LOOKING FOR A PLACE TO CALL HOME:
A Needs Assessment of Asians and Pacific Islanders Living With HIV/AIDS in the New York Eligible Metropolitan Area

The New York Academy of Medicine
May 2007

LOOKING FOR A PLACE TO CALL HOME:
A Needs Assessment of Asians and Pacific Islanders Living With HIV/AIDS
in the New York Eligible Metropolitan Area

Study Authors:
John J. Chin, Linda Weiss, Ezer Kang, David Abramson, Nick Bartlett, Elana Behar,
and Angela Aidala

For further information about this report, please contact John J. Chin, Ph.D., at
JCHIN@NYAM.ORG.

A PDF version of this report can be downloaded at:
http://www.nyam.org/initiatives/docs/looking/.

Cover design and layout by Vizual Efx: www.vizualefx.com.

THE NEW YORK
ACADEMY OF MEDICINE

RESEARCH TEAM
(TEAM MEMBERS ARE FROM NYAM EXCEPT WHERE NOTED)

John J. Chin, PhD, *Principal Investigator*

David Abramson, PhD (Columbia University)

Angela Aidala, PhD (Columbia University)

Nick Bartlett, MIA

Elana Behar, MS

Sara Berk, MPH (Columbia University)

Yu-Kang Chen, MA (APICHA)

James Egan, MPH

Ezer Kang, PhD (New York Presbyterian Hospital)

Andrea King, MPH (Columbia University)

Jeannine Melly, MPH

Tasha Stehling, MPH (Columbia University)

Nicole Tsang

Linda Weiss, PhD

COMMUNITY PARTNERS

Asian & Pacific Islander Coalition on HIV/AIDS, Inc. (APICHA)

Chinese American Planning Council, HIV/AIDS Services (CPC)

INTERVIEWERS AND INTERPRETERS (PROVIDED BY APICHA)

Kitseng Chao

Wei Chen

Shefali Rowshan, MSC

Noreen Daniel

Mariko Hashimoto, MSW

Michie Sato

Table of Contents

STUDY HIGHLIGHTS

- **Evidence of Late Testing.** The Asian/Pacific Islander (API) Quantitative survey showed that 36% of API participants had self-reported major medical problems[1] when first receiving HIV medical care, compared to 21% for the CHAIN New Baseline cohort (a representative sample of New Yorkers living with HIV/AIDS), suggesting delays in HIV testing and entering into care for APIs. This high rate of major medical problems at time of first HIV medical care is consistent with findings from previous analyses of epidemiologic data and indicates that a focus on getting APIs tested and into care is of critical importance.

- **High Rates of Barriers to Care.** API participants in the quantitative survey were more likely to report barriers to care as compared to individuals in the CHAIN New Baseline cohort. Fifty-two percent (52%) of the API participants reported at least one logistical barrier to medical care and social services, and 31% reported at least one provider barrier, compared to 12% and 12%, respectively, for the CHAIN New Baseline cohort. In terms of logistical barriers, more APIs reported language barriers (11%) and cost barriers (34%), in comparison to the CHAIN New Baseline cohort (for whom the rates were 1% and 4%, respectively). The most frequently reported provider barrier was that staff were disrespectful or insensitive (14% of API participants reported this barrier, compared to 7% in the CHAIN New Baseline cohort), which may reflect the perception of prejudice or discrimination, or different cultural expectations regarding demonstrations of respect.

  Given that more than half of the API Quantitative cohort preferred to receive services in languages other than English, it is surprising that only 11% reported language barriers. This may be an artifact of our recruitment, which occurred primarily through API-targeted AIDS service programs with solid language assistance programs, or an indication that the current system of concentrating specialized services for specific populations within a few organizations may be an effective approach. The effectiveness of such a system requires the larger network of providers to be aware of and able to refer to these specialized API-focused services.

- **High Rates of Being "In Care," but Problems with Adequacy of Care.** Only 35% of the API participants in the quantitative survey had medical care that meets "preferred practice guidelines," compared to 74% for the CHAIN New Baseline cohort. Forty-three percent (43%) of APIs experienced a service gap for "comprehensive medical care" as compared to 24% for the CHAIN New Baseline cohort. Participants who were ineligible for Medicaid because of immigration status found that ADAP was insufficient to cover general medical care; there were consistent complaints about lack of access to dental services.

- **Support Service Needs and Gaps.** In the quantitative survey, 87% of API participants exhibited a need for case management services, compared to 40% for the CHAIN New Baseline cohort. This may reflect greater support and service navigation needs among APIs resulting from stigma, isolation and language and cultural barriers. In qualitative interviews, participants reported service gaps in the areas of rental assistance/housing, financial assistance and job training, legal services related to immigration, and alternative pain management services (e.g., massage, acupuncture).

- **Housing Services.** Of the 9 API participants showing a need for financial housing services in the quantitative survey, none of them received such services.

- **Low HIV Prevention and Treatment Knowledge.** Participants had generally low HIV prevention and treatment knowledge. Knowledge levels may be related to level of acculturation and English proficiency.

- **Treatment Adherence.** Only 56% of the API Quantitative cohort that was on HIV medications reported being completely adherent, compared to 72% for the CHAIN New Baseline cohort.

- **Mixed Views Regarding the Importance of Shared Language and Culture.** With very few exceptions, participants with low English proficiency favored having a medical provider who spoke their primary language. The number of languages represented in the API community, however, poses a significant challenge to institutions trying to meet their linguistic needs. Attitudes about shared culture and ethnicity between provider and consumer were less consistent than attitudes about shared language. Some participants preferred seeing non-API providers for fear that API providers would not respect them or their confidentiality. Others did prefer API providers, feeling that shared cultural traits facilitate improved comfort and understanding. A number of participants commented on other provider characteristics that were as or more important to them than language and ethnicity. These included clinical competence, compassion, efficiency, and site characteristics such as location and operating hours.

- **Extreme Isolation and Mental Distress Because of HIV Stigma.** Reluctance to disclose one's HIV status because of HIV stigma was a major theme in the qualitative interviews. Many participants experienced extreme social isolation because of their fears about disclosing their HIV status and the sometimes negative responses they received when they did disclose. Social isolation appears to have had significant negative mental health consequences. In the API Quantitative cohort, 71% had low or very low mental health scores, compared to 50% for the CHAIN New Baseline cohort.

- **Low Utilization of Conventional Mental Health Services.** Given the high levels of isolation and mental distress expressed by study participants, relatively few had utilized mental health services. API participants with low or very low mental health scores had a 70% service gap for professional mental health services (compared to a 63% service gap in the CHAIN New Baseline cohort, indicating low mental health service utilization all around). In key-informant interviews, providers explained that the barriers were both the clients' reluctance to seek mental health services and the lack of appropriate services. Even when mental health providers who spoke clients' languages were available, sometimes they were located far away from the client or did not accept certain forms of payment. Language matching is particularly important for talk therapies.

  Qualitative interview participants were able to describe a number of activities that helped them to feel better, other than support groups or professional mental health services, including social events – such as dinners and holiday parties – at the social service agencies where they are clients. Many participants mentioned spirituality or a formal religious practice, including attendance at churches and temples, as important to maintaining their sense of well-being.

- **Severe Service Barriers and Issues of Family Separation for Undocumented Immigrants.** Undocumented immigrants experience negative economic and social consequences as a result of their immigration status. (Many of these problems are also experienced by documented immigrants who are not naturalized citizens or permanent

residents.) Most undocumented participants expressed a strong desire to have their status legalized and expressed frustration at the lack of availability of legal services or opportunities for legalization. In the API Quantitative survey, 43% of participants reported needing help with legal issues, compared to only 11% for the CHAIN New Baseline cohort.

Limited eligibility for public benefits. One of the most obvious vulnerabilities of being an immigrant is the more limited eligibility for public benefits. For example, to be eligible for Medicaid, one needs to be a US citizen or permanent resident (green card holder), an asylee or have PRUCOL status. While ADAP covers HIV care for undocumented and other uninsured immigrants, it is more limited than Medicaid in that it does not cover non-HIV-related conditions.

Separation from family. In addition to having an impact on eligibility for benefits, undocumented immigration status was related to a profound sense of social isolation and separation from family. Because they feared not being able to return to the US if they visited their countries of origin, undocumented immigrants were often separated from family on a long-term basis, and many said that they missed their families badly. Some study participants said that if they were not HIV positive, they would move back to Asia permanently. Being HIV positive, however, they felt that returning home was not an option, since they would not have access to the medical care they needed to stay alive.

Limited work options and financial pressures. Undocumented individuals have limited work options while also facing enormous financial pressures as a result of debts to smugglers and expectations from family members for remittances, especially if the family poured its resources into sending the person to the US. One undocumented participant expressed extreme distress about the prospect of becoming too ill to work, knowing that the smugglers would seek debt repayment from his family in Asia if he stopped paying. Some study participants also felt they could not plan for the future with their limited work options and the threat of deportation hanging over them.

- **Immigration and HIV Infection.** Analysis of qualitative interviews suggests that the vulnerabilities created by the immigration process may have been a factor in HIV infection for a number of the study participants in two ways. First, several of the Chinese participants who were undocumented immigrants believed they were infected prior to entering the US during long interim stays in Southeast Asia (up to three years), where they were separated from family, had little to do, and frequented sex workers. Second, several gay men believed they were infected soon after coming to the US; they said they engaged in a high volume of unprotected sexual activity because they viewed the US to be a place of sexual freedom and found a range of new sexual opportunities for which they were unprepared. Some said they had little awareness about HIV at the time.

  There was no consistent pattern of infection among the female participants in the study. Almost all of the female participants said they were infected by their boyfriends or husbands; the dynamics of immigration may have been a factor in some cases.

  Lack of HIV prevention knowledge, which is often related to being an immigrant, may also have been a factor in all of these cases. Recent immigrants often have lower levels of knowledge about HIV than US-born persons or more acculturated immigrants, especially if HIV education in the country of origin was lacking.

- **Programmatic and Policy Recommendations.** Please see pages 42-45 for four primary recommendations and seven supplementary recommendations.

BACKGROUND

In the US, the Asian & Pacific Islander (API) population continues to increase rapidly, with growth rates three times that of the general population. There are currently close to 12 million APIs in the US.[2] Close to 785,000 NYC residents are API, representing nearly 10% of the city's population.3 Although there is a preponderance of mainland Chinese (45%), APIs in NYC are diverse, including Asian Indians (22%), Koreans (11%), Filipinos (7%), Pakistanis (3%), Japanese (3%), Bangladeshis (2%), Southeast Asians and others (6%).[3] Almost 80% of NYC APIs are foreign-born.[4]

As of the end of 2004, an estimated 7,317 APIs in the US[5] and a reported 1,168 APIs in NYC[6] had been diagnosed with full-blown AIDS. NYC API cumulative AIDS cases account for a substantial portion (16%) of the national API cases. There are alarming indicators of rapid increase. In a review of HIV/AIDS data covering 2001 through 2004, the CDC found that APIs had the highest estimated annual percentage change (EAPC) in HIV/AIDS diagnosis rates. The EAPC for APIs was 8.1 for males and 14.3 for females.[7] In a similar analysis for the same period in NYC, the NYC Department of Health and Mental Hygiene reported that "the number of new HIV diagnoses each year has declined in all racial/ethnic groups except Asian/Pacific Islander."[8] Reflecting the addition of new HIV/AIDS diagnoses each year, the number of NYC APIs known to be living with HIV/AIDS rose by 15% between 2003 and 2004.[9, 10] (These figures do not reflect individuals who are HIV positive but who have not been tested for HIV.)

Known cases of AIDS among APIs may represent just the tip of the iceberg for several reasons. First, AIDS diagnoses among APIs may be underreported by as much as 33%.[11] Second, studies indicate that certain API subgroups engage in significant high risk behaviors, including unprotected intercourse with sex workers [12, 13] and unprotected anal intercourse (with rates ranging from 21% to 53%) among API men who have sex with men (MSM).[14-19] Third, AIDS has reached epidemic proportions in parts of Asia, home to 60% of the world's population. Approximately 8.5 million Asians are currently living with HIV, including 1.1 million infected in 2005 alone (nearly a quarter of the 4.9 million new infections world-wide that year).[20] The combination of the rapid spread of HIV in Asia, continued high levels of bi-directional migration between Asia and the US, and potential sexual network linkages between the infected and uninfected suggests that HIV/AIDS among APIs in the US will continue to rise, particularly if culturally competent and linguistically appropriate prevention services are not available.

The increase in the number of APIs living with HIV/AIDS – as a result of anti-retroviral therapies and new HIV infections – heightens the urgent need to understand the issues affecting this diverse population. This report adds to a small literature on the experiences and needs of APIs living with HIV/AIDS and provides recommendations for improving services for this group.

METHODS

This is a mixed methods study using focus groups, in-depth qualitative interviews and quantitative surveys of APIs living with HIV, and key-informant interviews with service providers. The study received IRB approval from both the NYCDOHMH and NYAM IRBs prior to start of data collection. All study participants, except for the providers, were given a metrocard incentive for each aspect of the study they participated in. Data collection occurred from January 2005 through July 2005.

Translation and Interpretation

Because of budget and time constraints, questionnaires and survey forms were prepared in English and Chinese only. All study forms were translated by a professional translation service into Chinese. The translated products were then reviewed by study staff who spoke and read Chinese. Discrepancies with the English version were discussed with the translator and resolved. Languages other than Chinese were handled with interpreters in several ways, which are described further below.

Focus Groups

One of the first data collection steps was to conduct three focus groups with HIV positive API sub-populations that have received relatively little attention in research activities: Mandarin-speaking heterosexual men, South Asians, and API women. The purpose of these focus groups was to capture any specific issues faced by these sub-populations and also gather preliminary data for designing and refining interview questionnaires and surveys. Detailed notes of the focus groups were taken and then typed up by the group facilitators. The Mandarin-speaking heterosexual men's focus group was conducted by two Mandarin-speaking facilitators. The South Asian group, made up of Hindi and Bengali speakers, was conducted by an English-speaking facilitator with a language interpreter. The women's focus group was conducted by an English-speaking facilitator with an interpreter for two of the women who spoke Cantonese.

At the end of the study, one consumer focus group and two provider meetings were held to review the preliminary study findings and solicit feedback.

Provider Interviews

Seven key-informant interviews were conducted with providers who were knowledgeable about the service needs of APIs living with HIV. Providers included case managers, program managers, an HIV primary care physician, and a lawyer with expertise in immigration law. The interviews provided context for understanding study participants' comments and informed interpretation of study results.

In-depth Qualitative Interviews

In-depth qualitative interviews were conducted with 35 APIs living with HIV recruited through the client rosters of the Asian and Pacific Islander Coalition on HIV/AIDS (APICHA) and the HIV/AIDS Services program of the Chinese American Planning Council (CPC). Together, APICHA and CPC are believed to serve the largest group of APIs with HIV in care in New York City (a combined total of 217 active API clients). Twenty-five (25) of the qualitative interview participants came from APICHA and 10 were from CPC. APICHA and CPC staff informed clients of the study by posting flyers, making announcements at client meetings, and talking to clients one-on-one. In interviews and feedback sessions to discuss an early draft of this report, staff of APICHA and CPC said that the clients who agreed to participate in the study were generally less concerned by HIV stigma and more connected to care than their general client populations, which is important to note when considering the generalizability of these findings for the larger API HIV positive population in New York City.

Attempts were made to recruit study participants through hospitals serving large numbers of APIs and through an ad in HX magazine (a popular gay bar magazine). These methods were not effective, presumably at least in part because of the high level of HIV stigma in API communities. One South

Asian physician at an HHC facility, for example, told us that he would inform his HIV positive API patients about the study but was doubtful any would participate because of their discomfort about disclosing their status. The trust that staff at APICHA and CPC had developed with their clients made recruitment efforts at those agencies more effective.

The interviews, which were generally 90 minutes to two hours long, were conducted by trained English- and Mandarin-speaking interviewers using a semi-structured interview guide. The interview guide covered a variety of areas, including level of acculturation, medical and social services access and utilization, barriers to testing and care, satisfaction with care, medication adherence, mental health, substance use, disclosure of HIV status to family and friends, immigration history, and circumstances surrounding time of HIV infection. All but 4 interviews were audio-recorded using digital recorders. (2 participants refused to be recorded; for an additional 2, there were technical difficulties. In these instances, detailed notes were taken and typed up by the interviewer and were used in place of transcripts in the analysis.)

There were 14 interviews in Mandarin and 15 in English. In addition, one Hindi-, one Japanese-, and two Bengali-language interviews were conducted by English-speaking interviewers with interpreters. An additional two interviews were conducted almost fully in Japanese, and these were translated and transcribed into English by a bilingual transcriber. Interviews in English were transcribed by a professional transcription service. Interviews in Mandarin were translated and transcribed in English by bilingual transcribers. English interviews were transcribed verbatim, preserving grammatical errors, while non-English interviews were translated into standard English.

Analysis of qualitative data

A preliminary codebook was developed based on 5 interviews. The preliminary codebook was pilot-tested by five members of the research team, then refined and finalized. The final codebook was then used to code all 35 interviews by 5 members of the research team. Codes were applied to the transcripts using NVivo, a software package for qualitative research. NVivo is designed to hold and manage multiple project documents, as well as a hierarchical set of codes, any or all of which can be attributed to particular blocks of texts. After the text is coded, searches can extract and compile appropriately coded excerpts from all project documents. Examples of codes include: "immigration barrier" (to code discussions of barriers to care because of immigration status); "enacted stigma" (to code participants' descriptions of being subject to actions or comments by others because of HIV stigma), "misconceptions" (to code participants' misconceptions about HIV transmission and treatment). Research team members met regularly to discuss emergent findings and the coding process and prepared interview summaries using a standard template. This analytic process led to the identification of the main themes and issues in the qualitative interviews, which are discussed in this report.

Because of the extensive quantitative survey with a larger number of participants, we did not focus on quantifying phenomena in our analysis of the qualitative interviews; rather, we focused on understanding complex dynamics and identifying important themes.

Quantitative Survey

An extensive quantitative survey was conducted with a convenience sample of 89 APIs living with HIV. Nineteen (19) of the participants in the quantitative survey also participated in the in-depth qualitative interviews described above. As shown in Table 1 below, the demographic profiles of the 35 qualitative interview participants and the 89 quantitative survey participants are fairly similar. One of the major differences between the qualitative and quantitative samples is the recruitment source. While the qualitative sample was recruited through APICHA and CPC, the quantitative sample was recruited through these agencies plus GMHC (65 from APICHA, 15 from GMHC and 9 from CPC). GMHC, which lacks culturally or linguistically targeted services for APIs, is likely to attract a more assimilated client base.

The quantitative survey was a modified version of the survey used in the CHAIN study, conducted since 1993 by the Mailman School of Public Health, Columbia University. The CHAIN study is a longitudinal study of a representative sample of persons living with HIV who are in care in New York City. CHAIN has enrolled 3 cohorts of HIV positive adults, two in NYC and one in the Westchester, Rockland, and Putnam region. 2,059 respondents have participated across the 3 cohorts, some as many as 8 times over a 7 year period. One of the great advantages of working with the CHAIN team and CHAIN instruments was that it allowed us to make comparisons between the API sample in this study and the representative CHAIN sample.

The quantitative survey was administered in English and Chinese by trained interviewers using survey forms in these languages. If the participant was not able to speak either of these languages, the English survey form was used with verbal interpretation by trained bilingual interviewers. This occurred in 16 cases, for Japanese (7 interviews), Hindi (4 interviews), Bengali (2 interviews), Gujarati (2 interviews) and Urdu (1 interview). Completion time for the survey ranged from one hour to more than three hours. Longer interviews tended to be those requiring verbal translation and those conducted in English with participants who spoke English with limited proficiency.

Analysis of quantitative data

Consistent with procedures used for the CHAIN study, quantitative data were entered into a Computer Assisted Personal Interview program and then converted to a statistical database (STATA) for analysis. Descriptive statistical analyses were conducted to characterize the sample population. Subgroup differences were then analyzed using chi-square analyses and t-tests. Findings for the API sample were compared to findings for the full CHAIN sample to understand differences between APIs with HIV and other New Yorkers with HIV.

Participant Characteristics

Table 1 below summarizes the participant characteristics for the API qualitative and quantitative interview samples. For comparison, we also report the characteristics of the 842 APIs known to be living with HIV/AIDS in NYC as of December 31, 2003, as reported by the New York State Department of Health.[21] The 842 cases include only those APIs who have been tested and diagnosed with HIV infection or AIDS and are still living; these cases does not include an estimate of APIs who are HIV positive but have not been tested. Because we make comparisons throughout this report to the CHAIN study cohort, basic demographics are provided on this sample as well. In order to control for temporal trends, most comparisons to the CHAIN study focus on baseline measures for the cohort recruited in 2002-2004.

In Table 2, additional data on country of birth and primary language are provided for the API Qualitative and Quantitative Samples. Where known, country of birth is also provided for the 842 known APIs living with HIV/AIDS in New York City, as reported by the New York State Department of Health. Similar data are not available for the CHAIN study cohort.

Table 1. Sociodemographic Characteristics

	API Qualitative Sample		API Quantitative Sample		NYC Known APIs Living with HIV/AIDS		NYC CHAIN New Baseline 2002-2004	
Total Sample	**n**	**%**	**N**	**%**	**n**	**%**	**n**	**%**
	35	100%	**89**	100%	**842**	100%	**684**	100%
Gender								
Male	**27**	77%	**75**	84%	**676**	80%	**416**	61%
Female	**8**	23%	**14**	16%	**166**	20%	**268**	39%
Sexual Orientation/HIV Risk Category*								
Gay/MSM/Lesbian	**14**	40%	**57**	64%	**339**	40%	**254**	37%
Bisexual	**5**	14%						
Heterosexual	**16**	46%	**31**	35%	**133**	16%	**398**	58%
Other/Unknown	**0**	0%	**1**	1%	**370**	44%	**32**	5%
Race/Ethnicity								
White, non-Hispanic	**0**	0%	**0**	1%	**0**	0%	**59**	9%
Black, non-Hispanic	**0**	0%	**0**	0%	**0**	0%	**361**	53%
Hispanic/Latino	**0**	0%	**0**	0%	**0**	0%	**253**	37%
Asian/Pacific Islander	**35**	100%	**89**	100%	**842**	100%	**1**	<1%
Other	**0**	0%	**0**	0%	**0**	0%	**10**	1%
Age								
20-34 years old	**5**	15%	**20**	23%	**728**	88%	**63**	9%
35-49 years old	**19**	56%	**44**	50%			**405**	59%
50+ years old	**10**	29%	**24**	27%	**96**	12%	**216**	32%
Country of Birth								
Foreign-Born	**34**	97%	**84**	94%	**371**	44%	**165**	24%
US-Born	**1**	3%	**4**	5%	**276**	33%	**518**	76%
Unknown	**0**	0%	**1**	1%	**195**	23%	**1**	<1%
Years in the US (foreign-born only)								
Less than 3 years	**2**	6%	**3**	4%	Not Available		**9**	6%
3-8years	**8**	23%	**21**	27%			**7**	5%
> 9 years	**24**	71%	**53**	69%			**133**	89%

* Data for the Sexual Orientation/HIV Risk category are not collected in the same way across the different data sources. The API Qualitative Sample uses "sexual orientation." The API Quantitative Sample and the CHAIN New Baseline Sample use "sexual history," and the NYC Known APIs Living with HIV/AIDS uses mode of HIV transmission. The Other/Unknown category for NYC Known APIs Living with HIV/AIDS includes IDU transmission (n=39, 5%), blood products transmission (n=8, 1%), pediatric transmission (n=9, 1%), and a very high number of unknown transmission (314, n=37%).

Table 2. Country of Birth and Primary Language for API Qualitative and Quantitative Samples

	API Qualitative Sample		API Quantitative Sample		NYC Known APIs Living with HIV/AIDS	
	N	%	N	%	n	%
Total Sample	**35**	100%	**89**	100%	**842**	100%
Country of Birth						
China	**13**	37%	**19**	21%	**62**	7%
Japan	**4**	11%	**12**	13%	**21**	2%
Indonesia	**3**	9%	**3**	3%	**7**	1%
Philippines	**3**	9%	**10**	11%	**38**	5%
Bangladesh	**2**	6%	**3**	3%	**13**	2%
Korea	**2**	6%	**4**	4%	**16**	2%
Malaysia	**2**	6%	**7**	8%	**9**	1%
Hong Kong	**1**	3%	**2**	2%	**9**	1%
India	**1**	3%	**6**	7%	**79**	9%
Singapore	**1**	3%	**2**	2%	**0**	0%
Taiwan	**1**	3%	**1**	1%	**6**	1%
United States	**1**	3%	**6**	7%	**276**	33%
Vietnam	**1**	3%	**2**	2%	**8**	1%
Burma	**0**	0%	**1**	1%	**0**	0%
Cambodia	**0**	0%	**1**	1%	**0**	0%
Guyana	**0**	0%	**3**	3%	**19**	2%
Jamaica	**0**	0%	**1**	1%	**0**	0%
Okinawa	**0**	0%	**1**	1%	**0**	0%
Pakistan	**0**	0%	**2**	2%	**14**	2%
Thailand	**0**	0%	**1**	1%	**8**	1%
Tibet	**0**	0%	**1**	1%	**0**	0%
Trinidad and Tobago	**0**	0%	**0**	0%	**12**	1%
Yemen	**0**	0%	**0**	0%	**6**	1%
*Other/Unspecified Foreign-Born**	**0**	0%	**0**	0%	**44**	5%
Unknown/Missing	**0**	0%	**1**	1%	**195**	23%

	API Qualitative Sample		API Quantitative Sample		NYC Known APIs Living with HIV/AIDS	
	N	**%**	**N**	**%**	**n**	**%**
Total Sample	**35**	**100%**	**89**	**100%**	**842**	**100%**
Primary Language *(qualitative sample)* or Preferred Language for Receiving Services *(quantitative sample)* **						
Chinese	**17**	49%	**23**	26%		
Cantonese	6	17%	4	4%		
Fukiense	5	14%	2	2%		
Fuzhounese	2	6%	1	1%		
Mandarin	2	6%	7	8%	Not Available	
Hokkien	1	3%	0	0%		
Sichuan	1	3%	0	0%		
Unspecified dialect	0	0%	9	10%		
English	**6**	17%	**40**	45%		
Japanese	**3**	9%	**6**	7%		
Bengali	**2**	6%	**2**	2%		
Cambodian	**1**	3%	**0**	0%	Not Available	
Gujarati	**1**	3%	**2**	2%		
Indonesian	**1**	3%	**2**	2%		
Korean	**1**	3%	**2**	2%		
Makassar	**1**	3%	**0**	0%		
Sumatera	**1**	3%	**0**	0%		
Tagalog	**1**	3%	**1**	1%		
Burmese	**0**	0%	**1**	1%		
Hindi	**0**	0%	**2**	2%		
Punjabi	**0**	0%	**1**	1%		
Spanish	**0**	0%	**1**	1%		
Urdu	**0**	0%	**1**	1%		
Vietnamese	**0**	0%	**1**	1%		
Unknown/Missing	**0**	0%	**4**	4%		

* Other/Unspecified Foreign-Born includes individuals of API race born in Burma, Canada, Nepal, and unspecified countries in Africa, Asia/Pacific Islands, Caribbean, Europe, the Middle East and Central and South America.
** For the API Quantitative sample, the question on language asked which language the respondent would prefer to be used for receiving services, rather than what his or her primary language is. Our previous use of both questions in other studies indicates that many respondents who have a non-English primary language may choose English as the preferred service language for a variety of reasons, including availability.

As Tables 1 and 2 show, demographic characteristics of the API qualitative and quantitative interview samples are similar. Thus, in the discussion below, we will use the results from each of these samples to inform the interpretation of the other.

The two study samples are similar in several respects to "known APIs living with HIV/AIDS in New York City," indicating the extent to which study findings may be generalizable to the larger population of APIs living with HIV/AIDS who have been tested for HIV. There are similar proportions of men and women across the three groups. Age distribution is also fairly similar, although the study samples are older. The study samples are more heterosexual, but the comparison is obscured by a large number of "unknown" sexual orientation in the data for known API HIV/AIDS cases in NYC. The study samples also have a markedly higher proportion of foreign-born individuals, although again, the comparison is obscured by the large number of "unknown" country of origin cases in the data for known API HIV/AIDS cases.

The NYC CHAIN New Baseline cohort is markedly different from the API study samples, which is in part to be expected given their different sampling goals. The API cohort, for example, has a much higher proportion of foreign-born persons. A more complete presentation of the API quantitative data, shown side-by-side with the CHAIN data from all three CHAIN cohorts, is provided in the Appendix. As shown in the Appendix tables, the API sample is better educated and has a markedly higher rate of employment than the CHAIN cohort. The educational distribution among APIs is reflective of the "dual" migration stream, which includes a relatively high number of highly educated persons, but also a similarly high number of poorly educated persons.[22] In fact, the API Quantitative sample and the CHAIN New Baseline cohort have fairly similar proportions of persons with less than a high school education (34% vs. 40%). Although there is a high rate of employment for the API Quantitative sample, the qualitative interviews suggest that the type of employment may frequently be in low-wage, informal sector jobs such as garment factories and restaurants,[22] whose demands may create barriers to care, as discussed further below.

RESULTS AND DISCUSSION

The themes that emerged from the analysis of the qualitative data form the structure of this section. The API quantitative data are incorporated to corroborate or contrast with the qualitative data and to quantify some of the phenomena emerging from the qualitative interviews. Because the CHAIN cohort is a representative sample of persons living with HIV in New York City who are in care, it is introduced into the discussion as a benchmark for comparison to the API Quantitative sample.

The following sections explore acculturation, service utilization and needs, barriers to and facilitators of HIV testing and care, the importance of language and culture, respondents' HIV knowledge, HIV stigma and social isolation, mental health, and the vulnerabilities created by the immigration process. This is followed by recommendations that are suggested by the study's findings.

Acculturation

Although we did not specifically recruit immigrants, 34 of the 35 participants in the qualitative part of the study were born outside of the US. Arrival date for immigrants in the sample varied, ranging from as recent as 2004 to as far back as 1974. All of the participants, including the one who was US-born, were connected to Asian cultures to varying degrees. Many celebrated Asian holidays, preferred eating Asian foods, had mostly or exclusively Asian friends and co-workers, and had friends and family still living in their countries of origin with whom they communicated regularly. Several visited Asia fairly regularly, but for many participants, visits to Asia were limited because of cost, time, poor physical health, and undocumented immigration status. Many participants watched Asian-language television, listened to Asian-language radio, and read Asian-language newspapers, although this was sometimes limited by availability.

Several participants said they could not speak English at all and lived almost entirely in a world made up only of other co-ethnics who spoke the same Asian language. One Chinese woman, for example, came to the US young enough to attend high school here, but at age 41 speaks very little English and works in a garment factory with mostly Chinese workers. Even in this environment, however, there can be language barriers. In her case, it was because the other Chinese workers spoke a different dialect of Chinese. This Cantonese-speaking participant had to learn Mandarin from her co-workers so she could talk to them.

Some participants were highly acculturated – or attempting to become so; they had a fairly high level of interaction with non-Asians, equal to or surpassing their interaction with Asians. Some explicitly expressed a desire to improve their English proficiency. For example, one participant mentioned preferring to watch English-language television with closed-captioning in English so he could improve his English-speaking ability; another was taking English classes.

Barriers to and Facilitators of Testing and Entering Care

Language and cultural barriers may be related to late testing and late entry into care. The API Quantitative survey showed that 36% of participants had self-reported major medical problems[1] when first receiving HIV medical care, compared to 21% for the CHAIN New Baseline cohort, suggesting delays in HIV testing and entry into care. This high rate of major medical problems at time of first HIV medical care is consistent with findings from previous analyses of epidemiologic data[23] and indicates that a focus on getting APIs tested and into care is of critical importance.

API participants in the quantitative survey were more likely to report barriers to care as compared to individuals in the CHAIN New Baseline cohort. (Because the survey asked for barriers "ever" experienced, it is not possible to determine whether the barriers were experienced recently for the first time or during ongoing care.) Fifty-two percent (52%) of the API participants reported at least one logistical barrier to medical care and social services, and 31% reported at least one provider barrier, compared to 12% and 12%, respectively, for the CHAIN New Baseline cohort (see Appendix, Table 3-5). In terms of logistical barriers, more APIs reported language barriers (11%) and cost barriers (34%), in

comparison to the CHAIN New Baseline cohort (for whom the rates were 1% and 4%, respectively). The most frequently reported provider barrier was that staff were disrespectful or insensitive (14% of API participants reported this barrier, compared to 7% in the CHAIN New Baseline cohort), which may reflect the perception of prejudice or discrimination or different cultural expectations regarding demonstrations of respect.

Given that more than half of the API Quantitative cohort preferred to receive services in languages other than English (see Table 2), it is surprising that only 11% reported language barriers. This may be an artifact of our recruitment, which occurred primarily through API-targeted AIDS service programs with solid language assistance programs, or an indication that the current system of concentrating services for specific populations within a few organizations may be an effective approach. The effectiveness of such a system requires the larger network of providers to be aware of and able to refer to these specialized API-focused services. (Language issues are discussed in more detail in the "Language and Culture" section below.)

The qualitative interviews provide more details on the ways that delayed entry into care occurred. These stories are instructive for addressing needs of the wider HIV positive API population, which may include many individuals who remain untested or not in care. A number of qualitative interview participants spoke of only being diagnosed with HIV after becoming very ill. In some cases, this was because of participants' own reluctance to seek care; in others, it was because the doctors they saw did not test them for HIV and provided inappropriate treatment.

For example, one participant, a minimally acculturated Chinese heterosexual male, had gone to a local doctor in Chinatown who did not screen him for HIV despite his declining pulmonary condition. Instead, the doctor treated him for asthma. About a week later, he was taken to an emergency room by a police officer who found him unconscious in Times Square. He was found to be HIV positive and remained in the hospital for 21 days.

Below are some additional examples of the self-reported health status, symptoms and experiences of the qualitative interview participants at the time of testing.

- "Deathly ill"
- Broke out into a rash
- Fainted on street and taken to hospital
- Had shingles
- Went to five or six doctors feeling sick; finally tested for HIV by a seventh doctor

The woman described in the last bullet was about 60 years old at the time of diagnosis in 1997, suggesting that her doctors may not have suspected HIV because of their assumptions based on her ethnicity, age and gender. Her doctors were apparently Chinatown doctors with general private practices who were not highly aware of HIV, although the doctor who tested her for HIV was also a Chinatown doctor. Previous studies have reported Asian immigrants' preference for seeing co-ethnic doctors in their neighborhoods because of shared language and fear of being reported to immigration officials; these doctors may not have sufficient training in recognizing symptoms of and screening for HIV.[24]

The stories of entering care illustrate the important role of HIV services specifically targeted to APIs, such as those provided by APICHA and CPC, and the importance of strong referral relationships with hospitals. In most of the stories, if participants were diagnosed with HIV in New York City after APICHA and CPC began providing case management services (about 1996), referral to these agencies by the hospitals happened almost immediately, thus connecting participants with much-needed language interpretation and support at a time filled with fear and disorientation. In some cases, however, participants had to self-refer. For example, soon after testing HIV positive, one participant heard about a

Chinese organization serving HIV positive individuals (CPC) on Chinese radio. She went there right away and became a client.

The stories also indicate the important role of friends in initiating the care that would lead to an HIV diagnosis. Even in cases where the friends were not told of the specific diagnosis, they were often instrumental in encouraging participants to go to a doctor or hospital. Those participants who were active in the gay community appeared to have access to additional HIV-related information and resources, presumably because of the high visibility of HIV in that community. One participant, for example, mentioned the local gay media (generally available only in English) as helpful in finding the services he needed. Another mentioned choosing a gay doctor for a check-up, confident that he would be screened for HIV:

> *…I went to a gay doctor because I wanted to be open about that and my health…. Who[ever] goes there, I think they're screened [for HIV] because it's a…predominantly gay population that they work with.*

Medical Care Utilization and Adequacy of Care

Because of the way the sample was recruited, there were few reports in the qualitative interviews of problems with staying in medical care after finally entering care, and most reported seeing their HIV specialist every 3 months. The quantitative data were consistent with this, with 100% of the API Quantitative cohort having a medical provider (compared to 97% for the CHAIN New Baseline cohort). The quality of care received by API participants, however, appears to vary. Only 35% of the API participants had medical care that meets "preferred practice guidelines," compared to 74% for the CHAIN New Baseline cohort (see Appendix, Table 2-2; "preferred practice guidelines" refers to an index based on the number of primary care visits within a 6-month period and the report of a complete physical exam and lab work; expected number of visits is contingent upon t-cell count and whether respondent was currently on HIV antiretroviral medications.). Forty-three percent (43%) of APIs experienced a service gap for "comprehensive medical care" as compared to 24% for the CHAIN New Baseline cohort (see Appendix, Tables 4-1 and 4-2; "comprehensive medical care" is based on the respondent reporting that his or her medical provider: provides well-care visits, is available to discuss health issues, is available 24 hours a day either directly or through a service or beeper). Participants' reports of sub-optimal care may be the result of not understanding the range of services available or a perception that they could not access the services even if they were aware of them, possibly because of language or cultural barriers.

The qualitative accounts of API participants' difficulties with their ongoing care are instructive. As described in more detail below, some of the participants' feelings of being disrespected may be related to their sense of being discriminated against because of their race/ethnicity or because of their low level of English proficiency. They may also have higher (or different) expectations regarding appropriate styles of communication or interaction. Other participants described other unsatisfactory aspects of their care experience. One participant, for example, complained of feeling rushed during medical exams, preferring that the physician spend more time with him explaining his health status. Another complained that his relationship with his physician was impersonal: "Even though they say they're HIV specialists, . . . I find . . . they are treating my HIV, my virus, they're not treating me." A number of participants reported long waits or neglect in emergency rooms.

One participant complained that it was difficult to coordinate medical appointments with his work schedule. Many of the participants worked in low-wage informal sector jobs, such as in restaurants and garment factories, with long hours and few (or no) benefits and employers who were intolerant of requests for time off. Some reported having worked extra hours to pay off debts to smugglers', which one participant reported as being $26,500 in 1990 and another as $50,000 in 1997.

Although both documented and undocumented participants appeared to have fairly consistent access to at least some form of medical care because of ADAP, one obvious limitation of ADAP is that it supports

only HIV-specific health care, leaving undocumented immigrants (and other immigrants who are ineligible for Medicaid) without general medical care. Participants who were ineligible for Medicaid because of immigration status complained most consistently about dental services. One participant, for example, complained that he had to wait a month for a dental appointment at the community health center he was referred to, even though he was experiencing tooth pain. APICHA was able to use emergency funds to send him to a private dentist for the urgent care. Another participant discussed going to an unlicensed dentist, despite his concern about unsanitary conditions there, because dental services were not covered by his insurance. One participant was sure that she was infected with HIV by an unlicensed dentist who did not sterilize his equipment.

Despite barriers and negative perceptions of care, participants' overall rating of their medical care in the quantitative survey was fairly high (83% satisfied, compared to 87% satisfaction rate for the CHAIN New Baseline cohort). Respondents' perceptions of the superior care available in the US as compared to their countries of origin may have been a factor in rating care as satisfactory; this perception can also be a motivator for staying in care:

> *First, here it's like medications [are offered] for HIV, and you get all the cares that you can, that you needed. Like in the Philippines when you needed something and you don't have no money, you just die in your bed without having those like...medication and anything for infection.*

Utilization of Support Services, Support Service Needs and Gaps

In the quantitative survey, 87% of API participants exhibited a need for case management services (regardless of whether they were receiving the services), compared to 40% for the CHAIN New Baseline cohort (see Appendix, Table 4-2). This may reflect greater support and service navigation needs among APIs resulting from stigma, isolation and language and cultural barriers. Because we recruited primarily through APICHA and CPC, most participants were relatively well-connected to support services. Almost all participants in the qualitative interview had a stable case management relationship with APICHA, CPC, or other organizations. In the quantitative survey, 31% of APIs experienced a service gap in comprehensive case management, and only 13% of APIs experienced a service gap in counseling case management, as compared to 40% and 39%, respectively for the CHAIN New Baseline cohort.

Although most participants recognized the importance of support services, some indicated that their need for support services was low or limited to particular services, such as food vouchers. Some participants seemed to comply with social service agencies' requests either out of dependency or gratitude to the social service agencies that had helped them. This form of compliance sometimes appeared as a kind of passivity towards one's own care, possibly arising in recognition of the difficulties of navigating the service system in the face of language and cultural barriers:

> *"Whenever [staff at the social service agency] tell me to come, I definitely come."*

The range of support services and providers accessed by participants with the help of APICHA and CPC, or on their own, included: food stamps, city financial assistance, emergency financial assistance from AIDS Service Organizations, legal assistance (APICHA, AIDS Center of Queens County, Gay Men's Health Crisis and HIV Law Project were specifically mentioned), nutrition programs (nutritionists, food pantry programs), support groups, transportation services, escort to and language interpretation during visits with service providers. Participants who accessed support services without the help of APICHA or CPC tended to have greater English proficiency.

Qualitative interview participants identified unmet needs in several support service areas. Each of these areas listed below was mentioned by several participants.

- *Rental assistance/housing:* This was mentioned by several participants. Although all were housed in some manner, some were living in sub-optimal or unstable conditions and some had previously

been homeless. For example, one participant lived with three other people, and two of them smoked; one lived in a place that he could no longer afford; and another was "kicked out" of his apartment by his partner and staying temporarily with friends. Some participants reported that finding adequate housing was more difficult for immigrants. Providers interviewed as part of this study confirmed that New York City public assistance, including housing assistance, was limited or not available for undocumented immigrants or immigrants who were not permanent residents or naturalized citizens. Consistent with the qualitative interviews, the quantitative survey showed that of the 9 API participants showing a need for financial housing services, none of them received such services (see Appendix, Tables 4-1 and 4-2).

- *Financial assistance and job training:* Although financial difficulties were implied by many participants, several explicitly discussed needing financial assistance or not having adequate financial resources because of lack of employment. One participant wished for assistance to find employment that would accommodate his weakened physical state. At least two gay male participants discussed resorting to sex work to support themselves. In the API Quantitative survey, 35% of participants reported having financial problems, and 28% reported having job-related problems, compared to 24% and 8%, respectively, for the CHAIN New Baseline cohort. In focus groups and interviews, providers and consumers noted that to find jobs, APIs living with HIV needed English-language and job skills training. Providers noted that standard ESL classes may be too advanced for many of their clients.

- *Immigration:* Several participants mentioned needing assistance with immigration issues, such as processing permanent residency or asylum applications. This is not surprising given that so many of them were undocumented. The need may, in fact, be greater than indicated in the interviews. When one undocumented participant was asked if he needed help with immigration-related problems, he responded, "I don't think about things out of my reach."

- *Alternative pain management:* Several participants mentioned wanting massage to help with muscle soreness and other bodily pain. One participant was prescribed medication for pain but felt that she was already taking too many pills. Another wanted a regular massage because of his belief in its healing power: "…I think touch is…one of the most healing things, so I used to get massage once a week, but it's quite expensive actually." In some cases, it appeared that participants thought of the healing touch of massage as important for their mental health, perhaps equivalent in their view to conventional mental health services, such as psychotherapy. Because APICHA offers free acupuncture services to clients, many of them availed themselves of that service, which for some clients played a role similar to massage. Unfortunately, providers reported that, given funding restrictions, clients are offered acupuncture sessions only once every two weeks, whereas once a week would be more therapeutic. Providers also reported that CARE Act funds cannot be used to support acupuncture services and that State monies are used instead.

Other needed services mentioned were mental health services and a women's support group. Because prevalence rates are relatively low and there are relatively few Asian women open enough about their HIV status to feel comfortable in a group setting, it has been difficult to start a support group for Asian HIV positive women. Some Asian women receiving social services may not want to see each other in a group due to confidentiality concerns. Language barriers are also a problem. If there are only a small number of Asian women who are interested in a support group, it is not likely they will all speak the same language. Scheduling difficulties as a result of family care responsibilities (as well as work outside the home) may also be a barrier to starting a group. CPC staff, however, reported that the agency has been successful in starting an HIV positive women's support group, which is attended by five Cantonese-speaking women and meets approximately once every two months. Our experience with organizing the API women's focus group for this study was that the women who participated enjoyed talking to each other, even though they had never met together in a group previously. Their willingness to participate in the focus group suggests that agencies may have better luck with recruitment if they bring women together with a stated purpose other than "support."

HIV Knowledge and Treatment Adherence

CD4 count and viral load

Despite the fact that almost all of the study participants had an HIV medical provider and were in case management services, as a group they had low levels of knowledge about HIV. Eleven percent (11%) of the API Quantitative cohort did not know their CD4 count, compared to only 2% for the CHAIN New Baseline cohort. Low knowledge may be related to treatment adherence problems. Only 56% of the API Quantitative cohort that was on HIV medications reported being completely adherent, compared to 72% for the CHAIN New Baseline cohort (see Appendix, Table 2-3).

Knowledge levels may be related to level of acculturation and English proficiency. Although there were exceptions, it appeared that qualitative interview participants who were less acculturated and had lower English proficiency had lower levels of knowledge about HIV, possibly because there is less information available in languages other than English. English speakers tended to have more detailed and exact knowledge about HIV.

Although some qualitative interview participants knew practically nothing about HIV, most participants at least knew that HIV was related to weakening the immune system. Beyond this, knowledge was often very partial, imprecise, or incorrect. One participant, for example, had only a vague idea of what viral load and CD4 count were, but he knew that one indicator should be low and one should be high to be healthy. Another participant believed HIV medications were a cure for her HIV because "they cannot find it," referring to her undetectable viral load. One participant said that his viral load will increase if he "goes out and fools around" and that it will "for sure increase" if he has sex without a condom.

Passivity about one's own care, arising from language barriers, may have been a contributing factor to low knowledge for at least one participant, who said that his doctor prepares a report on his lab results and gives it directly to his case manager. Low knowledge may also be related to general denial about having the disease. When asked about his understanding of viral load, one participant said: "Viral is… I do not know clear. I just feel tired once they mention the disease. I feel tired. If you do not talk (about AIDS), I am fine. If you talk, then I begin to think a lot so that I feel tired."

Partial knowledge can be a source of anxiety. One participant knew just enough to be afraid when his viral load increased. This fear was intensified by premature media reports of the spreading of a form of HIV infection that rapidly progresses to AIDS and then to death.

> *"…the other day, [I heard about] this new HIV thing going on [rapidly progressing virus]… I just found out about it five days ago, that…there's such a virus going on, and I thought, oh my God, don't tell me because suddenly my number [viral load] went up like a hundred-fold. You know what I'm saying, and that really freaked me out…I don't want to die. Not yet."*

HIV transmission and prevention

Study participants had similarly varying, but mostly low, levels of knowledge about HIV transmission. Most participants knew that HIV could be transmitted through blood and sexual activities, but many were unsure about maternal-child transmission. Sharing needles was mentioned occasionally. One participant said that transmitting HIV through sharing needles depended on how long one keeps the needle in.

Language and Culture

Although all participants in the qualitative portion of the study were recruited through organizations with a specific Asian focus, there was some variation among them with regard to stated preferences for Asian providers. With very few exceptions, participants with low English proficiency favored having a medical provider who spoke their primary language. The number of languages represented in the API community, however, poses a significant challenge to institutions trying to meet their linguistic needs. In our qualitative sample of 35, 15 different languages were spoken, including 5 distinct Chinese

languages/dialects, Korean, Japanese, Bengali, and Gujarati. Languages of the Philippines, Indonesia, and Cambodia were also represented in this relatively small sample.

Attitudes about shared culture and ethnicity between provider and consumer were less consistent than attitudes about shared language. As described in more detail below, some qualitative interview participants preferred seeing non-API providers for fear that API providers would not respect them or their confidentiality. Others did prefer API providers, feeling that shared cultural traits facilitate improved comfort and understanding. Many participants commented on other provider characteristics that were apparently more important than language and ethnicity. These included clinical competence, compassion, efficiency, and site characteristics such as location and operating hours. Regarding support services, participants generally expressed positive views of the API-targeted organizations that were our primary recruiting sites, and of their staffs and the services they provide. (Because many interviews took place at these agencies with their cooperation, views expressed about them may have been biased.)

Below we discuss issues of language and culture in more detail with regard to medical providers, and then separately in relation to social service providers, as the issues and concerns are somewhat different.

Issues of language and culture with medical providers

Reliance on interpreters

Both CPC and APICHA have staff that serve as interpreters for medical appointments and who are able to translate forms and other written documents. Many participants with limited English language skills used these services, primarily for their HIV medical appointments. Several would have preferred to communicate with their doctors directly: they expressed occasional difficulties with scheduling interpreters, felt guilty about asking for help and taking up staff members' time, were embarrassed that the interpreter would learn their HIV status and would be hearing personal information about them, or worried that information was lost or miscommunicated in the interpretation process.

> *"Of course it's better seeing a Chinese doctor. You don't need a translator! You can just say whatever you want without having to go through another person."*

One participant commented that he was embarrassed to talk about certain topics when he has a woman interpreter. When he had a sexually transmitted disease, he went to the doctor without an interpreter, telephoning CPC when he did not understand something the doctor said. Another felt he was treated differently than English-speaking patients.

> *"Because I am Chinese and do not understand the language, they ignore me. When an English speaker meets a doctor, they can chat a little bit. But I am ignored. This kind of thing happens."*

A number of patients from CPC spoke very highly of a doctor they all saw at Bellevue Hospital. Although he did not speak their language, and interpreter services were required, they valued his knowledge, skills, patience and compassion.

> *"He's very concerned about me, and he seems to care a lot. He asks me how I've been recently, and he tells me not to smoke, not to drink. He has a good heart. If he didn't care, he wouldn't tell me not to smoke or drink."*

> *"This doctor's very good. He's very careful; he enters all our information into the computer. He said my white blood cell count and red blood cell count are both good, as are my lungs and liver. This doctor, he has very much the professionalism of a physician. As he types into the computer, he explains to me, and tells me not to worry…He is very careful.*

Communication challenges for individuals with Limited English Proficiency

Although few participants claimed English as a first language, a portion were comfortable enough in English to utilize English-speaking providers without an interpreter. Those among this group with still limited English-language skills felt that communication and service delivery was compromised due to language barriers. A Filipina commented that she would be able to ask a Tagalog-speaking doctor more extensive questions and is not able to find the right words in English. A Japanese participant felt that, although he could understand 80% of what he hears in English, he was unable to explain his symptoms clearly enough. A participant from Indonesia had difficulty with technical terms. Early in the course of his treatment he agreed to whatever was recommended, essentially because he did not understand. Later, he changed his approach, refusing a recommended diagnostic procedure due to lack of understanding.

Yet others were satisfied with English-speaking providers. One person felt that the care he got was by now so routine that the need for extensive communication was minimal. Another commented that he preferred an English-speaking doctor because "the science language is English…all this research, everything's coming out in English."

Cultural concordance

Overall, there was no clear consensus among participants regarding the advantages of patients and providers sharing a culture. Some did prefer a shared culture, feeling that it facilitated enhanced communication.

> "More understanding,…easier…to understand what you're trying to say, where you're coming from, how you come to such a conclusion on certain things, on certain topics, and it's easier for, for the other person to understand or try to understand better, easier for them to step into your shoes."

A few commented that Chinese doctors would care more about their fellow Chinese than "American" doctors would. They felt discriminated against and ignored by non-Chinese doctors, and in one case a pharmacist.

> "When you go into the hospital, they will just treat us more inferior. If I want the doctor to come over, I will need to call him 3 or 4 times before he comes over. They don't pay attention to you."

Others expressed a different view, feeling that Asian doctors would be discriminatory due to deeply held prejudices against people with HIV. Several participants feared that a doctor who was from the same community would tend to spread gossip in the community. One respondent commented that a provider who shared the patient's culture may too easily understand things that the patient would prefer to keep vague.

Cultural barriers. For several participants the issue was not cultural similarity as much their own culture, particularly its emphasis on respect and deference to authority, and how their cultural training did not always serve them well in a medical context. One respondent explained:

> "We don't really say exactly what we want, and then the doctor might not exactly know what we want, and then they're just assuming that we don't want... Or maybe like, like we don't like to question a lot. If we do question a lot it's sort of like we're afraid that might bother them, you know… – it's like a lot of trouble, you know. We don't want them to think that we are, you know, troublesome so then we don't ask. I even sometimes have that, you know, even though I think I might be Americanized person, 'oh okay this question I shouldn't ask too many questions,' you know, like that."

It is not clear from the interviews whether participants felt that an Asian provider, knowing the culture, would be more proactive in terms of probing for problems or providing information that the patients may be hesitant to request.

Competing concerns

Many participants had experience with multiple cultures, either in their home country, in their travels, or in the US, and several commented that they could adapt to cultural differences. Some of these participants described other concerns as more significant than cultural concordance. In some cases these concerns were even more significant for these participants than language concordance. For example, two women noted the importance of having a woman doctor. One is currently seeing a male doctor but avoids telling him personal information about her body. Several gay men emphasized that a doctor's understanding of the issues around their sexuality was more important than understanding their ethnicity. Most of these men felt that Asian doctors were less likely to be accepting of their sexuality as compared to American doctors. One man, however, held a somewhat different view, commenting that an American doctor would not understand the difficulties of being gay in Asian society.

Issues of language and culture with support services

Preferences regarding language and culture of a medical provider may differ considerably from preferences regarding language and culture related to support services. Whereas technical competence may sometimes trump other concerns for a medical provider, verbal communication is key to effective case management, counseling, and other social services. Individuals with limited English proficiency may also have a greater need for language assistance in the social services arena because they may have difficulty completing forms in English even if they are able to converse adequately in English.

The comfort of shared culture and language

For the qualitative interview participants, most of their experiences with social service providers who spoke their language or shared their culture occurred at APICHA and CPC. Because participants by necessity were recruited almost entirely from these two CBOs, and several interviews were conducted by staff from those agencies, it was difficult to derive unbiased views of these organizations. Participants, however, spoke convincingly of the positive experiences they had in these programs. Among those sampled, which included several highly assimilated participants, shared culture and background seemed highly valued. Participants talked about a general comfort they feel due to the Asian focus of the organizations. One participant who had received services from a non-API AIDS Service Organization, felt excluded there. The API-focused organization was more comfortable to him.

> *"Yeah it is just because basically everyone's Asian, just to, you know, kind of like feel comfortable that they know our culture a little bit more than – the same background I guess…I'm not sure, but somehow the skin color makes us comfortable I guess."*

As the quotation above suggests, the comfort was not always dependent on an exact match between culture and ethnic background. For some, it was based on shared racial background. As one Chinese participant put it:

> *"I just found out [my provider] is Japanese…I said [he] was Chinese too. Everybody is Chinese to me."*

Beyond the level of comfort, Asian-focused community organizations offered or made referrals for the range of services commonly needed by APIs, including translation and interpretation services, literature provided in multiple languages, and services for undocumented immigrants.

The comfort of shared ethnicity and culture was a drawback for some participants, at least initially. One gay Indonesian participant said that he was afraid that if he went to an Asian-focused HIV organization, he might see some of the same people he sees at a gay bar that is popular among APIs. He eventually got over this discomfort and went to the Asian organization and was comfortable with the environment.

Lack of language resources

Unfortunately, even within API-focused agencies, language resources were not "deep" enough for some of the smaller language populations. One Bangladeshi couple who participated in the study said that there is only one person at their API-focused agency that can interpret for them. When that person is not available, it is difficult for them to get services. Because API-language speakers are relatively scarce in the service environment, staff of API-focused agencies tended to play multiple roles in participants' care, including interpreter, supportive counselor, escort to services, advocate, HIV prevention educator and treatment counselor.

Because of the lack of language resources in the general service environment, agencies may routinely refer API clients to APICHA and CPC without adequately consulting with the client. One study participant felt discriminated against when a provider told him to go to an Asian-focused agency for services because he was Asian. The participant felt that he should have been able to receive services where he was.

The general lack of language services may make APIs living with HIV more reliant in general on case management services, and also may make their cases more complex, as compared to other ethnic/racial groups. The quantitative survey showed that 94% of the API Quantitative sample had a case manager, compared to 74% of the CHAIN New Baseline cohort. Of those who had a case manager, APIs were more likely to have more case managers, with an average of 1.68 case managers per person compared to 1.48 for the CHAIN New Baseline cohort.

Food and scheduling

Other more concrete issues related to shared culture were raised by participants. For example, one participant who was a resident in a homeless shelter complained of cultural insensitivity with regard to food and scheduling. He was offered a hearty breakfast of eggs, bacon and ham in the morning, but he longed for rice porridge. He engaged in ancestor worship rituals in the morning, but because of the shelter schedule, which requires that residents be off the premises during the day, he had to finish these rituals very early in the morning. Food in particular is an issue that the API AIDS organizations we recruited from were very conscious of when thinking about creating culturally competent services. APICHA, for example, has a food pantry program that includes staple Asian foods.

HIV Stigma, Disclosure, and Isolation

Reluctance to disclose one's HIV status because of HIV stigma was a major theme in the qualitative interviews. Many participants experienced extreme social isolation because of their fears about disclosing their HIV status and the sometimes negative responses they received when they did. Unfortunately, as described further below, the social isolation appears to have had significant negative mental health consequences. For many participants, the level of isolation and distress was most severe more immediately after diagnosis, gradually decreasing as they developed new support systems. For others, however, isolation and attendant mental health problems continued many years after diagnosis.

Participants gave two basic reasons for being reluctant to disclose their HIV status to others. First, they did not want to be a burden to others and cause them to be unhappy:

> *"Telling one more person just means that one more person will have a hard time. I want my friends to be happy. I want everybody to be happy, so I don't tell them."*

> *"If I told people, everyone would suffer, so I didn't say anything. I'll be the only one that suffers."*

The desire not to cause others to worry was particularly strong with regard to parents, especially if parents were elderly. In a similar vein, one participant said, "the only way I know that you can be bad to your parents…[is to] pass away before your parents."

Related to the theme of not causing others to worry was the fear of infecting others, which intensified some participants' tendencies to isolate themselves from others. This was also found in a previous needs assessment study of APIs with HIV.24 Some respondents allowed this fear to affect their social behavior even though they knew that HIV could not be transmitted through casual contact and knew their fear was irrational:

> *"I'm afraid that...I will accidentally infect someone else. That's why I usually decline invitations to lunch or dinner."*

The second major reason for not disclosing HIV status was that participants feared rejection and discrimination because of HIV stigma. They thought of stigma as being related to (a) others' fear of HIV infection through casual contact, and (b) others' perception that a person who is HIV positive had engaged in "shameful" or "lewd" behavior.

> *"Everyone is scared of this [HIV]. As if by seeing me they will get HIV...They think AIDS patients are very lewd."*

Most study participants perceived a tremendous amount of HIV-related stigma in their environments. Participants often based their assessments of the level of stigma on comments made by colleagues, friends or family members who were unaware of participants' HIV status. Asked about how she thinks individuals in her community feel about HIV, one participant said:

"They seem to have a violently adverse reaction to this disease. Whenever someone mentions it, they get very scared. They're so terrified of it...I hear people making jokes, for example: 'Don't drink my water; if you have AIDS, I'll get it too!' and so on."

Actual enacted stigma (e.g., experiences of actual discrimination) also occurred, but were less frequently reported, possibly because participants were very cautious about disclosing their status. Many participants felt that HIV stigma was worse in API communities than in other racial/ethnic communities. One participant said:

> *"If someone finds out [about my HIV status], it won't be good. Chinese people are not as open as American people. They're very much more conservative. Not even your family member will forgive you."*

Fear of disclosure was fueled by the perception that gossip about their condition would spread quickly through the community and that they would "lose face."

> *"...I'm afraid of letting my colleagues, my friends, my relatives, or other people from [my home town] know [about my HIV status]. If they find out, it's over...If my brothers and sisters and other relatives find out, there will be no meaning in life...Everyone wants 'face.' If...you get this disease, and then all your relatives and friends find out, you'll never see them again."*

According to one participant, stigma in API communities is fueled by religious beliefs: "Homosexuality, and, of course, AIDS is worse. You deserve that...that's God's punishment, probably that's their attitude."

Sadly, because of stigma, a number of participants said that they had not disclosed their HIV status to anyone in their personal life, and that only their social and medical service providers knew of their status. Other accounts by participants, however, illustrated a range of levels of disclosure and acceptance by family members and friends. Some participants disclosed only to immediate family (e.g., spouses, parents, children); others disclosed only to friends (this seemed more common among men who identified as gay); and in rarer cases, some participants disclosed to practically everyone they knew. To illustrate the range of experiences, several accounts are provided below, ranging very low to high disclosure.

No disclosure outside of service environment

Except for his physicians and case managers, no one knows that this participant is HIV positive. He said that this situation is not hard for him and that he chooses it. Although he believes that his daughter would treat him well if she knew of his HIV status, he does not plan to tell her because he wants to "keep face." He said that his daughter thinks of him as a very serious person and would be disappointed if she thought he was the kind of person who could get HIV. He thinks other people would have a very negative reaction if he told them, and he does not feel like he could count on their support.

Partial disclosure within heterosexual East Asian couple

Both partners have HIV, have not disclosed their HIV status to anyone else, and rarely discuss HIV themselves.

> *Interviewer: How often do you talk about AIDS each month?*
>
> *Participant: We do not talk about it.*
>
> *Interviewer: From 1997 to now?*
>
> *Participant: No, we never talk about it.*
>
> *...*
>
> *Interviewer: Do you see doctors together?*
>
> *Participant: No, we go to different hospitals.*

Partial disclosure with a negative reaction

This participant had told no one except his service providers, his wife, and a friend about his HIV status. After disclosing, the friend did not want to see him anymore, and the participant and his wife are separated because of his homosexuality. The participant has a 26 year-old son who does not know about his HIV status: "I told my wife to lie to my son forever. Unless I am dead, she cannot let him know. . . . I depend on him for a living now. I need him to survive now. He covers my expenses." The participant said that he knew that his son held discriminatory attitudes about people with HIV because when they lived together and were watching Taiwanese television, an HIV-related commercial appeared and his son made disparaging remarks.

Heterosexual South Asian couple, where both partners are HIV positive, disclosed their status to some family members but remain very isolated

This married couple discussed their increasing isolation resulting from their both being HIV positive. They no longer socialize because of their fear of disclosure. For the same reason, they stopped attending the Hindu temple where they are members, even though religion is very important to them, especially for the wife, who is very religious and prays every day. The husband tells their neighbors that the HIV service providers who came to visit his home were there for his eye problems. Aside from service providers, they have disclosed their HIV status only to their two daughters. While the daughters (who are grown, with children of their own) have been somewhat supportive, they have also made hurtful remarks. For example, the woman had been taking care of her daughters' children, but after disclosing her HIV status, the daughters asked her not to bathe the children and to limit physical contact with them because they feared the children would be infected.

Partial disclosure to family members with supportive response, although with continuing isolation from community

This participant's husband had AIDS; he died after they both came to New York City. The husband's family knew he had AIDS and also learned that the participant was HIV positive, although the participant did not disclose her status to them. Some family members have reacted supportively. For example, the

participant's brother-in-law continues to care for her. The participant's daughter, who was planning to move to the US with her husband, also knew of the participant's HIV status. The participant was making plans to discuss her HIV status with her son-in-law so that he would not feel afraid of her. She seemed optimistic that her daughter and son-in-law would be supportive of her. However, the participant believes that a number of people in her community have become aware of her HIV status and that she is being stigmatized. She said that no one at her temple talks to her. She also said that in her community it is understood that no one should spend time with or eat with someone who has HIV, so she cooks all her own food and spends most of her time alone. She said that when she was sick and hospitalized no one visited her. She spends most of her time praying and going to her temple.

Wide disclosure of HIV status with supportive reactions

This participant told many of his family members about his HIV status, both in the US and in his country of origin. His comments suggest that the success of HIV treatment may facilitate disclosure since it may reduce family members' worry about the person's health, at least when stigma is not the main issue.

> *"I told my younger sister. And other than her, I also told one other family member, my aunt. I used to live with her. I told my parents as well. They live in Cambodia...I had explained to them what the disease is all about. Before, I had thought that I would only be able to live 3 to 5 years. Then, the doctor told me that if I take this medicine, I can still be able to live for a long time, like 15 to 20 years. I told my family not to worry about my life; I asked them not to make me worry...I have doctors here to take care of me, so they have no need to worry. I asked them to take care of themselves; I will be fine as long as they don't make me worry...They took it quite well.*

He continued:

> *I have [family members] in Virginia. They have no children but I used to live together with them. I just told them [about my HIV status]. My great aunt is very nice, try to help me, she doesn't understand, and she doesn't believe that there is no medication, no doctor to help the HIV people, you know. And she asked her brother, sister, and she talked to everybody. So I have a big family in Virginia, all they know. So that's too many. Big family, too many. I don't want to say to too many [people]. When they hear HIV people, they're very, very [scared]. She said she didn't know that. She knows now. I said [to her], 'HIV or AIDS is very confidential...you cannot tell anybody, I can sue you [laughter].' She says she's very, very sorry and she very regrets, and she understand...She tried to help me you know...Five aunt and three uncles, and all of them know my situation."*

His partly humorous account of his great aunt's disclosing his HIV status to other family members seems to indicate a fairly high level of comfort with disclosing his status, even though he expressed concerns.

Full disclosure

When this transgender (male-to-female) participant first learned of her HIV status in 1990, she worried that others would find out and that her business would suffer. She was nervous about going to clinics for treatment or taking her medications, as others might see her and guess that she was HIV positive. Over the years, however, she disclosed to more people, and in 2004, with the disclosure to her sister, came out completely to everyone important in her life as an HIV positive transgender woman. She said that all her friends and family, including her parents, have been supportive of her. She acknowledges that "coming out" as HIV positive and a transgender woman is an ongoing process and handles it straightforwardly:

> *"So even though I'm totally out to basically all my friends and everyone I know, ... if I go to the bars or whatever, the clubs, if someone approaches me, I'll tell them two things. I [say], 'before you waste your time or you waste my time, you have to know two things*

about me, and then you tell me if you want me to stay or you want to go. I'm HIV positive. I'm transgender.'"

HIV Stigma as a Barrier to Care

Stigma creates not only social problems and isolation, but also acts as a barrier to care and adherence. Several participants mentioned having difficulty taking their HIV medications because of HIV stigma. One participant said that on his trip to China, he stopped taking his medications because he did not want the hassle and was afraid that someone would learn about his HIV status. When he returned to the US, his doctor told him that not taking his pills had had a negative impact on his health. Another participant said that she throws her medication boxes away so no one will see them. Some participants who said they were reluctant to take pills at work because of fear of disclosure said that this is less of a problem now with new treatment regimens that involve fewer pills and fewer doses.

A related issue was reluctance to take off work to attend medical appointments. This may be a particular problem for APIs working in low-income, informal sector jobs, such as garment factories or restaurants, which may not offer sick leave. One participant said that when he has to take time off from work for medical appointments, he lies and says his wife is sick or makes up a similar excuse. He worried that if he misses too much work, his employers and co-workers will get suspicious. This has negatively affected his ability to get the care he needs.

Importance of Community Education on HIV to Reduce Stigma and Misinformation

Study participants often perceived API communities to have poorer HIV knowledge and to carry more stigmatizing attitudes about HIV compared to other communities. They felt that community education – through ethnic Asian-language newspapers, television and radio, the internet, and door-to-door campaigns – would be an important part of efforts to improve HIV-related knowledge and reduce HIV stigma in API communities. Some participants noted that HIV stigma may be less intense now because of regular coverage of HIV in local ethnic media and in the media of their countries of origin, plus involvement of celebrities in the Asia/Pacific region in HIV awareness campaigns. Because stigma leads to isolation and poor mental health, and creates barriers to care, such awareness-raising campaigns may have a substantial impact on the health and quality of life of APIs living with HIV/AIDS.

Some of the participants' comments in the qualitative interviews illustrate how HIV education can help improve relationships. When a participant was asked how HIV has affected his relationship with his children and with his HIV negative wife, he said:

> *"Because we have all listened to APICHA's and the doctors' explanations, we know that sexual activity can transmit the disease. We take care to use condoms...Other things, like eating, we do together and don't think about transmission."*

While providing education on HIV transmission may reduce fear and thus reduce stigma in API communities, anti-stigma efforts will also need to address negative attitudes that API community members may have about people with HIV because of their perceived behaviors (e.g., homosexual sex, non-marital sex, substance use). As one participant put it, people with HIV are "shunned by community," not just because others are afraid of getting infected, but because of "how you get it."

Mental Health and Utilization of Mental Health Services

Stigma and the resulting social isolation may be factors in markedly low levels of mental health among APIs with HIV. In the API Quantitative cohort, 71% had low or very low mental health scores, compared to 50% for the CHAIN New Baseline cohort. Some qualitative interview participants were taking psychotropic medications and saw a psychiatrist regularly, some were in talk therapy and felt positively about those experiences, and some attended support groups regularly and thought of them as essential for

maintaining their mental health. However, given the high levels of isolation and mental distress expressed by study participants, relatively few had utilized mental health services. API participants with low or very low mental health scores had a 70% service gap for professional mental health services (compared to a 63% service gap in the CHAIN New Baseline cohort, indicating low mental health service utilization all around)(see Appendix, Tables 4-1 and 4-2). In key-informant interviews, providers explained that the barriers were both the clients' reluctance to seek mental health services and the lack of appropriate services. Even when mental health providers who spoke clients' languages were available, sometimes they were located far away from the client or did not accept certain forms of payment. Language matching is particularly important for talk therapies.

Some participants freely acknowledged their mental distress and explicitly expressed a desire to see a mental health provider. For example, one participant said that he was angry all the time since his HIV diagnosis and wanted to see a therapist. He has been told by his providers that he can get therapy, but none has been provided yet.

> *"...I need to go to therapy, talking with therap[ist] about my situation with HIV. I'm so angry sometime ...I'm standing [on the subway] ...hold[ing] the rail. Somebody says excuse me, I be like 'excuse me!' I feel angry with that. I don't know why it make me angry somehow...I feel angry with people like that. I don't know why. That's why I never like going out... [At home] I'm breaking things, everything. I'm totally afraid. And that make me scared sometimes."*

It was more common, however, for participants to minimize their mental distress and to express skepticism about the value of mental health services for them, even when they were clearly experiencing problems. One participant for example, was regularly experiencing insomnia because of HIV-related worries, but did not want to see a therapist or attend a support group, and maintained that she was basically doing fine emotionally:

> *"I worry about myself and my health, I worry about the virus, and I worry about my son, what he will do if I die... [I get] two to three hours of sleep a night at most. I go to bed at midnight, and I get up at 7 am, but I'm not sure when I actually sleep in the middle. Sometimes I wake up with a splitting headache... I try to stay very strong. I have the responsibility of raising my son, so I try to stay optimistic."*

Participants often said that concrete life improvements, such as starting HIV medications or getting a job were more important to them than receiving mental health services. Skepticism about mental health services was sometimes expressed as a combination of curiosity about mental health services, coupled with an incredulousness that talking to a therapist could be helpful. Some participants expected that a single session should cure their mental distress or solve many of their life problems. When this did not occur, they were disappointed.

A number of participants expressed discomfort about attending support groups. For some, it appeared that the group setting made them uncomfortable. For others, it was a matter of not wanting to appear needy in front of others. One participant, for example, explained that he would only consider attending a support group after achieving a greater level of "control" over his life, somewhat defeating the purpose of attending a group:

> *"I'm too proud to join such thing, okay, it's my pride, the Asian and their pride. Yeah. And secondly, I told [my case manager] I would join but I want to go in not to seek help but more to share my experience, and in order for me to do that, I will join when I know I'm in control, totally in control. . ."*

Other Coping Methods and Sources of Emotional, Social and Spiritual Support

Qualitative interview participants were able to describe a number of activities that helped them to feel better, other than support groups or professional mental health services. These activities included listening to music by oneself and allowing oneself to cry; watching television; shopping; spending time and talking with friends and spouses; calling family members in one's country of origin; talking to one's case manager or medical provider; having one-night stands; going to clubs; practicing yoga, meditation and aromatherapy; getting a massage or acupuncture; and staying hopeful for a cure. A number of participants said that the social events – such as dinners and holiday parties (as opposed to formal support groups) – at the social service agencies where they are clients, are an important source of social support for them.

One newly enrolled client at an Asian-targeted AIDS service organization said that it is comforting just knowing he has a place to go for help:

> *"Well, one thing…that is very, very important, … one of the most important, … is the knowledge that I know that now there's a place I can go if something happened. …That really, really settle a lot of worries to the point where, … before I joined this, being HIV is part of my worries, maybe top three. Now… [it's] like maybe the top ten instead of top three… So and that way it give me more focus on doing other things …"*

Many participants mentioned spirituality or a formal religious practice, including attendance at churches and temples, as important to maintaining their sense of well-being. One participant, for example, said that he goes to his Buddhist temple six days a week, where he receives a great deal of support from the minister and the few members he has trusted enough to tell about his HIV status. The API Quantitative survey data are consistent with the qualitative interviews. In the API Quantitative cohort, 54% said that religion or spirituality was important or very important to them; the same proportion prayed or meditated at least once a month.

Religious practice was a mixed experience, however, for many respondents, providing them with a great deal of support, but also highlighting their separation from their communities. One participant said that he goes to his Korean Christian church every day but no one there knows about his HIV status. Another participant prays every day to comfort herself, but she no longer goes to her Hindu temple because she fears discrimination. Stigma may provide part of the explanation for the difference found in the quantitative survey between the proportion of respondents who said that religion or spirituality was important or very important (54%) and the proportion who said they attended a religious organization or service at least once a month (29%).

In one case, religious belief led to a reduction in medication adherence. The participant explained that although her medication had unpleasant side effects, she had never skipped a dose in the past, before becoming more religious. However, she said that more recently her trust in God has allowed her to skip her medications periodically, and that in this way she has eliminated her side effects while still remaining healthy.

A small number of participants, mostly gay men, reported using substances to help them cope with being HIV positive. In the quantitative survey, 12% of participants were currently using substances, and 13% had formerly used substances (not including alcohol). One participant, for example, was using crystal meth. He would like to stop but said that it has been difficult because crystal meth makes it easier for him to have sex, and thus stopping his use would mean sacrificing his sex life:

> *"…I'm very dull, yeah, I don't even think about having sex. And crystal really make me have the mood to have sex… So you know, …you enjoy sex, … you want to do it more often. So that's why I had to start using more crystal… So right now, I'm sacrificing having sex to have a healthier life."*

Another participant said that using substances helped him feel like he did before he learned of his HIV diagnosis:

"I feel like when I use this, I don't feel like...myself has changed. I just want to be like before, like oh, I feel like this is me and it's no different than before."

Issues for Undocumented Immigrants

Undocumented immigrants experience negative economic and social consequences as a result of their immigration status. (Many of these problems are also experienced by documented immigrants who are not naturalized citizens or permanent residents.) Most undocumented participants expressed a strong desire to have their status legalized and expressed frustration at the lack of availability of legal services or opportunities for legalization. Not surprisingly, in the API Quantitative survey, 43% of participants reported needing help with legal issues, compared to only 11% for the CHAIN New Baseline cohort.

One of the most obvious vulnerabilities of being an immigrant is the more limited eligibility for public benefits. For example, to be eligible for Medicaid, one needs to be a US citizen or permanent resident (green card holder), an asylee or have PRUCOL status. (PRUCOL stands for "Permanent Resident Under Color of Law" and is sometimes granted to immigrants with HIV as a "compassionate" exception. Although PRUCOL status helps undocumented immigrants access certain benefits and relieves them of the fear of being deported, there are certain disadvantages to the status. For example, individuals with PRUCOL status are not permitted to re-enter the US if they leave the country, and PRUCOL status individuals permanently waive their right to apply for permanent residency. Providers interviewed in the study said that few lawyers are available to work on PRUCOL cases.)

While ADAP covers HIV care for undocumented and other uninsured immigrants, it is more limited than Medicaid in that it does not cover non-HIV-related conditions. Dental services under ADAP are also more limited as compared to Medicaid. ADAP, for example, will cover a tooth extraction, but not a crown or bridge, according to key informants. Providers also reported that ADAP does not cover psychiatric services or psychotherapy. (Providers noted that Medicaid is not much better, covering only 8 to 12 sessions.) In addition, undocumented or visa-holding immigrants are ineligible for City public assistance, and thus cannot access certain housing benefits that the City offers persons living with HIV. One study participant reported that he was especially happy lately because he had just received PRUCOL status, making him eligible to receive Medicaid and housing assistance, which allowed him to move out the shelter system.

In addition to having an impact on eligibility for benefits, undocumented immigration status was related to a profound sense of social isolation and separation from family. Because they feared not being able to return to the US if they visited their countries of origin, undocumented immigrants were often separated from family on a long-term basis, and many said that they missed their families badly. Some study participants said that if they were not HIV positive, they would move back to Asia permanently. Being HIV positive, however, they felt that returning home was not an option, since they would not have access to the medical care they needed to stay alive. One study participant's case illustrated this dilemma well. She missed her two sons in Malaysia but did not want to jeopardize her health by trying to visit them.

"Sometimes when we get to very sad topics... [Subject is crying.] ...I live each day as it comes, and I try to take care of my body. The thing that gets me upset...My sons are growing up so quickly, and I'm scared that they will learn wrong... My elder son cries when he prays. I ask him why, and he says that he prays that Jesus will bring his mother back to visit him, because I haven't been back for 6 years.

...

If I got this disease in Malaysia, I'd be doomed. I don't have enough money to see the doctor in Malaysia. Where would I get the money? Where would I even get such wonderful medications to...help me?"

Another participant said:

> *"...if you ask me how, how [HIV] has changed my life now, okay, one thing I know for sure...I was thinking maybe I should go home, but if I go home, I was thinking ...I could not get medication or whatever. If I stay here, I at least have that, yeah...I just, I really miss my family. I really, really miss my family."*

Undocumented individuals have limited work options while also facing enormous financial pressures as a result of debts to smugglers and expectations from family members for remittances, especially if the family poured its resources into sending the person to the US. One undocumented participant expressed extreme distress about the prospect of becoming too ill to work, knowing that the smugglers would seek debt repayment from his family in Asia if he stopped paying. In such circumstances, the fear of discrimination because of HIV stigma may be especially high because it could lead to loss of employment. Some study participants also felt they could not plan for the future with their limited work options and the threat of deportation hanging over them. Having limited work options made one participant feel overly dependent on his partner. He said that when they argue, he thinks about moving out, but he does not pursue this line of thought because he cannot support himself.

Immigration and HIV Infection

Analysis of qualitative interviews suggests that the vulnerabilities created by immigration may have been a factor in HIV infection for a number of the study participants in two ways. First, several of the Chinese participants who were undocumented immigrants believed they were infected prior to entering the US during long interim stays in Southeast Asia (up to three years), where they were separated from family, had little to do, and frequented sex workers.

> *"I was in Thailand in 1990 for half a year. I had hired prostitutes. I had never done this at home, because my wife and children were home. I had contact with sex workers in Thailand, so I surmised that I was infected in Thailand. I would not have gotten it anywhere else."*

The existence of this pattern of infection is supported by another study that involved HIV subtype analysis in a purposive sample of individuals living with HIV in NYC, which included Chinese immigrant men who stopped in Burma or Thailand for 6 to 9 months before arriving in the US, during which time they reported having engaged in high-risk activity with female sex workers. Their HIV subtype was found to be the most common heterosexually transmitted subtype in Thailand.[25]

The second way that immigration may have been a factor in HIV infection was found among gay men. Several gay men believed they were infected soon after coming to the US; they engaged in a high volume of unprotected sexual activity because they viewed the US to be a place of sexual freedom and found a range of new sexual opportunities for which they were unprepared. Some said they had little awareness about HIV at the time.

> *"You know, because it was very easy – you know, a lot of bars on the street, maybe next street, maybe over there, a theater, a bath house, a park, any sex place . . . book store, too many kind of . . . places – you know, influence you."*

Bathhouses and other high-risk places may have been more desirable than clubs or bars because they allowed for quick access to sex, which may be important if work hours are long, and because having sex in these environments would not necessarily require English proficiency. Language and cultural barriers, however, may have made safer sex negotiation more difficult.

At least for one undocumented participant who was gay, inhibitions against unsafe sexual activity may have been weakened by the belief that being HIV positive could enhance the probability of gaining asylee status. One participant, in fact, reported that he was successful in gaining asylee status based on being gay and being HIV positive. But another participant who applied on this basis was denied. Regarding his

lowered inhibitions, he said that he did not actively seek to get infected but that believing that HIV infection might help his case, he was less careful than he might have been otherwise.

> *"...At first I'm thinking being positive might be an advantage . . . for me because of my immigrant status, but I got the wrong information."*

There was no consistent pattern of infection among the female participants in the study. Almost all of the female participants said they were infected by their boyfriends or husbands; the dynamics of immigration may have been a factor in some cases. Several women said that they met their boyfriends or husbands after coming to the US and thus were not familiar with their pasts. One woman thought that her husband, whom she married in India, may have been infected when he came to the US before her and they spent two years apart. Traditional gender role norms may have made it more difficult for some of the women to ask about their partners' sexual histories or to negotiate safer sex (e.g., condom use). For women who are married before coming to the US and whose legal immigration status depends on their husbands, power differentials may be even more pronounced.

Lack of HIV prevention knowledge, which is often related to being an immigrant, may also have been a factor in all of these cases. Recent immigrants often have lower levels of knowledge about HIV than US-born persons or more acculturated immigrants, especially if HIV education in the country of origin is lacking.18

SUMMARY AND CONCLUSION

This study has aimed to elucidate the issues and needs for APIs living with HIV/AIDS, a population whose size and needs continue to grow. Although APIs living with HIV/AIDS make up a relatively small percentage of HIV/AIDS cases in the New York City area, they constitute a sizable group with clearly emerging special needs. The perception of APIs with HIV/AIDS as a small group, coupled with a stereotype of APIs as a "model minority," has meant that these special needs have often been overlooked or poorly understood. And unfortunately, the number of APIs living with HIV/AIDS continues to grow at a rapid pace because of continued new infections occurring among APIs here in the US. In fact, recent data show that HIV/AIDS diagnosis rates are increasing faster among APIs than in any other racial group. It is also possible that the growing number of HIV/AIDS cases among APIs in the US may be related to the AIDS epidemic in the Asia/Pacific region, which is increasing at an alarming rate.

The study confirms certain earlier discoveries, for example, that many APIs with HIV require services related to bridging language and cultural barriers. Other findings are less obvious and sometimes surprising.

Many APIs with HIV, reflecting the larger API community in NYC, continue to have low levels of acculturation and English proficiency, even after many years of living in the US. In addition to experiencing cultural and language barriers, APIs more frequently reported cost barriers to care compared to other HIV positive New Yorkers, possibly reflecting restrictions on Medicaid and other forms of public assistance for undocumented and other immigrants. Possibly because of these barriers, APIs appear to experience severe delays in getting tested for HIV and entering medical care. Compared to other HIV positive New Yorkers, the participants in the API quantitative survey were more likely to have major medical problems at the time of receiving their first HIV medical care. This high rate of major medical problems among APIs is consistent with findings from analyses of epidemiologic data23 and indicates that a focus on getting APIs tested and into care is of critical importance.

While the study participants reported few difficulties staying in care after finally entering, the API quantitative survey indicates that the medical care many of them were receiving was sub-standard. Only 35% of the API participants had HIV medical care that met "preferred practice guidelines," compared to 74% for the CHAIN New Baseline cohort, a representative sample of people with HIV who are in care in NYC. Participants who were covered only by ADAP complained of gaps in general medical care. They most consistently complained about difficulties with receiving dental care. With regard to support services, participants noted the need for greater housing assistance (especially for undocumented participants), financial assistance (including job training), legal services related to immigration and alternative pain management services (such as massage and acupuncture). Mental health services and a women's support group were also mentioned.

Study participants' knowledge regarding HIV treatment and prevention was disconcertingly low. Low knowledge may be related to lower rates of complete medication adherence. Compared to other HIV positive New Yorkers, APIs were less likely to know their CD4 count and were markedly less likely to have complete adherence to HIV medications. Lower knowledge about HIV may be related to lower levels of acculturation and of English proficiency and passivity about one's care, perhaps arising in recognition of the difficulties of overcoming language and cultural barriers.

Regarding language and culture, most participants expressed feeling more comfortable with service providers who speak their primary language and share the same ethnic or racial background. In addition to valuing linguistic and cultural similarity with their providers, APIs with HIV also valued provider competence, demonstrations of compassion and warmth, gender matching, non-judgmental attitudes regarding HIV and homosexuality, and a respect for confidentiality. For some study participants, these concerns overrode the wish to have an API provider who speaks their language. For smaller ethnic/language groups, such as Bangladeshis, language resources were lacking, often leaving participants from these groups reliant on a single person for accessing all of their care.

One of the most consistent themes to arise from the qualitative interviews was related to HIV stigma. Study participants perceived a very high level of HIV stigma in their families and communities and were thus reluctant to disclose their HIV status and tended to be extremely isolated. It was not uncommon for participants to report that they had disclosed their HIV status to only their service providers. Extreme isolation appeared to be related to high levels of mental distress among participants. Many participants reported intense feelings of anger, loneliness, despair and worry. This was reflected in the quantitative survey, which showed that APIs were much more likely to have low to very low levels mental health scores compared to other New Yorkers living with HIV.

Despite having high levels of mental distress, many participants were reluctant to seek formal mental health services. According to providers, service system barriers – such as lack of mental health professionals who speak appropriate languages and poor coverage by ADAP and Medicaid – contribute to low mental health service utilization among APIs with HIV. Moreover, many participants were distrustful of mental health services, preferring to find their own methods for coping, such as socializing with friends and engaging in religious or spiritual practices. In some cases, actual or perceived HIV stigma interfered with these pursuits.

The added difficulties for undocumented APIs were also readily apparent from the interviews. Difficulties included limited eligibility or complete ineligibility for public assistance programs and Medicaid, leaving substantial gaps in support and care. Undocumented status also contributed to participants' sense of isolation in that it restricted their ability to visit family in their countries of origin. Many undocumented participants expressed intense sadness about their separation from family members and a strong desire to see them. Because of their undocumented status, they would risk not being able to return to the US if they left. Being "stuck" in Asia would jeopardize their health, as medical care for persons with HIV in the US continues to be far more accessible and of higher quality than the care offered in most Asian countries.

Participants' stories indicated a possible link between the vulnerabilities created by the immigration process, increased HIV risk behavior and HIV infection. Several undocumented male participants believed they were infected with HIV when they frequented sex workers in Southeast Asia for prolonged periods of time during their passage to the US. Several gay male participants said they increased their unprotected sexual activity after arriving in the US because they saw it as a land of sexual freedom. Unfortunately, few were properly informed about the risks of HIV infection. API women in the study were often infected by their boyfriends or husbands after arriving in the US. A number of participants described having little to no information about HIV and safer sex techniques.

The study has two main limitations. First, because of time and budget constraints, it was not possible to translate the study instruments into languages other than English and Chinese. This limited our ability to recruit from other language groups, although the use of verbal interpretation helped to remedy this problem. A second limitation of the study is that it utilized a convenience sample (again due to time and budgetary constraints), which is not necessarily representative of the wider population of HIV positive APIs in NYC. All participants were receiving some level of medical care and support services. According to staff at APICHA and CPC, those clients who agreed to participate tended to be less afraid of stigma and generally more connected to services than those clients (also in care) who declined to participate. The actual picture of APIs with HIV may, in fact, be more dire than what is reported here, with even greater levels of isolation and barriers to care. Alternatively, APIs with HIV who are not receiving services at APICHA or CPC may be more independent and less reliant on the supportive services available through these organizations.

The limitations of convenience sampling may have been mitigated by recruiting from the two organizations that, combined, are responsible for providing most of the support services targeted to APIs living with HIV in New York City. Together, their active clients make represent a substantial proportion (26%) of the number of APIs known to be living with HIV/AIDS in NYC. Thus, the findings may be

somewhat reflective of the total population of APIs who are living with HIV/AIDS and are in-care in New York City. In key-informant interviews and feedback sessions, providers at APICHA and CPC confirmed that our findings are compatible with the knowledge they have gained from serving this population.

It may be helpful for future studies to focus on specific sub-groups that may be overlooked in a study that has a more general view of APIs, such as this one. Future studies, for example, may focus on specific ethnic groups, such as South Asians (e.g., Indians, Pakistanis, Bangladeshis), or demographic groups (e.g., API women). Further study on some of the main problems that arose in this study may also be important, such as high rates of major medical problems at the time of first HIV medical care, low rates of medical care that meets preferred practice guidelines, high rates of isolation and mental distress, high levels of HIV stigma in API communities, and the impact of undocumented status. Certain relationships between relevant factors may also be explored further, such as the relationship between acculturation, HIV treatment knowledge and treatment adherence, or between acculturation and mental health. Finally, further study to design and evaluate interventions for providing support and care to APIs living with HIV is warranted. Such interventions might include programs to reduce stigma in API communities, as stigma appears to underlie many of the problems that APIs living with HIV are facing.

POLICY AND PROGRAMMATIC RECOMMENDATIONS

The following recommendations were developed in light of the study findings, with feedback and comments by the staff of APICHA and CPC. Four primary recommendations are provided regarding mental health, early testing and diagnosis, HIV stigma, and improving prevention education for new immigrants. These primary recommendations are followed by seven additional supplementary recommendations.

Primary Recommendations

1. Improve Access to Mental Health Services for APIs:

   a. Address mental health needs as close to the time of HIV diagnosis as possible, when mental distress may be most acute.

   b. Train physicians and case managers on how to discuss mental health services with API clients – how to address their doubts, questions and anxieties about mental health services, and also how to manage their expectations.

   c. Provide counseling skills training to physicians and case managers. Because of reluctance to seek mental health care, and high levels of isolation resulting from HIV stigma, the physician or case manager may be seen as important source of emotional or social support, being one of the few people who know about the person's HIV status.

   d. Provide training to mental health professionals on the particular needs, experiences and expectations that APIs with HIV might bring to the therapeutic relationship.

   e. Provide mental health services in appropriate API languages.

   f. Educate API clients on what mental health services are – how they help and how they work.

   g. Recognize API clients' ways of finding emotional and social support that fall outside of conventional mental health and support group services. Expand activities that are not formal mental health services, but which are supportive, including meals and social events.

   h. Work with API religious institutions to provide support to clients.

2. Close the Gap between HIV Infection and HIV Testing and Reduce Misdiagnosis by Training API Doctors who are not HIV Specialists (But Who May Have First Contact with HIV Positive APIs) to Recognize and Screen for HIV.

   Training should cover:

   a. HIV positive APIs' concerns and fears about receiving care.

   b. The importance of maintaining nonjudgmental attitudes

   c. Patient confidentiality

3. Support Programs and Media Advertising in Multiple API Languages to Encourage Early Testing and Reduce HIV Stigma.

   Anti-stigma programs can be carried out collaboratively between AIDS Service Organizations and key API community institutions (including religious organizations). Media campaigns can include multi-lingual ads in ethnic media (print, radio, television) and in transportation systems (subways, buses). Advertising on HIV testing in API communities may also reduce fear-based HIV stigma by portraying HIV infection as a treatable health condition. Anti-stigma campaigns should also aim to reduce judgmental attitudes about APIs with HIV who are perceived to have engaged in "unacceptable" behaviors (e.g., homosexual sex, non-marital sex, and substance use).

4. Develop New Venues for Providing Prevention Education to New Immigrants (Including Women and Men who have Sex with Men).

Appropriate venues may be immigrant community organizations, such as religious organizations and social organizations, which may have the earliest contact with new immigrants. Workplaces may also be effective venues, since many study participants expressed not having time for much other than work. These organizations and workplaces may require training and capacity-building to engage in such activities. Because of HIV stigma, developing relationships with these places may require a great deal of sensitivity.

Supplementary Recommendations

5. Continue to Support Seamless Referral from HIV Diagnosis into Culturally and Linguistically Appropriate Support Services.

Extensive linkage and referral relationships with organizations like APICHA and CPC appear to have contributed to the fact that there were surprisingly few reports of unaddressed language barriers and few stories of APIs waiting for days in hospitals with a new HIV diagnosis and no one to turn to who could speak their language. Such problems were reported frequently by providers earlier in the epidemic when organizations like APICHA and CPC did not exist or were not providing direct services.

6. Address Unmet Needs, Especially for Undocumented APIs, in the Following Areas:

   a. Medical coverage for undocumented APIs and other API immigrants who are not eligible for Medicaid. (ADAP is insufficient for general medical care.) Implement methods for evaluating adequacy of care and remedying inadequacies.

   b. Dental services, especially for APIs not eligible for Medicaid.

   c. Rental assistance/housing, especially for undocumented APIs who are not eligible for HASA assistance.

   d. Financial assistance and job training, including job training and job placement for those with disabilities that limit ability to work. According to providers, other useful training to help clients establish financial security and get jobs includes English language classes. English language classes may need to start at a much more basic level than most ESL classes (e.g., teaching the alphabet). Providers reported that clients are also especially interested in computer training.

   e. Legal assistance with immigration issues (e.g., applying for a green card or PRUCOL status).

   f. Alternative pain management, such as massage and acupuncture. Because API clients may be particularly resistant to using traditional mental health services, these have the added potential of complementing or even substituting for some traditional mental health services.

7. Provide Training to all Medical Providers Regarding Sensitivity to API Patient Concerns, Including:

   a. Patients' discomfort regarding personal matters, particularly when patient and provider (or patient and interpreter) are of different genders.

   b. Patient discomfort with asking for assistance or information from providers.

   c. Patients' perception of discrimination because of racial, language and cultural differences.

8. Provide Training to Case Managers and Escorts/Interpreters to Handle Multiple Roles, Including HIV Prevention Educator, Treatment Counselor and Supportive Counselor.

This is especially important in light of lack of information, tremendous isolation, and reluctance to seek mental health services among APIs, especially those with limited English proficiency. Case

managers and escorts/interpreters may need to invest more time per client because of API clients' high level of need in these areas.

9. Sustain and Improve Cultural Sensitivity and Language Appropriateness of Services

   a. Expand interpreter pools to ensure appropriate and sufficient language coverage and allow matching by gender when necessary.

   b. Create service systems and operating hours that accommodate schedules of low-wage informal sector workers (garment factory, restaurant) who may have no vacation or sick-leave, unusual work hours, and whose employers may be intolerant of asking for time off.

   c. Be sensitive to cultural practices (e.g., ancestor worship in the morning) and cultural food preferences.

   d. API-focused agencies should also consider how to remain welcoming to US-born APIs.

   e. Be sensitive to various facets of a person's identity; not just ethnicity and language, but also, for example, sexual orientation and gender.

10. Develop Client "Empowerment" Workshops and Trainings Targeted Specifically to APIs to Address Problems with Navigating the Health Care System, Dealing with Stigma and Isolation, and Finding Jobs. Topics can include the following:

    a. How to talk to doctors.

    b. Understanding the service system.

    c. Strategies for taking pills at work, etc., for people who are afraid of being identified as HIV positive.

    d. Treatment education: CD4, viral load, etc., especially for limited-English-proficient clients, with informational materials in multiple API languages.

    e. HIV transmission and prevention, again with materials in multiple API languages.

    f. Dealing with HIV disclosure, discrimination and isolation.

    g. Dealing with homophobia (for gay men).

    h. HIV and relationships/dating.

    i. Job training (including computer skills), finding a job.

    j. English-language and health literacy training.

    In a focus group, consumers noted that some aspects of this sort of training may be better provided on a one-to-one basis between case managers or peer educators and clients because of the reluctance of some clients to commit to attending trainings. Consumers in the focus group also suggested that peer educators could provide training to clients as they wait for their appointments. This approach would require additional training for case managers and peer educators.

11. Advocate for Expanding Options for Legalizing Immigration Status on a Humanitarian Basis through Changes in Policy and Procedure at the Federal Level.

LITERATURE CITED AND NOTES

1. "Major medical problems" are self-defined by respondents in the survey. Survey respondents were asked, "when you first went to [your first HIV medical provider] were you feeling healthy or did you have some medical problems," and were given the choice of answering, "no medical problems," "minor health problems," or "major health problems."

2. U.S. Census Bureau. The Asian Population: 2000. Washington DC 2002.

3. New York City Department of City Planning. Demographic Profile - New York City 1990-2000. Available at: http://home.nyc.gov/html/dcp/pdf/census/demonyc.pdf. Accessed 8/10/04, 2004.

4. Karpati A, Kerker B, Mostashari F, et al. Health Disparities in New York City: NYC Department of Health and Mental Hygiene; 2004.

5. Centers for Disease Control and Prevention. HIV/AIDS Surveillance Report, 2004. Atlanta: US Department of Health and Human Services, Centers for Disease Control and Prevention; 2005.

6. NYCDOHMH. October 2005 Quarterly Dataset. New York: New York City Department of Health and Mental Hygiene, HIV Epidemiology Program; October 2005.

7. Racial/ethnic disparities in diagnoses of HIV/AIDS--33 states, 2001-2004. MMWR Morb Mortal Wkly Rep. Feb 10 2006;55(5):121-125.

8. NYCDOHMH. HIV/AIDS in New York City, 2001-2004. New York: New York City Department of Health and Mental Hygiene, HIV Epidemiology Program; February 2006.

9. NYCDOHMH. HIV surveillance and epidemiology program, 4th quarter report. New York: New York City Department of Health and Mental Hygiene, HIV Surveillance and Epidemiology Program; October 2004. vol. 2, no. 4.

10. NYCDOHMH. HIV epidemiology program, 4th quarter report. New York: New York City Department of Health and Mental Hygiene, HIV Epidemiology Program; October 2005. vol. 3, no. 4.

11. Kelly JJ, Chu SY, Diaz T, Leary LS, Buehler JW. Race/ethnicity misclassification of persons reported with AIDS. The AIDS Mortality Project Group and The Supplement to HIV/AIDS Surveillance Project Group. Ethnicity & Health. 1996;1(1):87-94.

12. Bhattacharya G. Health Care Seeking for HIV/AIDS among South Asians in the United States. Health and Social Work. 2004;29(2):106-115.

13. Loue S, Lane SD, Lloyd LS, Loh L. Integrating Buddhism and HIV Prevention in U.S. Southeast Asian Communities. Journal of Health Care for the Poor and Underserved. 1999;10(1):100-121.

14. Matteson DR. Bisexual and Homosexual Behavior and HIV Risk Among Chinese-, Filipino-, and Korean-American Men. Journal of Sex Research. 1997;34(1):93-104.

15. Choi KH, Coates TJ, Catania JA, Lew S, Chow P. High HIV risk among gay Asian and Pacific Islander men in San Francisco. AIDS. 1995;9(3):306-308.

16. Lemp GF, Hirozawa AM, Givertz D, et al. Seroprevalence of HIV and risk behaviors among young homosexual and bisexual men. The San Francisco/Berkeley Young Men's Survey. JAMA. 1994;272(6):449-454.

17. Valleroy LA, MacKellar DA, Karon JM, et al. HIV prevalence and associated risks in young men who have sex with men. Young Men's Survey Study Group. JAMA. 2000;284(2):198-204.

18. Yoshikawa H, Wilson P, Hsueh J, Rosman EA, Chin J, Kim JH. What front-line NGO staff can tell us about culturally anchored theories of change in HIV prevention for Asian/Pacific Islanders in the U.S. American Journal of Community Psychology. September 2001;32(1-2):143-158.

19. Khan S. Culture, Sexualities, and Identities: Men Who Have Sex with Men in India. Journal of Homosexuality. 2001;40(3/4):99-115.

20. UNAIDS. AIDS epidemic update: December 2005. Geneva: UNAIDS; December 2005.

21. New York State Department of Health. Unpublished data for cases diagnosed through December 31, 2003. Albany, NY: New York State Department of Health, Bureau of HIV/AIDS Epidemiology; January 4 2005.

22. Kwong P. The New Chinatown. New York: The Noonday Press; 1987.

23. Eckholdt H, Chin J. Pneumocystis carinii Pneumonia in Asians and Pacific Islanders. Clinical Infectious Diseases. 1997;24(6):1265-1267.

24. Kang E, Rapkin BD, Springer C, Kim JH. The "Demon Plague" and Access to Care among Asian Undocumented Immigrants Living with HIV Disease in New York City. Journal of Immigrant Health. 2003;5(2):49-58.

25. Achkar JM, Burda ST, Konings FA, et al. Infection with HIV type 1 group M non-B subtypes in individuals living in New York City. J Acquir Immune Defic Syndr. Jul 1 2004;36(3):835-844.

APPENDIX: QUANTITATIVE SURVEY DATA — Analyses of API Quantitative Survey Data, with Comparisons to CHAIN Study Cohorts

Table 1-1. Economic Resources

	NYC CHAIN New Baseline 2002-04		NYC CHAIN Original Baseline 1994-95		NYC CHAIN Refresher Baseline 1998		API Group 2005	
Total Sample	**n**	%	**N**	%	**n**	%	**n**	%
	684	100%	**648**	100%	**254**	100	**89**	100%
Educational attainment								
Less than high school	**259**	40%	**210**	32%	**118**	46%	**30**	34%
High school graduate	**290**	44%	**328**	51%	**99**	39%	**30**	34%
Some college	**24**	4%	**39**	6%	**20**	8%	**2**	2%
College graduate	**47**	7%	**54**	8%	**13**	5%	**6**	7%
Post-graduate	**35**	5%	**17**	3%	**4**	2%	**20**	23%
Employment status								
Employed full-time	**20**	3%	**67**	10%	**17**	7%	**22**	25%
Employed part-time	**86**	13%	**90**	14%	**22**	9%	**29**	33%
Not employed	**572**	84%	**490**	76%	**215**	85%	**36**	41%
Volunteer	**5**	1%					**1**	1%
Annual household income								
<$10,000	**487**	73%	**325**	50%	**185**	73%	**32**	37%
$10,000 - $14,999	**89**	13%	**108**	17%	**30**	12%	**14**	16%
$15,000 - $24,999	**42**	6%	**92**	14%	**18**	7%	**13**	15%
$25,000 - $44,999	**32**	5%	**56**	9%	**10**	4%	**12**	14%
$45,000+	**10**	2%	**31**	5%	**7**	3%	**13**	15%
Refused/Don't Know	**5**	1%	**36**	6%	**4**	2%	**3**	3%
Fairly often/ very often, respondent did not have enough money in the household for...								
Rent	**56**	9%	**102**	16%	**21**	8%	**9**	10%
Utilities	**73**	12%	**103**	16%	**22**	9%	**6**	7%
Food	**80**	13%	**129**	20%	**32**	13%	**3**	3%
Medical care	**13**	2%	**47**	7%	**8**	3%	**6**	7%
Clothing	**133**	22%	**188**	29%	**48**	19%	**9**	10%
Recreational activities	**180**	29%	**245**	38%	**50**	20%	**16**	18%

Table 1-2. Family & Household Characteristics

	NYC CHAIN New Baseline 2002-04		NYC CHAIN Original Baseline 1994-95		NYC CHAIN Refresher Baseline 1998		API Group 2005	
	n	**%**	**n**	**%**	**n**	**%**	**n**	**%**
Total Sample	**684**	100%	**648**	100%	**254**	100	**89**	100%
Current marital status								
Married/Registered Domestic Partners	**66**	10%	**67**	10%	**42**	17%	**22**	25%
Separated	**62**	9%	**66**	10%	**34**	13%	**4**	4%
Divorced	**84**	12%	**85**	13%	**42**	17%	**10**	11%
Widowed	**68**	10%	**37**	6%	**11**	4%	**0**	0%
Never married	**403**	59%	**392**	61%	**125**	49%	**53**	60%
Current partner relationship								
Not in partner relationship	**350**	51%	**336**	52%	**120**	47%	**55**	62%
Living with spouse or partner	**138**	20%	**149**	23%	**52**	20%	**20**	22%
Non-coresident partner relationship	**196**	29%	**163**	25%	**82**	32%	**14**	16%
Current living situation								
Own or rent an apartment or house	**519**	76%	**513**	79%	**177**	70%	**78**	88%
"Doubled up" with friend or relative	**25**	4%	**39**	6%	**15**	6%	**3**	3%
Welfare hotel or motel	**58**	8%	**41**	6%	**12**	5%	**2**	2%
Specialized AIDS housing	**33**	5%	**16**	2%	**27**	11%	**2**	2%
Drug treatment program housing	**14**	2%	**18**	3%	**19**	7%	**0**	0%
Shelter, street, or other public place	**17**	2%	**11**	2%	**1**	<1%	**1**	1%
Hospital, nursing home, hospice	**15**	2%	**6**	1%	**0**	0%	**0**	0%
Jail, prison, halfway house	**2**	<1%	**0**	0%	**0**	0%	**0**	0%
Other	**0**	0%	**4**	1%	**3**	1%	**3**	3%
Stability of housing in past 6 months								
Stably housed	**502**	73%	**423**	65%	**183**	72%	**77**	87%
Unstably Housed or Doubled-Up	**67**	10%	**101**	16%	**49**	19%	**12**	13%
Homeless at least one night	**115**	17%	**124**	19%	**22**	9%	**4**	4%

Table 1-3: HIV Diagnosis and Early Medical Care

	NYC CHAIN New Baseline 2002-04		NYC CHAIN Original Baseline 1994-95		NYC CHAIN Refresher Baseline 1998		API Group 2005	
	n	%	n	%	n	%	n	%
Total Sample	684	100%	648	100%	254	100	89	100%
Year of HIV or AIDS diagnosis								
1978-1989	166	24%	217	33%	14	6%	8	9%
1990-1995	280	41%	441	67%	117	46%	21	24%
1996-2000	192	28%			123	48%	28	31%
2001-2005	46	7%					31	35%
Time between diagnosis and HIV medical care								
Less than 3 months	491	72%	504	78%	214	84%	73	82%
Greater than 3 months	193	28%	144	22%	40	16%	16	18%
Health at time of initial HIV medical care								
No medical problems	339	50%	321	50%	113	45%	37	42%
Minor medical problems	197	29%	156	24%	67	26%	19	22%
Major medical problems	145	21%	165	26%	71	28%	32	36%
Life circumstances at time of initial HIV diagnosis [1]								
Married or in a regular relationship	436	64%	255	57%	123	49%	50	56%
Drinking a lot	275	40%	166	37%	60	24%	15	17%
Using drugs regularly	366	54%	221	49%	93	37%	17	19%
Had adequate medical insurance	436	64%	255	57%	129	48%	50	56%

[1] *Questions for original cohort were asked in wave 3 (1997) and N=451.*

Table 1-4. Current Health Status

	NYC CHAIN New Baseline 2002-04		NYC CHAIN Original Baseline 1994-95		NYC CHAIN Refresher Baseline 1998		API Group 2005	
	n	%	**n**	%	**n**	%	**n**	%
Total Sample	**684**	100%	**648**	100%	**254**	100	**89**	100%
Most recent t-cell count								
Greater than 500 copies per mm³	**213**	31%	**126**	19%	**71**	28%	**28**	31%
201-500 copies per mm³	**303**	44%	**210**	32%	**102**	40%	**44**	49%
Less than 200 copies per mm³	**156**	23%	**269**	42%	**64**	25%	**7**	8%
Missing/Don't know	**12**	2%	**43**	7%	**17**	7%	**10**	11%
Stage of HIV infection								
Asymptomatic HIV	**234**	34%	**128**	20%	**68**	27%	**30**	34%
Symptomatic HIV	**88**	13%	**93**	14%	**42**	17%	**14**	16%
Clinically-diagnosed AIDS	**362**	53%	**427**	66%	**132**	57%	**45**	51%
Current use of antiretroviral therapy								
None	**162**	24%	**586**	90%	**54**	21%	**18**	20%
Non-HAART Combination therapy	**82**	12%	**62**	10%	**68**	27%	**11**	12%
HAART	**440**	64%	**0**	0%	**132**	52%	**60**	67%

Table 1-5. Risk Characteristics

	NYC CHAIN New Baseline 2002-04		NYC CHAIN Original Baseline 1994-95		NYC CHAIN Refresher Baseline 1998		API Group 2005	
	N	%	**n**	%	**n**	%	**n**	%
Total Sample	**684**	100%	**648**	100%	**254**	100	**89**	100%
HIV risk								
MSM	**136**	20%	**150**	23%	**36**	14%	**31**	35%
Problem drug use	**269**	39%	**275**	42%	**84**	33%	**7**	8%
MSM + problem drug use	**53**	8%	**67**	10%	**11**	4%	**3**	3%
Heterosexual and other	**226**	33%	**156**	24%	**123**	48%	**48**	54%
Sexual history								
Exclusively heterosexual	**398**	61%	**368**	57%	**186**	74%	**31**	35%
Men who have ever had sex with men	**192**	29%	**219**	34%	**46**	18%	**53**	60%
Women who ever had sex with women	**62**	10%	**60**	9%	**21**	8%	**4**	5%
Drug use								
Never used drugs	**181**	26%	**149**	23%	**85**	33%	**66**	74%
Former drug use	**340**	50%	**307**	47%	**131**	52%	**12**	13%
Current drug use	**163**	24%	**192**	30%	**38**	15%	**11**	12%
Injection drug use								
Never injected drugs	**449**	66%	**380**	59%	**177**	70%	**84**	94%
Ever injected drugs	**235**	34%	**268**	41%	**77**	30%	**5**	6%
Mental health component summary score (MCS)								
<37.0 (very low mental health score)	**261**	38%	**227**	35%	**77**	30%	**31**	35%
37.0 - 42.0 (low mental health score)	**80**	12%	**95**	15%	**29**	11%	**32**	36%
>42.0 (average mental health score)	**343**	50%	**318**	50%	**148**	58%	**26**	29%
Dually-diagnosed individuals (Low mental health & drug use)								
<37.0 MCS + current drug use	**78**	11%	**78**	12%	**15**	6%	**6**	7%

Table 1-6. Presentation Categories and Risk by Gender

Characteristic	Total N	Gender	
		Female	Male
Total Sample	**89**	14	75
HIV Risk			
MSM	**35%**	0%	41%
Problem Drug Use	**8%**	7%	8%
MSM + Problem Drug Use	**3%**	0%	4%
Heterosexual & Other	**54%**	93%	47%
Housing Stability			
Stably Housed	**87%**	86%	87%
Unstably Housed or Doubled-Up	**9%**	7%	9%
Homeless at least one night	**4%**	7%	4%
Substance Abuse			
Never used drugs	**74%**	86%	72%
Former drug user	**13%**	14%	13%
Current drug user	**12%**	0%	15%

* p < .05　　　　　　***p < .01*　　　　　　**** p < .001*

Table 2-1. Self-reported Health Status by Sociodemographic Differences

Characteristic	Gender		Risk Group				API Group 2005	NYC cohort 2002-4
	Female	Male	MSM	PDU	MSM/ PDU	Other		
(Total N=89)	14	75	31	7	3	48	89	684
In general, would you say your health is...								
Excellent or very good	7%	43%	65%	0%	33%	25%	37%	32%
Good	57%	24%	16%	43%	33%	35%	29%	32%
Fair or poor	36%	33%	19%	57%	33%	40%	34%	36%
Physical & Mental Health [2]								
Low Physical Health Score (<45)	43%	37%	19%	71%	67%	44%	38%	49%
Low Mental Health Score (<37)	21%	37%	55%	43%	33%	21%	35%	38%
T-cell count								
>501	29%	32%	39%	43%	100%	21%	31%	23%
201-500	36%	52%	48%	43%	0%	54%	49%	44%
≤200	14%	7%	3%	14%	0%	10%	8%	31%
Missing/Don't know	21%	9%	10%	0%	0%	15%	11%	2%
Opportunistic infections (OI)								
OI in past 6 months	7%	12%	16%	0%	33%	8%	11%	33%

1 Cells represent the percentage of CHAIN participants with each characteristic who report specific clinical outcomes or health status measures, for example, the percentage of men with a t-cell count greater than 500.

2 These scores are drawn from a standardized scale, the Short Form 36 of the Medical Outcomes Scale. Mental health scores below 37.0 are highly correlated with clinical psychiatric symptomatology.

* p < .05   ** p < .01   *** p < .001

Table 2-2. Health Services & Insurance by Sociodemographic Differences

Characteristic [1]	Gender		Risk Group				API Group 2005	NYC cohort 2002-3
	Female	Male	MSM	PDU	MSM/ PDU	Other		
(Total N=89)	14	75	31	7	3	48	89	684
Hospital & ER Use								
Any in-patient use	7%	7%	6%	14%	0%	6%	7%	19%
Any ER Use	0%	12%	10%	14%	0%	10%	10%	32%
Medical Care Characteristics								
Meets preferred practice guideline[2]	50%	32%	19%	29%	67%	44%	35%	74%
Meets primary care characteristics of access and well-care[3]	57%	58%	57%	86%	100%	52%	58%	77%
Insurance								
Private	7%	23%	35%	0%	0%	15%	20%	2%
Medicaid	50%	36%	29%	71%	0%	42%	38%	90%
Other public insurance[4]	43%	41%	35%	29%	100%	44%	42%	7%
None	0%	0%	0%	0%	0%	0%	0%	<1%

1 Cells represent the percentage of CHAIN participants with each characteristic who report specific clinical outcomes or health status measures, for example, the percentage of urban respondents with Medicaid insurance
2 Refers to an index of preferred practice guidelines based on the number of primary care visits within a 6-month period, the report of a complete physical exam and lab work. Number of visits are contingent upon t-cell count and whether respondent is presently on HIV antiretroviral medications.
3 Based on respondents reporting that primary care physician is available for (1) well-visits and vaccinations, (2) health advice or information, (3) after-hours access either directly or through a service.
4 This includes Medicare, ADAP and veterans' insurance.

Table 2-3. Medical Characteristics by Sociodemographic Characteristics

Characteristic [1]	Gender		Risk Group				API Group 2005	NYC cohort 2002-3
	Female	Male	MSM	PDU	MSM/ PDU	Other		
(Total N=89)	14	75	31	7	3	48	89	684
Year of HIV/AIDS Diagnosis								
Prior to 1989	0%	11%	13%	14%	33%	4%	9%	24%
1990-1995	29%	23%	13%	43%	0%	29%	24%	41%
1996-2005	71%	65%	71%	43%	67%	67%	66%	35%
HIV Stage								
Asymptomatic	29%	35%	45%	29%	0%	29%	34%	34%
Symptomatic HIV	7%	17%	16%	14%	33%	15%	16%	13%
AIDS	64%	48%	39%	57%	67%	56%	51%	53%
HIV Combination Therapy								
None	21%	20%	35%	14%	0%	13%	20%	24%
Non-HAART	7%	13%	0%	29%	67%	15%	12%	12%
HAART[2]	71%	67%	65%	57%	33%	73%	67%	64%
Adherence (API on HIV medications, N=71)								
Not completely adherent	45%	43%	40%	33%	0%	50%	44%	28%
Completely adherent	55%	57%	60%	67%	100%	50%	56%	72%

1 Cells represent the percentage of CHAIN participants with each characteristic who report specific clinical outcomes or health status measures, for example, the percentage of MSM respondents on HAART
2 HAART is Highly Active Antiretroviral Therapy, which are HIV medications prescribed as per NIH guidelines.

Table 2-4. Percent on HAART Among AIDS-Diagnosed Original and New Cohorts

	API Group	New Cohort	Original Cohort, 2000 (Wave 8)
Sample (N=45/362 /320)	**87%**	**70%**	**63%**
Gender			
Female (9/128/ 149)	78%	73%	57% +
Male (36/234 / 171)	89%	68%	67%
Risk characteristic			
MSM (12/76 / 65)	83%	64%	74%*
Problem Drug User (4/142 / 134)	75%	64%	63%
MSM + Problem Drug User (2/37 / 30)	50%	78%	43%
Heterosexual and other (27/107 / 91)	93%	79%	59%
Substance Abuse History			
Never used drugs (30/93 / 32)	90%	78%	66% **
Former drug user(9/182 / 224)	89%	66%	67%
Current drug user (6/87 / 64)	67%	68%	45%
Household Income			
Less than $10,000 annual household income (17/246 / 185)	100%	70%	62%
Greater than $10,000 annual household income (25/107/ 135)	84%	71%	64%
CD4 count			
CD4 > 500 (11/143/ 96)	73%	68%	56%
200< CD4< 500 (22/145 / 148)	91%	74%	65%
CD4<200 (7/74/ 76)	86%	64%	66%
Education			
Greater than high school (34/239 / 215)	85%	68%	60%
Less than high school (11/123/ 105)	91%	73%	68%
Age categories			
20-34 years old (9/32 / 25)	89%	69%	56%
35-49 years old (22/213 / 202)	77%	69%	65%
50+ years old (14/117 / 93)	100%	70%	59%
Insurance			
Private (10/9 / 25)	90%	67%	64%
Medicaid (19/322 / 270)	84%	69%	62%
Other Public – ADAP, Medicare, CHAMPUS (16/30 / 22)	88%	77%	73%
None (0/1/ 3)	n.a.	(1)	(1)

*⊥ p < .1   * p < .05   ** p < .01   *** p < .001*

Table 3-1. Access, Satisfaction, and Comprehensiveness of Medical Care Services

Characteristics	NYC CHAIN New Baseline 2002-4 (N=684)	NYC CHAIN Original Baseline 1994-95 (N=648)	NYC CHAIN Refresher Baseline 1998 (N=254)	API Group 2005 (N=89)
Having a Medical Care Provider				
Yes	97%	97%	98%	100%
No	3%	3%	2%	0%
Satisfaction with Medical Care Provider				
Satisfied	87%	82%	88%	83%
Dissatisfied	13%	18%	12%	17%
Comprehensive Medical Care [1]				
Not comprehensive care	23%	49%	37%	39%
Comprehensive care	77%	51%	63%	61%

1   *Comprehensive medical care is based on the respondent reporting that his or her medical provider: (1) provides well-care visits, (2) is available to discuss health issues, (3) is available 24 hours a day, either directly or through a service or beeper*

Table 3-2. Access and Satisfaction of Case Manager Services

Characteristics	NYC CHAIN New Baseline 2002-4 (N=684)	NYC CHAIN Original Baseline 1994-95 (N=648)	NYC CHAIN Refresher Baseline 1998 (N=254)	API Group 2005 (N=89)
Number of Case Managers				
0	27%	41%	15%	7%
1	46%	35%	57%	48%
2	21%	16%	22%	33%
3+	7%	9%	6%	13%
Mean Number of Case Manager Among Who Has Case Manager				
Mean Number	1.48	1.67	1.4	1.68
Satisfaction with Case Manager				
Satisfied	66%	49%	76%	87%
Dissatisfied	34%	51%	24%	13%

Table 3-3. Need and Service Use for Ancillary Services

		NYC CHAIN New Baseline 2002-4 (N=684)	NYC CHAIN Original Baseline 1994-95 (N=648)	NYC CHAIN Refresher Baseline 1998 (N=254)	API Group 2005 (N=89)
Mental Health Services					
Mental health score > 37.0 (N=423/413/177/58)	*Not currently receiving mental health service*	45%	46%	53%	67%
	Currently receiving mental health service	55%	54%	47%	33%
Mental health score <37.0 (N=261/227/77/31)	*Not currently receiving mental health service*	39%	45%	42%	52%
	Currently receiving mental health service	61%	55%	58%	48%
Drug and Alcohol Treatment Services					
Among former drug users, expressed a need for drug treatment (N=236/307/81/8)	*Not currently receiving any drug treatment*	77%	23%	32%	100%
	Currently receiving drug treatment	23%	77%	68%	0%
Among current drug users, expressed a need for drug treatment (N=94/192/27/8)	*Not currently receiving any drug treatment*	62%	32%	37%	87%
	Currently receiving drug treatment	38%	68%	63%	13%

Table 3-4. Reported Problems and Progress Towards Resolving Problems

Problem area	NYC CHAIN New Baseline 2002-4 (N=684)		NYC CHAIN Original Baseline 1994-5 (N=648)		NYC CHAIN Refresher Baseline 1998 (N=254)		API Group 2005 (N=89)	
	having a problem	no progress/ problem has gotten worse*	having a problem	no progress/ problem has gotten worse*	having a problem	no progress/ problem has gotten worse*	having a problem	no progress/ problem has gotten worse*
Housing	35%	48%	38%	59%	36%	39%	39%	49%
Financial issues	24%	61%	46%	60%	25%	53%	35%	45%
Legal issues	11%	42%	21%	52%	11%	56%	43%	65%
Job-related issues	8%	66%	8%	65%	6%	73%	28%	52%
Home care	4%	41%	10%	56%	2%	75%	8%	57%
Clothing/Household items	10%	72%	24%	72%	14%	60%	2%	100%
Child care	<1%	0%	3%	57%	2%	75%	3%	67%
Transportation	9%	58%	22%	68%	11%	86%	8%	86%
Food	8%	42%	25%	64%	10%	68%	28%	24%

Note: Problems were identified by respondents in response to the question: Did you need help or assistance in this area in the last six months?"
* percentages among who have a problem

Table 3-5. Barriers to Medical Care and Social Service

	NYC CHAIN New Baseline 2002-4 (N=684)		NYC CHAIN Original Baseline 1994-5 (N=648)		NYC CHAIN Refresher 1998 (N=254)		API Group 2005 (N=89)	
	Medical Care	Social Service	Medical Care	Social Service	Medical Care	Social Service	Medical Care	Social Service
LOGISTICAL BARRIERS								
Reported at least one logistical barrier	12%	15%	33%	30%	7%	7%	52%	26%
Language barriers	1%	2%	3%	5%	<1%	<1%	11%	7%
Cost too much	4%	1%	12%	4%	2%	<1%	34%	6%
Unsure where to go for services	4%	11%	11%	17%	3%	6%	12%	16%
Transportation	6%	6%	21%	15%	3%	2%	15%	8%
Need for child care	<1%	1%	5%	4%	0%	0%	2%	4%
PROVIDER / STAFF BARRIERS								
Reported at lease one staff barrier	12%	15%	29%	23%	9%	9%	31%	17%
Didn't trust staff to safeguard privacy	2%	2%	6%	5%	2%	<1%	8%	7%
Staff not competent	5%	7%	11%	11%	5%	4%	13%	6%
Staff disrespectful/insensitive	7%	8%	11%	11%	6%	4%	14%	5%
Staff didn't understand the problem	4%	9%	11%	12%	5%	4%	9%	8%
Staff didn't listen	7%	9%	14%	15%	6%	7%	8%	5%
Respondents nervous about what provider might say regarding condition	3%	3%	15%	5%	4%	2%	8%	2%
Felt discriminated because of sexual orientation	1%	2%					3%	1%
Felt discriminated because of drug use	2%	3%					1%	0%

Table 4-1. Measuring Needs & Service Gaps – Definitions

Service	NEED	SERVICE GAP
HEALTH		
Comprehensive medical care	Positive HIV serostatus	Primary HIV medical provider does not provide ALL of the following: (1) Routine check-ups, well visits, vaccinations, (2) Source of health advice, (3) 24-hour access for medical emergencies
Patient/Provider communication	Positive HIV serostatus	Patient doesn't know t-cell or viral load, OR says current doctor "could do a better job explaining my treatment options to me"
Treatment adherence	On antiretroviral medications	Among non-adherent, not receiving treatment adherence services
Antiretroviral therapy	T-cell less than 200	Not on antiretroviral combination therapy
CASE MANAGEMENT		
CM: Comprehensive care model	(1) Current drug user OR (2) very low mental health score OR (3) recent episode of unstable housing OR (4) experienced a barrier to medical or social service because didn't kow where to go, couldn't get child care, couldn't get transportation, or couldn't afford care or (5) says there's not enough money in the household for rent, utilities, food, or clothing	Among those with a need, no CM developed a care plan, assisted in getting or referring client to social services, or helped fill out forms for benefits or entitlements in past 6 months
CM: Counseling model	(1) Scored very low on mental health score OR (2) current drug user OR (3) practiced unsafe sex in past 6 months	Among those with a need, no CM counseled client regarding personal life, drug or alcohol problems, practicing safer sex, or periodically checked up on client in past 6 months
HOUSING		
Financial Housing Services	(1) Fairly often or very often not enough $$$ for rent, OR (2) reported that s/he needed help with eviction, paying rent, or maintaining rental subsidy	No housing service received, OR client not living in specialized AIDS housing
Permanent Housing Services	(1) At least one episode of unstable housing or doubled-up in past 6 months, OR (2) reported that s/he needed help related to homelessness, critical need to move, physical access issues, poor housing quality, or dangerous neighborhood	No housing service received, OR client not living in specialized AIDS housing

Service	NEED	SERVICE GAP
MENTAL HEALTH		
Professional Mental Health (Low or Very Low Mental Health Score)	Scored low or very low on mental health score (Mental component summary (MCS) $\leq$ 42.0)	Respondent did not report receipt of professional MH service (psychiatrist, psychologist, therapist, therapeutic social worker) in prior 6 months
Professional Mental Health (Very Low Mental Health Score)	Scored very low on mental health score (Mental component summary (MCS) $\leq$ 37.0)	Respondent did not report receipt of professional MH service (psychiatrist, psychologist, therapist, therapeutic social worker) in prior 6 months
Supportive Mental Health	Scored above 37.0 on mental health score AND (1) reported a need for help with emotional or psychological problems OR (2) felt couseling regarding sexuality and sexual issues was considerably or extremely important OR (3) strongly disagreed that "most of the time I am in firm control of my feelings and behavior"	Respondent did not report receipt of supportive MH service (support groups, clergy, case managers, peer workers) in prior 6 months
TRANSPORTATION		
Transportation Services	(1) Delayed or didn't get med or soc svce because couldn't get transportation, OR (2) reported that s/he needed help or assistance with transportation in prior 6 months	No reported transportation service in prior 6 months

Table 4-2. Measuring Needs & Service Gaps – Comparing NYC CHAIN & API Group

	NYC CHAIN 2002-04				API Group 2005			
Service	**NEED**		**SERVICE GAP**		**NEED**		**SERVICE GAP**	
[Note: see Table 4-1 for definitions of services]	Num-ber with Need	Propor-tion of Full Cohort (n=622) with Need	Among those with Need, the Number with a Service Gap	Proportion of those with Need Experien-cing Service Gap	Num-ber with need	Propor-tion of Full Cohort (n=89) with Need	Among those with Need, the Number with a Service Gap	Proportion of those with Need Experien-cing Service Gap
HEALTH								
Comprehensive medical care	622	**100%**	148	**24%**	89	**100%**	38	**43%**
Patient/ Provider communication	622	**100%**	235	**38%**	89	**100%**	*data not available*	
Treatment adherence	*440*	*71%*	*82*	*19%*	*71*	*80%*	*data not available*	
Antiretroviral therapy	*127*	*20%*	*35*	*28%*	*7*	*8%*	*1*	*14%*
CASE MANAGEMENT								
CM: Social work model	*466*	*75%*	*186*	*40%*	*78*	*87%*	*24*	*31%*
CM: Counseling model	*348*	*56%*	*134*	*39%*	*78*	*87%*	*10*	*13%*
HOUSING								
Financial Housing Services	*156*	*25%*	*50*	*32%*	*9*	*10%*	*9*	*100%*
Permanent Housing Services	*126*	*20%*	*37*	*29%*	*0*	*0%*	*not applicable*	
MENTAL HEALTH								
Professional Mental Health (Low or Very Low)	331	**53%**	208	**63%**	63	**71%**	44	**70%**
Professional Mental Health (Very Low)	233	**37%**	147	**63%**	31	**35%**	19	**61%**
Supportive Mental Health	85	**14%**	29	**34%**	*data not available*			
TRANSPORTATION								
Transportation	132	**21%**	101	**77%**	22	**25%**	*data not available*	