, launched a movement that screamed “The Chinese must go!” The Chinese became scapegoats during the period of economic
depression and were targeted for discriminatory legislation and racist violence. White mobs looted and burned Chinese homes and businesses, sometimes for several weeks, in anti-Chinese riots with little interference from authorities. **Ironically, this Act came less than twenty years after the Chinese played the instrumental and critical roles in the construction of the transcontinental railroad and in the development of agriculture and fishing industry on the West Coast.**

Along with the categories “lunatics,” and “idiots,” this Act prohibited the immigration of all “Chinese laborers” into the United States for ten years, later extended to twenty. By 1892, the Japanese, Koreans, Asian Indians and Filipinos were also excluded. Amended again in 1902, this time the ban had no expiration date.

With the U.S. occupation of the Philippines in the early 1900s Filipinos became U.S. nationals and could not be barred from the U.S. In the 1920s, Filipinos were aggressively recruited to fulfill agricultural labor needs in Hawaii and the West Coast. Alarmed at the growing number of Filipinos, the exclusionists worked for the passage of the Tyding-McDuffie Act 1934. Making, the Philippines part of the commonwealth with a promise of independence. Filipinos were reclassified as “aliens” limiting Filipino immigration to the U.S. to fifty persons per year.

The Immigration Act of 1917 designated India as one of the Asian countries in the ‘barred zone.’ The U.S. government categorized the Asian Indians as Caucasians because they and Scandinavians are racially and linguistically related. Theoretically, Asian Indians in America should have been granted naturalization rights. American exclusionists soon realized that the only way to exclude Asian Indians from naturalization was to somehow “change” their skin color.

The Asians who managed to stay despite the onslaught of vicious legal maneuvers and racial violence had their access to decent livelihood severely curtailed. From the 1850s through the 1870s selective race-based legislation, regulations and ordinances expelled the Chinese and Japanese out of communities and economic sectors. In recent history the principle of exclusion from neighborhoods and livelihoods was imposed most forcefully through the internment of Japanese-Americans and nationals in concentration camps during World War II.

In all these experiences there was lack protection from racist and exclusionary tyranny that spanned through many decades. **The treatment of the most vulnerable members of society is a great indicator of how healthy a country’s sense of fairness and justice is.** When we fail to examine the issues behind the disregard, neglect and lack of real interest in underserved communities we will see a society that can easily be divided, communities divorced and alienated from each other, leaving the wealth, resources and power of this nation in the hands of the small minority ruling over the vast majority of the disadvantaged, historically discriminated masses of people.

Yes, we do not have the numbers. But the diversity of the A&PI communities makes our work even more intense. **The prevalence of the disease in these communities remains high. Yet many have no access to insurance. Those who are newly-arrived are unaware of the resources that are available. They speak in**
many tongues, bring with them many belief systems, and come from highly diverse cultures. There is stigma attached to death and disease. Prejudice towards homosexuality is rampant. Women have little to say about their own wellbeing. These are special and critical needs. They have to count. A&PIs are getting infected.

The fact that we are or our ancestors are non-white and foreign-born has a lot to do with the extent of our marginalization. Numbers or lack of it or being termed minority communities does not capture the essence of our chronic exclusion. The ruling class in this country certainly is a minority being less than 1% of the population but this is one case where numbers do not really tell the same story. Depending on whose interest is served, numbers are manipulated to achieve a political end.

The work of the members of this A&PI EtE Subcommittee, brings not only service to the under-served members of our community but also brings strength to all who are moving steadily away from the margins of political power into the center where we can determine and direct our healthy and just future.

Finally, in keeping with our promise to the First People of this land, I would like to end with the words of Dr. Martin Luther King, Jr. “Our nation was born in genocide when it embraced the doctrine that the original American, the Indian, was an inferior race. Even before there were large numbers of Negroes on our shore, the scar of racial hatred had already disfigured colonial society. From the sixteenth century forward, blood flowed in battles over racial supremacy. We are perhaps the only nation which tried as a matter of national policy to wipe out its indigenous population. Moreover, we elevated that tragic experience into a noble crusade. Indeed, even today we have not permitted ourselves to reject or feel remorse for this shameful episode. Our literature, our films, our drama, our folklore all exalt it. Our children are still taught to respect the violence which reduced a red-skinned people of an earlier culture into a few fragmented groups herded into impoverished reservations.”

I end with an excerpt of a poem I have written:
To begin to address
That Black lives matter
Let’s get rid of the illusion
That white people matter more
Inclusion is not good enough anymore
We must insist
Those who built the table
Put food on the table
Should be at the table
With the blessing of the First People of this land
We are the United People of America.

Sources:
1) Everything You Need to Know About Asian-American History by Lan Cao and Himilce Novas
2) Asian American Legal History Chronology by John Hayakawa Torok
Advisory Group Process:

In November 2019, the New York State Department of Health, AIDS Institute (AI) convened an ETE advisory group of subject matter experts from the API community. Recruitment for the advisory group represented the diversity of organizations and individuals that serve Asian and Pacific Islanders throughout New York State. The ETE advisory group, with support from AI staff and administration, was tasked with producing a set of implementation strategies to guide AI planning on implementing the Blueprint for ending the epidemic among API in New York State. Additional subject matter experts were recruited to the API ETE Advisory Group as needed throughout the strategy development process.

The API ETE Advisory Group met in person two times; once for an initial meeting in November 2019, and for a second time in January 2020. In the interim, the Advisory Group met three times via conference call and worked remotely to develop their proposed implementation strategies.

Through this process, the API Advisory Group identified three key areas of focus for strategies to implement the ETE Blueprint with the greatest impact for Asian and Pacific Islanders in New York State:

1) Data
2) Trust-building and Stigma Reduction
3) Linkage to Care
Focus Area 1: Data

The Morbidity and Mortality Weekly Report (MMWR) shows that among all racial groups in the U.S., Asians and Pacific Islanders (APIs) had the only statistically significant increases in HIV/AIDS diagnosis rates in the most recent four-year period. Because HIV rates in API communities are still relatively low, we have a critical opportunity to develop effective prevention programs for API American communities before these alarming indicators translate into markedly higher HIV prevalence in API communities in the U.S., as has occurred in other U.S. communities and in the Asia/Pacific region.

According to the MMWR, “average annual rates of HIV diagnoses ... were calculated using race/ethnicity- and age-specific census data as the denominators,” indicating that changes in underlying population size were taken into account, especially important given the rapid growth of the API population.\(^2\)

To this end the advisory group members have established the following strategies to address data collection limitations and needs.

1. **In statewide HIV/AIDS surveillance data, disaggregate API data by country of origin and calculate the percentage of infection for each country of origin.**

   The intention of this strategy is to better measure the impact of HIV/AIDS on small communities and inform outreach strategies for NYS’s linguistically and culturally diverse API population. For example, the 2018 New York City HIV/AIDS surveillance HIV Diagnosis by Place of Birth data reveals that South Eastern Asians have the highest rates of new diagnoses among the Asian regions listed. South East Asia includes seven countries, Brunei, Burma, Cambodia, Timor-Leste, Indonesia, Laos, Malaysia, the Philippines, Singapore, Thailand, and Vietnam. These countries display an incredible amount of diversity. Having country-level data is critical to creating prevention strategies given these countries have unique languages and risk behaviors.

   Related Blueprint Recommendation(s):
   - BP29: Expand and enhance the use of data to track and report progress

2. **Convene a statewide summit of providers, researchers and community to discuss data collection and sharing, as well as other focus areas presented by the API ETE Advisory Group:**

   The goal of the Asian and Pacific Islander (API) Ending the Epidemic (ETE) NYS Summit is to bring together API providers to collaborate to end challenges and disparities API populations face in relation to health care, specifically around HIV/AIDS. The API ETE Summit intends to recognize the importance of community partners and providers across NYS to address barriers including medical mistrust, cultural and family acceptance, communication and language barriers, social and economic determinants of health, generation gaps, immigration, access to care, substance use, and transgender services. This summit will engage clinicians, pharmacies, community partners and providers, community members, and our target population in how to best utilize resources to improve data collection and analysis, address themes and patterns, provide comprehensive statistics that are available to all, and ultimately end the HIV epidemic among API populations.

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Breakout sessions would vary based on participants, panelists, and presenters. Potential areas of focus include:
- Health equity
- Data collection by country of origin
- Opioid and injection drug use
- Data collection on gender non-conforming non-binary (GNCNB) API

Related Blueprint Recommendations:
- BP7: Use client-level data to identify and assist patients lost to care or not virally suppressed
- BP29: Expand and enhance the use of data to track and report progress

3. Foster collaboration in data collection/analysis among community health centers that serve API populations.

API data are not currently disaggregated by any health department in the U.S. or by the federal government. One suggested strategy to aid in data collection is to encourage collaborative, community-based data collection and analysis including the following strategies:

- Standardize intake forms and provider reporting forms to increase the options race/ethnicity markers to capture country of origin/birth
- Share disaggregated data
  - Consider working with Association of Asian Pacific Community Health Organizations (AAPCHO) to increase collaboration and data sharing practices
  - Encourage involvement with hospital systems to share data on service utilization
  - Integrate data collection for API communities into the Delivery System Reform Incentive Program (DSRIP) outcome measures
- Share PrEP utilization data to inform prevention interventions; this information is not provided on the ETE Dashboard
- Create abstracts and presentations to share API research at 2020 USCA and ETE Summit
- Assess and utilize research analysis methods that do not rely on categories of statistical insignificance

Related Blueprint Recommendations:
- BP Section 4: Recommendations in support of decreasing new infections and disease progression
4. **PrEP utilization data reports (e.g. etedashboardny.org), should disaggregate API from the “other” race/ethnicity category.**

PrEP utilization data reports should disaggregate API from the “other” race/ethnicity category (see strategy 2), as state-level data often significantly strengthens applications for funding opportunities.

Related Blueprint Recommendation(s):
- BP14: Develop mechanisms to determine PrEP and nPEP usage and adherence statewide
- BP29: Expand and enhance the use of data to track and report progress

5. **Assess Service Utilization Data**

- The implementation of Service Utilization Data is essential due to API community members seeking other services and neglect receiving HIV care services. Data utilization/addressing services used by the API community can mobilize community members in accessing care. As of current, there is no published data to support this statement; hence, the need to collect data related to service utilization. By identifying the needs of the API communities; we can promote HIV testing and stigma reduction in tandem with correlated services. Therefore, we can address the needs and support the referral process to care.

Related Blueprint Recommendation(s):
- BP29: Expand and enhance the use of data to track and report progress

6. **Collect information to improve data driven outreach on social media outlets used by API; different communities use different apps.**

- Support community-led outreach activities at sex parties

- Create a resource that provides information on the sex-seeking behaviors of the API community, including information about social media outlets, sex parties, etc.

The following apps/websites were identified by the API Advisory Group as those frequented by API at risk of acquiring or living with HIV:
- Facebook private groups for sex parties
- Hornet App
- Sniffies Website
- Blued App
- Perry Street owned apps (Grindr and Jack’d)
- WeChat
- Line

Related Blueprint Recommendation(s):
- BP28: Equitable funding where resources follow the statistics of the epidemic
- BP29: Expand and enhance the use of data to track and report progress
7. Encourage the participation of API communities in the U.S. 2020 Census.

According to the Census Bureau, key findings from studies of hard-to-count populations indicate the following factors put Asians and Pacific Islanders at risk for not being counted in the Census 2020:

- **Language and cultural barriers.** Three-fourths (3/4) of APIs speak a language other than English at home, and 35% has limited English proficiency.

- **Fear of the government.** The Census Bureau cites, “Some Asian immigrants are from countries that do not have a census system or have used such a system to harm community members; this may heighten distrust.” Ethnic and racial minorities are most likely to stop participating in the US Census, given the chilling effect of the push to add a citizenship question, even as it was ultimately unsuccessful.

- **“Unconventional Households.”** APIs live with extended family, or with multiple families, which can present challenges for counting in the Census.

Additionally, We Count Census 2020 has identified that New York City has had poor self-response rates than other areas of the United States in the last census, and it is predicted that communities at risk in New York City will be at even higher risk of responding to the Census because of distrust of the government (e.g. recent policies, such as Public Charge, has heightened fear of immigrants of government authorities).

Stakeholders in this community are partnering to educate community members about the importance of the census, including how this impacts the following:

- Resource allocation for communities, such as schools, hospitals, and public transportation
- Representation in the U.S. Congress
- Guidance in decision-making for programs and policies over the next decade

It is important for gatekeepers to educate members of the community about the safety of the census, how it is not connected to immigration authorities and it is safe for everyone to answer, including undocumented communities. Given the invisibility of APIs in HIV public policy, it is even more urgent for Asian and Pacific Islander community gatekeepers and stakeholders to work together in ensuring an accurate count of API communities.

The Complete Count 2020 has provided a plan to increase participation in the Census 2020, including the following ways:

1. **Person-to-person contact.** This will be a key factor in getting undercounted communities to respond to the census, whether via community canvassing, phone or text banking.

2. **Partnerships.** Agencies and community organizations serving Asians and Pacific Islanders must work in partnership to develop and conduct outreach activities for the community. Partnerships must include stakeholders, such as elected officials, houses of worship, labor unions, and small, family-owned businesses.
Given the urgency, We Count 2020 has identified the following timeline for partners:

- April 1, 2020: Census Day

Related Blueprint Recommendation(s):
- BP29: Expand and enhance the use of data to track and report progress

8. Advocacy to Expand Language Categories at the Federal Level

- In HealthIT.gov, the language category does not include Mandarin or Cantonese, instead it simply lists “Chinese”, which is not a language. As a result, Electronic Medical Records, like eClinical Works, do not include language categories for Mandarin or Cantonese in their standard list of languages. To overcome this barrier, advocacy to the federal government to expand their language categories is necessary.

- It is suggested advocacy happens from the New York State Department of Health and healthcare associations.

Related Blueprint Recommendation(s):
- BP Section 4: Recommendations in support of decreasing new infections and disease progression
Supporting Evidence for Data Implementation Strategies:

**HIV DIAGNOSES OVER TIME**

**FIGURE 2.1:** Trends in HIV diagnoses, NYC 2001-2018

<table>
<thead>
<tr>
<th>HIV Diagnoses</th>
<th>2001</th>
<th>2018</th>
<th>EAPC</th>
<th>P Value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Total</td>
<td>5,859</td>
<td>1,917</td>
<td>-5.72</td>
<td>&lt;0.01</td>
</tr>
<tr>
<td>Gender</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>3,882</td>
<td>1,484</td>
<td>-4.66</td>
<td>&lt;0.01</td>
</tr>
<tr>
<td>Female</td>
<td>1,976</td>
<td>334</td>
<td>-9.53</td>
<td>&lt;0.01</td>
</tr>
<tr>
<td>Transgender</td>
<td>61</td>
<td>59</td>
<td>-0.39</td>
<td>0.09</td>
</tr>
<tr>
<td>Race/Ethnicity</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Black</td>
<td>3,060</td>
<td>879</td>
<td>-7.09</td>
<td>&lt;0.01</td>
</tr>
<tr>
<td>Latino/Hispanic</td>
<td>1,767</td>
<td>697</td>
<td>-6.54</td>
<td>&lt;0.01</td>
</tr>
<tr>
<td>White</td>
<td>898</td>
<td>219</td>
<td>-5.04</td>
<td>&lt;0.01</td>
</tr>
<tr>
<td>Asian/Pacific Islander</td>
<td>118</td>
<td>104</td>
<td>0.72</td>
<td>0.09</td>
</tr>
<tr>
<td>Native American</td>
<td>13</td>
<td>1</td>
<td>-8.70</td>
<td>&lt;0.01</td>
</tr>
<tr>
<td>Age Group (Years)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>0-12</td>
<td>87</td>
<td>2</td>
<td>-20.4</td>
<td>&lt;0.01</td>
</tr>
<tr>
<td>13-19</td>
<td>203</td>
<td>79</td>
<td>-5.26</td>
<td>&lt;0.01</td>
</tr>
<tr>
<td>20-29</td>
<td>1,124</td>
<td>670</td>
<td>-1.75</td>
<td>&lt;0.01</td>
</tr>
<tr>
<td>30-39</td>
<td>2,069</td>
<td>517</td>
<td>-7.86</td>
<td>&lt;0.01</td>
</tr>
<tr>
<td>40-49</td>
<td>1,528</td>
<td>276</td>
<td>-6.70</td>
<td>&lt;0.01</td>
</tr>
<tr>
<td>50-59</td>
<td>631</td>
<td>200</td>
<td>-5.18</td>
<td>&lt;0.01</td>
</tr>
<tr>
<td>60+</td>
<td>219</td>
<td>122</td>
<td>-2.78</td>
<td>&lt;0.01</td>
</tr>
</tbody>
</table>

The number of new HIV diagnoses reported in NYC from 2001 to 2018 decreased overall and based on all genders, ages at diagnosis, boroughs of residence and most race/ethnicity and transmission risk categories. This decrease was significant (P value <0.01) for all subgroups except transgender people, Asian/Pacific Islander people and transgender people with sexual contact.

<table>
<thead>
<tr>
<th>Race/Ethnicity</th>
<th>2001</th>
<th>2018</th>
<th>EAPC</th>
<th>P Value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Black</td>
<td>3,060</td>
<td>879</td>
<td>-7.09</td>
<td>&lt;0.01</td>
</tr>
<tr>
<td>Latino/Hispanic</td>
<td>1,767</td>
<td>697</td>
<td>-4.54</td>
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</tr>
<tr>
<td>White</td>
<td>898</td>
<td>219</td>
<td>-5.64</td>
<td>&lt;0.01</td>
</tr>
<tr>
<td>Asian/Pacific Islander</td>
<td>118</td>
<td>104</td>
<td>0.72</td>
<td>0.09</td>
</tr>
<tr>
<td>Native American</td>
<td>13</td>
<td>1</td>
<td>-8.76</td>
<td>&lt;0.01</td>
</tr>
</tbody>
</table>

This graph shows that API have not had consistent changes in HIV diagnoses over time, that in fact the EAPC (estimated annual percent change) for API is up by 0.72. The line also increases and decreases over time while Black, Latino/Hispanic, White and Native American make a downward trend.¹
This table shows there was a total of 104 API HIV diagnosed in the year 2018. For concurrent AIDS Diagnosis, API represent 34.6% (or 36 individuals), and is the highest within its own group as compared to the other race/ethnicities. It is important with this population to shift to community level data, where evidence shows that within the API community, 1 in 3 APIS who have an HIV diagnoses are diagnosed with AIDS. When we examine by Men/Women, we see that the percent remains consistent (see below tables). Further research is needed to collect and examine this by age group, area-based poverty level etc. to know how to frame initiatives based on API HIV characteristics, to which is found too often missing.
FIGURE 11.1: HIV diagnoses by country of birth, NYC 2018

FIGURE 11.2: Average annual HIV diagnosis rates by sub-region of birth, NYC 2013-2018

Rates calculated using 2013-2017 American Community Survey 5-Year Estimates of Sub-Regional Populations. Names of sub-regions are those used by the Census Bureau. For a list of countries included in each sub-region, see pages 95 to 104 of: https://www2.census.gov/programs-surveys/acs/tech_docs/code_lists/2017_ACS_Code_Lists.pdf.
In order for more comprehensive educational materials, having a data point regarding place of HIV diagnoses contacted will allow us to see how to frame items. For example, we see that South Eastern Asia has higher rates of new HIV diagnoses, and due to the diversity of API (different languages, culture norms, perceived susceptibility, stigma) having data regarding place of HIV diagnoses may provide insight to the customs and information to curate awareness materials and strategies. Additionally, we can see here a large immigrant population, and we must consider the varying different experiences to strengthen HIV initiatives.
This graph shows viral suppression within 3 months of new diagnosis. Across the board this is not a feasible rate, we can consider that data points regarding in-care vs out-of-care (do they come every 3 months, once a year, how often do they test for HIV in their visits, etc), may be related to concurrent diagnoses of AIDS above. Standard protocols for ensuring patients routinely (ideally 3 months) come in and get tested will increase viral suppression.
Lastly, we see here from the EPI Data Brief for Asian Americans in NYC, not ever tested for HIV amongst Asian Americans were higher than those ever being tested (not ever tested higher at above 50%).

Here are some concluding statements from the EPI data Brief:
Chinese adults were less likely to have ever been tested for HIV (34%) compared with South Asians (49%), Filipino (47%*), and Other Asians (46%). • South Asians were about twice as likely to report not getting needed medical care in the past year (14%) compared with Chinese (8%), Filipino (7%*), and Korean adults (6%*).

References
2. King L, Deng WQ. Health Disparities among Asian New Yorkers. New York City Department of Health and Mental Hygiene: Epi Data Brief (100); March 2018
Focus Area 2: Trust-Building and Stigma Reduction

Immigrants’ vulnerability can also be influenced by factors related to stigma and marginalization. A variety of factors can contribute to this: differences in appearance (for example, wearing traditional dress), cultural and religious practices, language barriers, speaking with an accent (even among immigrants who speak English), and skin tone.

Being part of a stigmatized group can make immigrants reluctant to seek care because of concerns about poor treatment. If providers do not have adequate resources to serve immigrant groups, longer waits and frustration affect both patients and providers. As noted earlier, immigrants and those with limited English proficiency are generally less satisfied with their care than U.S.-born or English-speaking populations. Further, immigrants are more likely than U.S.-born populations to report discrimination in health care. Perceptions of being discriminated against can reinforce feelings of stigmatization and lead to decreased use of health services in the future.

Another approach to increasing immigrants’ enrollment in public health programs is face-to-face outreach. Although this type of outreach can be labor intensive, it can help alleviate fears, build trust, and provide accurate information to families.

1. **Include diverse API faces in health campaign materials (e.g. PrEP Aware Week) and on tools developed to promote and educate communities (i.e. scratch off risk cards).**

   - Materials should be developed in multiple languages. Differentiation should be made between traditional and simplified Chinese.
   - The faces and languages featured should reflect data on HIV prevalence in NYS.
   - Images should reflect diversity by age, gender and country of origin.

   Related Blueprint Recommendation(s):
   - BP11: Undertake a statewide education campaign on PrEP and nPEP

2. **Expand outreach and education on sexual health (including STIs, substance use, recommended vaccinations, etc.), and gender-affirming care to community gatekeepers, including religious organizations and leadership, especially from temples and consulates, student-led organizations, and complementary medicine providers.**

   Although research is limited on provider education among the API community, anecdotal reports from the API Advisory Group indicate that primary care providers for API individuals, including those at high risk of or living with HIV, may be lacking gender-affirming and LGBTQIA care training. They suggest the following action items to address this implementation strategy:

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3Kathryn Pitkin Derose, José J. Escarce, and Nicole Lurie, Immigrants And Health Care: Sources Of Vulnerability, Health Affairs 2007 26:5, 1258-1268

• Conduct training/education for small private practices in geographic areas with large API populations
• Collaborate with Asian-American physician associations to engage in trainings and workshops on sexual health
• Partner with medical and other health professional schools to increase education about API culture and culturally sensitive sexual health care, including continuing education opportunities.
• It is important to gain an understanding of substance use in the API community, especially as it relates to HIV risk factors. Substance use varies widely among API communities and is not always addressed in the course of primary care. More research about the burden of substance use in API communities is needed in order to develop culturally responsive harm reduction strategies that take substance use into account.
• Conduct outreach and education in urgent care settings to engage providers
• Provide front line staff in community based and clinical settings with basic cultural competency trainings annually.
• Promote collaborations between AIDS Service Organizations with non-HIV related programs to offer onsite HIV/STI/Viral Hepatitis counseling and testing at programs and venues frequented by API communities and to increase points of entry into the system to address sexual health issues.

It is necessary for providers to receive training on gender concepts (understanding gender identity, sex at birth, sexual orientation, and gender expression) and health disparities for LGBT and API communities, particularly resulting from stigma and discrimination that these communities experience, leading or contributing to social isolation, substance misuse, mental health issues. Most particularly, there is a need to share best practices in working with these communities.

There are many agencies that have excellent training resources for providers, including the one released by the National LGBT Health Education Center:
https://www.lgbthealtheducation.org/publication/learning-guide/

New York City also has local resources for in-person trainers in LGBT culturally competent care, that include, but are not limited to Callen Lorde Community Health Center, and Apicha Community Health Center.
3. Develop and promote educational tools for local health organizations on HIPAA to build trust and decrease stigma such as a consumer-facing video series on confidentiality to be used in waiting rooms. The video series should include resources and be translated using subtitles in various languages.

- Create short videos outlining basic rights related to medical visits, including confidentiality, HIPAA, rights and responsibilities, ADA, discrimination, etc. The video should be available to clients in waiting rooms, but also easily accessible online. Videos should be available with an API individual speaking the appropriate language with subtitles to accommodate visually and/or hearing-impaired individuals. Resources such as websites should be clearly stated in the video for access to additional information, educational information, and local community-based organizations that may offer related services.
- In clinical settings, patients are required to fill out medical release information. The general populace does not understand what HIPAA is, thus clients are not aware that there are protections in place for their confidentiality.
- To promote more accessibility: a video with API faces (for representation), professionally translated, with culturally sensitive language, can help with the decrease of stigma and encourage testing. Universal materials for small community-based organizations to share the importance of HIPAA do not currently exist.
- There is a strong perception that looking for HIV/AIDS care is a challenging process, usually fueled by stigma. Clients have expressed concerns about confidentiality breaches within their own communities and even going to non-Asian & Pacific Islander specialized care to avoid being recognized by a member of their own community.

4. Continued funding/expansion of family acceptance programs for LGBTQIA API

- Use data driven and culturally sensitive approaches to help API individuals navigate the “coming out” process.
- Consider socioeconomic factors (e.g., living at home past 18, caring for elder family members etc.) when engaging and promoting engagement in care and treatment.
- Use family acceptance programs as an opportunity to link API to appropriate behavioral health services, as stressors associated with family acceptance can lead to depression and other mental health issues. Safe spaces need to be created to address acculturation, etc. For example, Apicha Community Health Center’s Project Connect is a program for API who identify as Lesbian, Gay, Bisexual, Transgender, Queer, Questioning, and Intersex (LGBTQI). LGBTQI API individuals experience barriers accessing services and are often underserved due
to a spectrum of reasons including culture, linguistic isolation, and the lack of supportive networks.

Related Blueprint Recommendation(s):
- BP28: Equitable funding where resources follow the statistics of the epidemic

5. Focus initiatives to increase outreach for sex workers, specifically to massage parlors including information on legal issues (Know Your Rights). Information should be made available for owners and managers.

- Educational materials should be distributed to female sex workers (FSW) employed in massage parlors in areas where massage parlors are clustered (i.e., Flushing Queens, Midtown Manhattan, Sunset Park Brooklyn). Educational materials should be made available in English, Korean, and Simplified Chinese and contain information on HIV prevention and available services. In addition to information on HIV prevention and available resources, material should include a “Know Your Rights” section. Educational materials should be distributed to both FSW + massage parlor owners/managers.

For example, provide handheld cards that highlight basic rights to individuals engaging in sex work who are arrested. Example below provided by SWOP Behind Bars (www.swopbehindbars.org). Cards should be available in different languages to alleviate possible language barriers with law enforcement.

![Handheld Cards](image)

Related Blueprint Recommendation(s):
- BP24: Remove disincentives related to possession of condoms
- BP28: Equitable funding where resources follow the statistics of the epidemic

6. Utilize DOH surveillance data to develop focused outreach/resources for API who have been concurrently diagnosed with AIDS.

- NYCDOHMH HIV Annual Surveillance Report includes calculated row percentages of concurrent diagnoses among API in NYC with difference between those in care and not in
care. Ensure the NYS HIV Annual Surveillance Report provides comparable calculated row percentages.

- NYSDOH AIDS Institute has an internal work group tasked with reviewing the NYS HIV/AIDS concurrent diagnoses. Ensure the work group appropriately reflects the API population and include additional calculations to compare API concurrent diagnoses among the general NYS API population compared to the other race/ethnicity population subgroups.

Related Blueprint Recommendation(s):
- BP29: Expand and enhance the use of data to track and report progress

7. **Provide resources to funded agencies to ensure health service/program staff are linguistically and culturally competent and are informed of the issues associated with immigration status.**

- Support and promote “Know Your Rights” workshops and trainings by legal programs to community-based programs, to ensure staff gain a better understanding of clients’ legal options and rights, ensuring referrals to obtain legal services as needed.
- Host 2-3 community HIV/AIDS awareness events in the different boroughs where there are gaps in services
- Hold a news/press conference to discuss the outreach/strategies that impact the sustainability of the message
- Ensure NYS AIDS Advisory Council evaluates effectiveness of the API Advisory Group implementation strategies and consults with advisory group leadership to make any required changes or adopt new approaches.

Related Blueprint Recommendation(s):
- BP28: Equitable funding where resources follow the statistics of the epidemic

8. **Provide cultural competency trainings with information on stigma reduction strategies to increase cultural responsiveness, sensitivity to traditions and language-appropriate services among HIV/AIDS providers, public health officials, and advocates.**

- Conduct focus/work groups to create effective and culturally sensitive messaging and to determine the best medium of delivery.
- Utilize a famous Asian or Pacific Islander spokesperson for testimonial with a central message regarding HIV/AIDS.
- Trainings must integrate specific information about local immigrant communities and the diversity among API to adequately meet their health and HIV prevention/treatment needs.

Related Blueprint Recommendation(s):
- BP28: Equitable funding where resources follow the statistics of the epidemic

9. **Focus on stigma reduction around aging Asian population – “age is not a condom”; aging is seen differently among API**
• Education programs aimed at prevention of HIV/AIDS among API adults who ages 65 years old and older. This program would focus on educating older API adults on HIV/AIDS and other sexually transmitted infections (STIs) in order to heighten awareness, ensure a healthier sexual experience and reduce the spread of infections.

• The 50 and older HIV/AIDS population faces a double stigma, involving both ageism and the biases associated with HIV/AIDS. Additionally, cultural expectations, such as fear of bringing shame to the family, family silence about sex, and the stigmatization of homosexuality and drug use in the general API community, may result in limited access to information about HIV/AIDS prevention.

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Supporting Evidence for Implementation Strategy #4:

Family acceptance of LGBTQ identities is a key indicator of better health and wellness outcomes for LGBTQ people. A vast body of literature shows that LGBTQ youth who have their identity affirmed and accepted by their parents are less likely to attempt suicide, be depressed, use illegal drugs, and engage in unprotected sex. Family acceptance is clearly protective and family rejection clearly increases risk. Often times, parents and other biological family members express that rejection of LGBTQ identity comes from “love” and “care”—that is, biological family members believe that rejecting an LGBTQ youth’s identity will protect the youth from the harms that arise in a homophobic and transphobic world. For API families, the idea that rejection can be protection is exacerbated by the fact that many API communities place a great deal of value in conformity, meeting expectations of society, “saving face,” religion, and traditional marriage and childrearing structures.

The Family Acceptance Project at San Francisco State University strategically engages with families of LGBTQ youth. The Project engages gently with parents or relatives who believe they are doing what’s best for their LGBTQ child by rejecting their identity. However, through the use of research, therapy, storytelling, and role modeling, the Project demonstrates to parents that sexual orientation and gender identity cannot be changed by a parent, and that instead, rejection of their LGBTQ child puts the child at risk for serious harm.

There has been little peer-reviewed research examining API family acceptance of LGBTQ youth. The Human Rights Campaign released a comprehensive report, “Coming Out: Living Authentically as LGBTQ Asian and Pacific Islander Americans,” that explored some of the major challenges that LGBTQ API individuals faced when living openly. Additionally, there have been innovative multimedia projects created by API LGBTQ community organizations. Most notably, the #FamilyisStillFamily initiative created videos in several Asian languages featuring parents of LGBTQ children and their experiences of acceptance and affirmation which aired on ethnic television and international channels.

More research and development of best practices for families of LGBTQ API individuals is needed. Additionally, there is a severe dearth of focus on family acceptance for LGBTQ Pacific Islanders, with most of the resources and content creation featuring primarily or even exclusively Asian individuals. However, it is clear that education and awareness-raising about the importance of acceptance for the well-being of LGBTQ children and adolescents is crucial. Additionally, messages and media that show API parents and families unconditionally accepting and affirming their LGBTQ children are powerful tools to challenge traditional values and approaches that lead to rejection and stigmatization of LGBTQ API individuals.

Resources:
Family Acceptance Project: https://familyproject.sfsu.edu/
#FamilyisStillFamily: http://familyisstillfamily.org/
Asian Pride Project: www.asianprideproject.org
National Queer Asian Pacific Islander Alliance: www.nqapia.org
Q-Wave: www.q-wave.org
SALGA NYC: www.salgany.org
GAPIMNY: www.gapimny.org

LGBT and API Cultural Competency Resource:
LGBT communities have identified that LGBT competency among medical providers, as well as other health and human service providers, is key in improving the health outcomes of this community.

At minimum, there is a necessity for providers to receive training on gender concepts (understanding gender identity, sex at birth, sexual orientation, and gender expression) and health disparities for LGBT and API communities, particularly resulting from stigma and discrimination that these communities experience, that lead to or exacerbates social isolation, substance misuse, mental health issues. Most particularly, there is a need to share best practices in working with these communities.

There are many agencies that have excellent training resources for providers, including the one released by the National LGBT Health Education Center: https://www.lgbthealtheducation.org/publication/learning-guide/

New York City also has local resources for in-person trainers in LGBT culturally competent care, that include, but are not limited to Callen Lorde Community Health Center, and Apicha Community Health Center.

Supporting Evidence for Implementation Strategy #5:
Female sex workers (FSWs) in the US and worldwide are at greater risk for HIV compared to the general population due to the nature of their occupation (e.g., multiple sex partners, unprotected sex, violence victimization) and underlying structural vulnerabilities [1]. Asian immigrant FSWs in particular experience additional risks because of intersectional stigma that is rooted in their multiple marginalization as women and immigrants (often undocumented) engaging in illegal behavior. The majority of Asian immigrant FSWs work in illicit massage parlors that offer sexual services [2,3]. It is estimated that there are more than 9,000 illicit massage businesses in the US [4] with 475 found in New York City (NYC) alone in 2013 in our pilot studies [5]. For most FSWs, financial hardship as a reason to enter into such work increases the likelihood of coercion; Asian immigrant FSWs in particular are often paying off migration debts [6]. These vulnerabilities may contribute to inconsistent condom use, high levels of substance use, and violence victimization among Asian immigrant FSWs [7,8,9]. Findings from our pilot studies similarly showed high
sexual risk in this population: 68% of Asian immigrant FSWs in NYC indicated that massage parlor owners never provided condoms; 53% said they had never been tested for HIV.

References:

Focus Area 3: Prevention, Linkage and Retention

1. **Expansion of Telehealth:** Use Telehealth as an opportunity to link individuals to providers and case managers. Use telehealth, in conjunction with local or mail laboratory testing services, for continuing PrEP, PEP, and HIV care.

   Telehealth improves access to services for consumers who hope to eliminate travel to and wait time at their providers’ offices, whether close by or far from their base geographic area. Consumers who may feel most comfortable accessing healthcare from far away providers for such reasons as familiarity, cultural competence, anonymity/confidentiality, etc., can stay more connected to those services via telehealth.

   Expansion of telehealth will require the availability of translation services. Also, individuals using telehealth as an alternative to frequent in-person provider visits may be unaware of supportive CBO’s and services available, especially in rural areas. Utilizing CBO services may assist with retention in care. Case managers and patient navigators can use telehealth to keep connected with clients and to re-engage those lost to follow-up.

   • Example: Client in Madison County using Telehealth may be connected to a case manager from ACR Health. Madison County has limited services or cultural groups, but ACR Health in Onondaga County also serves Madison County.

Providers and health care organizations should become familiar with New York State Medicaid Expansion of Telehealth February 2019 Guidelines: 

Related Blueprint Recommendation(s):
- BP Section 2: Link and retain persons diagnosed with HIV in care to maximize virus suppression so they remain health and prevent further transmission
- BP28: Equitable funding where resources follow the statistics of the epidemic
- BP29: Expand and enhance the use of data to track and report progress

2. **Promote CDC-recommended screening, diagnosis, and treatment of STIs among high priority populations.** This includes extragenital testing. Materials focused on women and STI testing should be developed with the faces of API women and TGNC individuals.

   Chlamydia and gonorrhea infections are common in non-genital sites in some populations such as men who have sex with men (MSM). Because extra-genital infections are common in MSM and most infections are asymptomatic, routine annual screening of extra-genital sites in MSM is recommended.

Related Blueprint Recommendation(s):
- BP Section 4: Recommendations in support of decreasing new infections and disease progression
3. Integrate rapid HIV testing and linkage into non-HIV-specific mobile clinics, offering HIV testing along with other routine health screenings e.g., blood pressure, blood sugar, cholesterol, dental services, or benefits enrollment.

The API advisory group members have noticed a reticence among the API community they serve to publicly acknowledge personal engagement in sexual health care. There might be more uptake, however, of non-HIV-specific health services delivered by mobile units at large API community gatherings, e.g., the NYC Lunar New Year parade. They suggested that engagement in HIV testing could be increased by coupling it with mobile clinics that aren’t traditionally associated with sexual health.

Related Blueprint Recommendation(s):
- BP1: Make routine HIV testing truly routine
- BP2: Expand targeted testing

4. Include diverse API faces in U=U promotion and public health campaigns.

Undetectable equals Untransmittable is a powerful public health campaign, which has the potential to reduce stigma and increase engagement across the HIV care continuum for all communities. Asian and Pacific Islanders should be represented in any statewide sexual health campaigns, especially as they are disproportionately impacted by HIV in New York State. In addition, campaigns should be translated into the appropriate languages to reach the intended API audience.

Related Blueprint Recommendation(s):
- BP25: Treatment as prevention information and anti-stigma media campaign.

5. Continue to promote education on comprehensive sexual health risk assessments for clinical providers. Promote the integration of HIV prevention and sexual health care into primary care, with a special focus on women.

Related Blueprint Recommendation(s):
- BP23: Promote comprehensive sexual health education.

Resources:

http://etedashboardny.org/

https://blog.apicha.org/i-swallow-daily-api-artists-discuss-prep-stigma-representation

http://johnchin.net/Article_Files/MP_Study_10.11.19_FINAL.pdf