South Asian Immigrant Women’s HIV/AIDS Related Issues:
An Exploratory Study of New York City
APICHAs mission is to combat AIDS-related discrimination and to support, empower and advocate for the health and welfare of Asians and Pacific Islanders in New York City, particularly community members living with AIDS and HIV infection.

Board of Directors

Errol A. Chin-Loy, Chair
John Hayakawa Torok, Secretary
Paul Cheng Jr., FHFMA, Treasurer

Smita Biswas, M.D.
Steven Chang, N.P.
John J. Chin, Ph.D.
Clayton Keene
Jean R. Lobell, Ph.D.
Suki Terada Ports

Therese R. Rodriguez, Executive Director, Ex-officio member
South Asian Immigrant Women’s HIV/AIDS Related Issues:
An Exploratory Study of New York City

Final Report Prepared for the South Asian Communities

And
Department of Health and Human Services
(Federal Office of Minority Health)
September 1, 2004

Report prepared by
Margaret Abraham
Professor of Sociology
Hofstra University
and
Roopa Chakkappan, MPH
Sung Won Park, APICHA

Project Team:
Margaret Abraham
Roopa Chakkappan
Malabika Das
Sapna Patel
Sung Won Park, APICHA/RARE Liaison

Acknowledgments: Thanks to all the participants of this project including Malabika Das and Sapna Patel, the Community Working Group & RARE Project Director Sheila Pack Merrifield, Oisika Chakrabarti, Cynthia Bogard, and Tariq of Shaheen Int’l Restaurant. A special thanks to Chandra Sunkara for his help with data analysis. This project could not have been done without the support of APICHA.

This report is a publication of APICHA, Inc.

© APICHA 2005
# Contents

**Introduction**  
Why Study HIV/AIDS in South Asian Communities in the US?  

**What is this Project About?**  
Four Month Exploratory Project  
Community Consultation and Involvement  

**Goals of the Project**  
Sample and Data Collection  

**Methodology**  
Data Analysis  
Limitations of the Study  

**Findings**  
Community Norms and Context  
HIV/AIDS Knowledge, Perceptions and Attitudes  
Related Perceptions and Attitudes  
Risk Behavior  
Barriers to Accessing Information and Using Services  
Cultural Factors  
Denial  
Stigma  
Patriarchal Norms and Values  
Structural Factors  
Lack of Access to Free or Affordable Health Care  
Lack of Linguistic and Cultural Competency in Service Delivery  
Mistrust of Public Institutions  
Strategies for Education, Prevention and Treatment  
Role of Media  
Public Venues  
Access to Information Through Websites  
Education Outreach through Schools  
Religious Leaders and Religious Sites  
Increasing Capacity of Community-Based Organizations  
Access to Free and Affordable Healthcare Coverage  

**Recommendations**  

**Conclusion**  
Endnotes  
Appendix: Research Team & Community Working Group
Why Study HIV/AIDS in South Asian Communities in the US?

HIV/AIDS remains an urgent public health issue. Since the early 1990s, an estimated 40,000 new HIV infections have occurred annually in the United States. The number of persons in the United States living with HIV continues to increase, and of an estimated 850,000--950,000 persons living with HIV, an estimated 180,000--280,000 (25%) persons are unaware of their serostatus. The need to increase HIV/AIDS awareness and to prevent the transmission of HIV among the diverse population of the United States is imperative in addressing the AIDS epidemic.

In recent years, South Asia has witnessed an alarming increase in HIV/AIDS. The subcontinent of India is estimated to have the highest HIV/AIDS prevalence rate in the world (about 4.58 million Indians living with HIV/AIDS at the end of 2003), second only to South Africa. Today South Asian communities in the U.S. are rapidly increasing, with Asian Indians forming the largest group within this population. [See Table 1] According to the U.S. Census, between 1990 and 2000, the South Asian population doubled to more than two million. In New York State there are approximately 251,724 Asian Indians, 20,269 Bangladeshis, 32,692 Pakistanis and 2,692 Sri Lankans. Within New York State, New York City has the largest South Asian population. This growth of the South Asian population is significantly influenced by recent immigration patterns. In addition there is considerable travel between South Asia and the United States.

Despite the rapid increase in the South Asian population, there is a severe paucity of published research on HIV/AIDS related issues among South Asians in the United States. In 2003, however, a study was conducted to assess HIV-related knowledge, risk perceptions, and risk behaviors among a community based sample of South Asian women in greater Boston. The researchers found low HIV risk and risk perceptions among these South Asian women. To date, there is no systematic large scale assessment of the scope or magnitude of the prevalence of HIV/AIDS in the South Asian communities in the United States. The problem is compounded by the unavailability of disaggregated data and inconsistencies among the various government agencies in the definitional criteria used to collect information for South Asians. The lack of a reliable baseline also challenges the ability to assess ongoing changes within South Asian communities in the United States. This has considerable consequences for South Asian individuals and communities. It leads to relative invisibility of their needs and concerns and prevents an understanding of the factors that contribute or hinder South Asians’ knowledge, perceptions, attitudes,
behaviors and responses to HIV/AIDS. The intersections of gender, ethnicity, immigration status, class, and economic viability and how they play out in addressing HIV/AIDS for South Asians in the United States gets minimized or ignored. Marginalization of HIV/AIDS-related issues for South Asian communities implies that individuals from these communities may face barriers in receiving information and necessary preventive and healthcare services. It may also lead to inadequate policies, paucity of educational resources and lack of effective prevention and treatment services for this vulnerable population. In addition, the transnational dimension of South Asian communities combined with the growth of the AIDS epidemic in South Asia compel us to look at the issue of HIV/AIDS in the South Asian Communities in the United States.

Table 1 South Asian Population in the United States and New York State

<table>
<thead>
<tr>
<th>Origin</th>
<th>Current Residence</th>
<th>Total</th>
<th>Male</th>
<th>Female</th>
</tr>
</thead>
<tbody>
<tr>
<td>Asian Indian</td>
<td>United States</td>
<td>1,678,765</td>
<td>893,095</td>
<td>785,670</td>
</tr>
<tr>
<td>Asian Indian</td>
<td>New York State</td>
<td>251,724</td>
<td>133,311</td>
<td>118,413</td>
</tr>
<tr>
<td>Bangladeshi</td>
<td>United States</td>
<td>41,280</td>
<td>23,707</td>
<td>17,573</td>
</tr>
<tr>
<td>Bangladeshi</td>
<td>New York State</td>
<td>20,269</td>
<td>11,960</td>
<td>8,309</td>
</tr>
<tr>
<td>Pakistani</td>
<td>United States</td>
<td>153,533</td>
<td>85,600</td>
<td>67,933</td>
</tr>
<tr>
<td>Pakistani</td>
<td>New York State</td>
<td>32,692</td>
<td>19,069</td>
<td>13,623</td>
</tr>
<tr>
<td>Sri Lankan</td>
<td>United States</td>
<td>20,145</td>
<td>10,441</td>
<td>9,704</td>
</tr>
<tr>
<td>Sri Lankan</td>
<td>New York State</td>
<td>2,692</td>
<td>1,502</td>
<td>1,190</td>
</tr>
</tbody>
</table>

Source: Census 2000
Four Month Exploratory Project

This is an exploratory four month project on South Asian Immigrant Women’s HIV/AIDS Related Issues in NYC. The project was funded by a very small grant by the Department of Health and Human Services under the Rapid Assessment, Response, and Evaluation (RARE) programs and with the support of The Asian and Pacific Islander Coalition on HIV/AIDS (APICHA), a community-based organization in New York City. One of the goals of this project is to share findings with the South Asian communities and to provide recommendations to the Department of Health and Human Services (Federal Office of Minority Health). Though limited in scope due to rigid time and budget constraints, this exploratory project helped us gain valuable preliminary insights. The findings and recommendations provide some direction for future research. It helps identify some of the key issues involved in addressing HIV/AIDS and moreover the report indicates the need to increase outreach, enhance resources and develop policies and practices for the South Asian communities, including important segments such as South Asian immigrant women.

Community Consultation and Involvement

Central to this exploratory project is that it is community centered and there is community input throughout the project. To achieve this goal a Community Working Group (CWG) was created at the outset of the project. The Community Working Group included members of various Asian community based organizations that serve the South Asian communities. It also included health care providers, city council and local health department representatives, an inter-faith representative, researchers and individuals working with at-risk populations. [See Appendix]
Goals of the Project

• To better understand South Asian Immigrant Women’s HIV/AIDS related issues by examining HIV/AIDS knowledge, perceptions, attitudes, and perceived susceptibility in the South Asian immigrant community in New York City.

• To assess their knowledge of available resources and utilization of services.

• To explore strategies for effective outreach with regard to education, prevention, and treatment of HIV/AIDS for South Asian communities in the United States.

• To share the findings with South Asian and Asian communities and to provide recommendations to the Department of Health and Human Services.
A multi-method approach was used in this exploratory project and included both qualitative and quantitative methods. This approach was utilized to maximize preliminary information for a diverse population, given time and budget constraints. All field team members were trained in data collection and analysis techniques.

Sample and Data Collection

Data collection tools included pre-focus group questionnaires, focus groups, a one-day street survey and personal interviews. Although the primary focus was on South Asian immigrant women, both immigrant women and men were included in the non-random sample to better assess the differences and commonalities. The Community Working Group reviewed the data tools and gave important input to ensure they were appropriate for the community and data collection.

Focus Groups: Four focus groups were conducted with 22 participants from an expected total of thirty two. The small focus groups helped to maximize in-depth information from the participants and provided a safe space for discussion. Recruitment for focus groups included developing a contact list which categorized potential participants by key criteria including variations in age, religion, country of origin, education, occupation, and relationship and immigration status. Referral and a snowball sampling approach with attention to group variability were utilized. Field members contacted approximately 73 potential participants including community service providers and South Asian immigrant men and women. Each participant was provided $20. The duration of each taped and transcribed focus group was approximately 90 minutes. Note takers were also present for each focus group. Topics covered the norms, values and beliefs that influence risk and protective behaviors, access, and utilization of services by South Asian immigrant women and men.

Pre-Focus group questionnaire: (N =22) Prior to the focus-group session, participants signed consent forms and completed an anonymous brief pre-focus questionnaire. This was obtained to get a demographic profile and to get some basic information on each focus group participant’s knowledge base, perceptions, awareness of available resources and utilization of services and to identify what issues are perceived as important to the South Asian communities.
The demographic profile for the pre-focus group is:

Gender: Female =64%, Male =36%
Age Group: 18-25 yrs =9%, 26 to 39 yrs =36%, 40 yrs and older =55%
Country of Origin: Bangladesh =14%, India =50%, Pakistan =18% & other =18%

**Personal Interviews:** (N=6) Six personal interviews were conducted with members active in the South Asian communities or who had some understanding of HIV/AIDS related issues so as to better understand the cultural context and explore challenges and potential outreach strategies. These participants were also selected from the master contact list that was developed to select potential focus-group participants. Each personal interview was taped and transcribed.

**Street Survey:** (N= 48) A one-day self-administered street survey was conducted among South Asian immigrant women and men to explore specific questions about their HIV/AIDS knowledge, perceptions, attitudes, and perceived risk behavior susceptibility, their knowledge of available resources and utilization of services and to identify their opinion of what issues are perceived as important to the South Asian communities. Demographic measures included age, country of origin, gender, educational attainment, religion, relationship status, year of migration, sexual orientation, and living arrangement. [See Table 2]

The street survey was conducted in Jackson Heights, a predominately South Asian neighborhood and commercial district. Of the 70 surveys administered a total of 48 surveys were used for the sample. Upon survey completion, a resource sheet was available to all participants. Participants were also given a lunch incentive for two. This incentive was donated by a member of the community, Tariq of Shaheen Int’l Restaurant, in support of this community-based initiative.
Data Analysis

Data was analyzed using the process of triangulation. Analysis of the data included content analysis of taped, transcribed focus groups and personal interviews. Qualitative data was coded inductively and deductively to capture key issues, patterns, and themes that emerged from the focus group and personal interviews. Focus-group data analysis also included looking for the range of variation on each topic among participants. Quantitative data from the street survey and pre-focus group tool were entered into Statistical Package for the Social Sciences (SPSS) for analysis. Given the small size of the data sets, data analysis primarily included descriptive statistics such as frequencies and cross tabulations. Individual items and aggregated mean scores were used to assess knowledge base, perceptions, attitudes, perceived susceptibility, and importance of issues to the community.

Limitations of the Study

The generalizability of the results of this project is limited because of the small sample size and non-random recruitment method. In addition, there are potential biases due to the reliance on self reporting and the use of the English language for the street survey (translators for some languages were present if needed). The small sample size reflects the exploratory nature of this project and suggests the need for a larger study to develop a systematic baseline for the South Asian communities in the United States.
Table 2  Demographic Profile of Street Survey Respondents (N=48)

**Gender**

<table>
<thead>
<tr>
<th>Male</th>
<th>33.3%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Female</td>
<td>66.7%</td>
</tr>
</tbody>
</table>

**Education Level**

<table>
<thead>
<tr>
<th>27.1% Graduate or more</th>
</tr>
</thead>
<tbody>
<tr>
<td>47.9% Bachelors, some college</td>
</tr>
<tr>
<td>25% High School or less</td>
</tr>
</tbody>
</table>

**Religion**

<table>
<thead>
<tr>
<th>41.7% Islam</th>
</tr>
</thead>
<tbody>
<tr>
<td>31.3% Hinduism</td>
</tr>
<tr>
<td>12.5% Christianity</td>
</tr>
<tr>
<td>2.1% Sikhism</td>
</tr>
<tr>
<td>2.1% Jainism</td>
</tr>
<tr>
<td>8.3% Other</td>
</tr>
<tr>
<td>2.1% None</td>
</tr>
</tbody>
</table>
**Findings**

**Community Norms and Context**

“...culturally, it’s difficult for people to accept that it might be a problem in the community, in the immigrant community here, South Asian. It’s perceived as a problem that ‘they’ have, that other people have, not something that’s here. But, I think that’s why most people, women that I know of, don’t get tested. It’s because they don’t feel that they are at risk.” [FGP]

Public Health interests are best served when they receive community support and participation increases when local leaders lend their political support. To date, HIV/AIDS has not received much attention as a public issue within the South Asian immigrant communities in the United States. Analysis of the data indicates that while HIV/AIDS is acknowledged as an important health issue by participants in this project, it has yet to become a prominent public health issue for South Asian communities in the United States. The findings of this study indicate that the lack of public discussion of HIV/AIDS in South Asian communities in the United States is linked to cultural and structural factors. Cultural factors include certain assumptions of gendered relations based on patriarchal norms, values and beliefs prevalent within the South Asian communities but not necessarily unique to these communities. They include norms and values around sexuality, family, and community. HIV/AIDS-related issues have been frequently cast within a moral framework and it appears that this association with notions of morality partially plays out within the context of constructing South Asian community and culture. At first glance it appears that the lack of public debate on HIV/AIDS among South Asian communities is frequently interlocked with cultural and structural factors. Taboos, notions of family, gender relations, community, and expectations are intricately intertwined with the structural barriers based on policies and practices of the social, legal, economic, and health systems in the United States.

Sexual taboos and the silence around sexuality contribute to the lack of attention to HIV/AIDS as a public health issue by the South Asian communities. Discussions on sexuality and sexual behavior are viewed as taboo in many South Asian families and within the community particularly if it pertains to homosexuality. There is considerable homophobia within the South Asian communities. Compulsory heterosexuality and monogamy is assumed to be the norm despite the reality of many South Asian women and men’s lives. Some participants in focus groups and personal interviews point out that while sexual taboos, stigma, and patriarchy play an important role in the context of morality in South Asian
cultures, these cultural constructs are also prevalent among other communities. The issue is how much these notions are emphasized and the ways they are manifested.

Structural factors in the South Asian context pertain to institutional systems particularly those related to immigration, health, education and employment. Lack of access to health care, mistrust of health agencies, and fear of institutional repercussions prevent people from accessing the services thereby minimizing the problem and importance of HIV/AIDS as public health issue for South Asian communities in the United States.

**HIV/AIDS Knowledge, Perceptions and Attitudes**

“It’s a disease that is transmitted through contact of body fluids, through sexual contact, it’s a disease that can be passed on from a mother if she is carrying to her pregnant child. I think it can probably be carried through breast milk, through blood transfusion, sexual.” [FGP]

“Yes, it gets transmitted through sexual activities, whether it is homosexual or straight sex and it gets transmitted also by needles, use of these needles, where they do drugs…” [FGP]

The findings from the multiple sources of data in this study indicate that the HIV/AIDS overall knowledge base is average among South Asian immigrant women and men but serious gaps exist within this knowledge base. Survey data (n=48) shows that on a scale of seventeen items to assess respondents’ knowledge base, both women and men have an average knowledge base. Female and male respondents answered 58% and 57% of the seventeen statements correctly. In terms of age, among the three age groups in the survey sample (age groups: 18-25, 26-39, 40-59) the older immigrants (40-59) tend to have a lower knowledge base (47% correct answers) than the other age groups. Educational attainment impacts the HIV/AIDS knowledge base. HIV/AIDS knowledge base increased with education. Respondents with graduate education or more had 69% correct answers compared to 54% for bachelors or less and 52% for high school or less. [See Table 3]
Responses to specific statements in the street surveys indicate serious gaps in knowledge leading to incorrect perceptions [See Table 3a]. For example, only 19% of both female and male respondents knew the statement “All babies born to mothers with HIV/AIDS will also be HIV-infected” was false. Similarly, only 29% of both female and male respondents answered correctly that “In most cases, HIV/AIDS can be detected by a test given within three months after a person is infected.” Surprisingly, 53% of female respondents and 56% of male respondents thought that “There is a cure for AIDS”. There was also a gender difference in response to the statement about the modes of HIV transmission. The statement, “Blood, semen, vaginal fluids, and breast milk are the only fluids that can transmit HIV/AIDS”, was answered correctly by 50% of female respondents compared to only 31% of male respondents.
### Table 3a: Results of Knowledge Base Questions (N=48)

<table>
<thead>
<tr>
<th>Questions Asked/Correct Answer</th>
<th>% of Correct Answers</th>
<th>Female</th>
<th>Male</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>All babies born to mothers infected with HIV/AIDS will also be HIV-infected. False</td>
<td>19%</td>
<td>19%</td>
<td>19%</td>
<td></td>
</tr>
<tr>
<td>Anybody can get HIV/AIDS. True</td>
<td>72%</td>
<td>69%</td>
<td>71%</td>
<td></td>
</tr>
<tr>
<td>In most cases, HIV/AIDS can be detected by a test given within three months after a person is infected. True</td>
<td>28%</td>
<td>31%</td>
<td>29%</td>
<td></td>
</tr>
<tr>
<td>Latex condoms provide effective protection against HIV/AIDS during sex. True</td>
<td>62%</td>
<td>63%</td>
<td>62%</td>
<td></td>
</tr>
<tr>
<td>Diaphragms, birth control pills &amp; patches provide effective protection against HIV/AIDS during sex. False</td>
<td>63%</td>
<td>38%</td>
<td>54%</td>
<td></td>
</tr>
<tr>
<td>You can get HIV/AIDS by sharing needles used to inject drugs/or medicines. True</td>
<td>94%</td>
<td>81%</td>
<td>90%</td>
<td></td>
</tr>
<tr>
<td>Blood, semen, vaginal fluids, and breast milk are the only fluids that can transmit HIV/AIDS. True</td>
<td>50%</td>
<td>31%</td>
<td>44%</td>
<td></td>
</tr>
<tr>
<td>There is a cure for HIV/AIDS. False</td>
<td>47%</td>
<td>44%</td>
<td>46%</td>
<td></td>
</tr>
<tr>
<td>If you touch someone with HIV/AIDS, you are likely to get HIV/AIDS. False</td>
<td>94%</td>
<td>75%</td>
<td>61%</td>
<td></td>
</tr>
<tr>
<td>You can get HIV/AIDS from using public toilets. False</td>
<td>63%</td>
<td>69%</td>
<td>72%</td>
<td></td>
</tr>
<tr>
<td>You can get HIV/AIDS by giving blood. False</td>
<td>41%</td>
<td>63%</td>
<td>48%</td>
<td></td>
</tr>
<tr>
<td>You can get HIV/AIDS by sharing food utensils with someone with HIV/AIDS. False</td>
<td>78%</td>
<td>69%</td>
<td>75%</td>
<td></td>
</tr>
<tr>
<td>Most people with HIV/AIDS quickly show signs of being sick. False</td>
<td>41%</td>
<td>56%</td>
<td>46%</td>
<td></td>
</tr>
<tr>
<td>You can get HIV/AIDS by having a blood transfusion. True</td>
<td>81%</td>
<td>75%</td>
<td>79%</td>
<td></td>
</tr>
<tr>
<td>You can get HIV/AIDS from kissing. False</td>
<td>66%</td>
<td>63%</td>
<td>65%</td>
<td></td>
</tr>
<tr>
<td>Most gay men have HIV/AIDS. False</td>
<td>31%</td>
<td>56%</td>
<td>40%</td>
<td></td>
</tr>
<tr>
<td>You cannot get HIV/AIDS if you are having sex with only one partner. False</td>
<td>66%</td>
<td>63%</td>
<td>65%</td>
<td></td>
</tr>
</tbody>
</table>
Findings

Data from the focus group interviews show that most of the participants were knowledgeable about HIV, its impact on the immune system, the modes of transmission and protection measures. Participants noted that information in the South Asian communities came from books, magazines, education in schools, movies, word of mouth, friends, doctors, the “March on AIDS” and from information about HIV/AIDS among celebrities in the U.S. like Magic Johnson and Rock Hudson. The focus groups identified unprotected sex as the main mode of transmission. Other modes of transmission discussed were non-sterile needle use, blood transfusion and mother-to-child transmission. Nearly all participants in the focus group noted that there was no cure for the disease. Some also acknowledged the socio-political context and referred to the disease as “demoralizing”. Although 65% of the street survey respondents responded correctly by not identifying kissing as a mode of AIDS transmission, some focus-group participants were unsure of whether kissing was an AIDS-related risk behavior. Abstinence, using condoms and use of clean needles were the most popular protective measures noted in all focus groups. A very high percentage (90%) of respondents to the survey data knew that the use of non-sterile needles increases susceptibility to HIV/AIDS.
Related Perceptions and Attitudes

“I think one [perception] is that it’s about class, that poor people get it, because there is so much morality associated with the disease and then among upper middle class or higher income people, would just have better healthier lifestyles because they’re kind of morally equipped to handle sexuality. I think there’s a real taboo around it… I also think there is also a perception that HIV/AIDS are all about sex. That it’s not about blood transfusions. That it’s primarily about sex and sexuality. The perception is that most South Asians are very conservative, and they’re very conservative also means that they are very good and so therefore are not as vulnerable. So the people who are vulnerable are the ones who are not good among us and the ones not good among us are usually seen, based on class… Sure, I think a lot of it comes down to the difference between behavior and identity. So, meaning that there may be a lot of South Asians who engage in a very non-conservative lifestyle, right? That’s not their identity, it remains hidden…” [PI]

Perceptions based on incorrect knowledge point toward an attitude of othering in the South Asian communities. Here the term othering is used to describe the tendency of individuals and groups to attribute a problem to a group other than one’s own. This othering in the context of HIV/AIDS is not unique to South Asian communities but also exists within mainstream American society and among other ethnic minorities. In focus groups (with the exception of a few participants) and in personal interviews, othering was used primarily to describe the larger South Asian communities’ attitude toward HIV/AIDS rather than a reflection of the focus group or personal interview participants’ own attitudes. Participants in focus groups and interviews described “the community attitude” to HIV/AIDS as “a problem of others.” The notion of others refers to racial or ethnic communities and the gay community. Within the South Asian communities, othering was used for specific nationalities or the lower socio-economic class within the South Asian communities. This attitude of othering is also substantiated in the street survey responses around AIDS and gay men. On the specific statement, “Most Gay men have HIV/AIDS” approximately 60% of respondents answered “true” or “don’t know.” This perception was much higher among female respondents (69%) than male respondents (44%). In addition, approximately 45.5% of the respondents (N=47) agreed with the statement “Most people with HIV/AIDS deserved to get it because of their lifestyle” indicating notions of morality associated with HIV/AIDS.
Perceived vulnerability was measured by asking respondents if they were worried about getting AIDS. Women respondents had a much lower perceived vulnerability compared to men. Fifty-one percent of women in the street survey strongly or slightly agreed to the statement, “I am not worried about getting HIV/AIDS” compared to 31% men. This trend is also shown in other perceived vulnerability data in which 39% of women did not feel the need to protect themselves from HIV/AIDS compared to 28% of men. This might be explained by information from the focus groups and personal interviews that point to assumptions particularly among married immigrant women that they are in monogamous relationships which reduce their susceptibility. This could reflect slightly lower perceived vulnerability patterns for the female participants and stresses the need for more gendered education awareness initiatives. Focus groups and personal interviews too point to the assumption, particularly among married immigrant women, that they are in monogamous relationships, and that this reduces their susceptibility. Survey data indicates that 34% responded “true” or “don’t know” to the statement, “You cannot get HIV/AIDS if you are having sex with only one partner.” As noted earlier, the perception that HIV/AIDS is not a problem within the South Asian community also lends itself to a certain degree of complacency within the community and increases a sense of low perceived susceptibility. The slightly lower perceived vulnerability pattern among the female participants also stresses the need for a more gendered approach to HIV/AIDS prevention education initiatives.
Risk Behavior

“I just want to add that in terms of my own South Asian experience, I have a lot of South Asian friends…there is often times a lot more fear…I don’t know if this is only true for South Asians but I am speaking in the South Asian context…a lot of times South Asian women in relationships are convinced into having unprotected sex and that is a constant fear.. it’s not necessarily that they want to do that but for one reason or the other it happens.. and I have seen that pattern happen…” [FGP]

“…men who come without their wives, they tend to become sexually active when they are here and they bring their wives over and in the meantime they do not use protection, and they don’t get tested and possibly transmit STDs to their wives.” [FGP]

Studies indicate that gender roles often give men primary authority over sexual and reproductive health decisions. Within the patriarchal family, women may have little power and little choice in addressing issues such as condom usage. In addition, accepted standards of behavior may make it difficult for women to negotiate or even discuss sexual issues with their partners. The findings in this project, in terms of risk behavior, are limited, as condom usage was the only indicator for risk behavior that was measured. Data from the survey and focus group point to two different trends. In the street survey data, 55% of women indicated that they discuss sexual intimacy issues with partners whereas 64% of men indicated that they discuss sexual intimacy with partners. Also 48% of women indicated that their partner uses condoms during sex compared to 36% of men. Although survey data does not show any significant lack of condom use or inability to discuss sexual intimacy issues with partners, focus group data suggests that South Asian male patriarchy and infidelity are part of risk behavior. Women’s lack of power within an abusive relationship leaves them vulnerable to sexual violence. Beyond the psychological and emotional abuse that nonconsensual sexual activity inflicts, this vulnerability also puts women at risk of being infected with sexually transmitted diseases that their partners may have contracted.

The findings from the multiple sources of data indicate the need to increase the knowledge base for South Asian immigrant women and men. Lack of knowledge leads to false perceptions about transmission modes, reduces perceived vulnerability, may increase risk behavior, impacts attitudes among segments of the population and lends itself to othering. There is a serious need for educational outreach and to develop strategies that increase access to information on HIV/AIDS prevention and treatment among South Asian immigrants.
Barriers to Accessing Information and Using Services

“I think it is difficult to say whether a service actually exists if it’s not accessible to your community, if there’s nobody there that speaks the language, they’ve never done outreach where you live—they may exist—there may be a building, but it really doesn’t exist for you...so, I think, that’s something that is kind of a barrier...” [FGP]

“I think people don’t want to be tested in a place where someone else might know about it.” [PI]

There are multiple barriers that South Asians face in accessing information and using services. These barriers are both cultural and structural. Key cultural barriers include denial, stigma, and patriarchy. Key structural issues include the high cost of health care and lack of health insurance, mistrust of government agencies due to fear of breach of confidentiality, and fear that information sharing by institutions will negatively impact immigration-related issues.

Cultural Factors

Key cultural barriers include denial of the prevalence of risky sexual behaviors among South Asians and complacency around the risk of contracting HIV/AIDS. Other important factors that prevent accessing information and services include fear of stigma and isolation by family and community members, as well as patriarchal norms and values that influence gender relations. Patriarchal community norms particularly limit women’s ability to make choices and decisions as they relate to their lives and bodies.
Denial

“If you are getting married to somebody that your parents selected and they are coming from a decent background there is a huge denial of our sexuality. So that’s a basic problem. So we are assuming that a 20 year old or a 25 year old has never experienced sex or has never gone out or has never dated anybody. We assume that even if they have dated it is very platonic, so it seems fine because there will not be any infections.” [FGP]

Large numbers of South Asians are in denial of risky sexual behavior and the possibility of the prevalence of HIV/AIDS within their communities. This stems from the perception that acknowledging the prevalence of risky behavior may challenge some of the normative assumptions around sexuality, family, community and morality. Denial is also based on the assumption of compulsory heterosexuality and marriage as synonymous with monogamy. There is a lack of acknowledgement of extra-marital affairs and same-sex sexual relations as coexisting with heterosexual marriages/relationships. Denial is also linked to upholding the model minority image of the South Asian immigrant community and fear of any negative impact on the individual or collective image. Hence there is both denial and resistance to addressing issues such as homophobia, infidelity, HIV/AIDS and class issues.

Stigma

“In my experience with clients they [HIV positive South Asian clients] hide from the family and they do not get any support, especially the gay clients. I know a positive gay client who never talks to his parents but before he was positive he talked to his parents and his parents accepted him and went around with him but none of the people accepted him and their friends did not accept him and society did not accept him. Then the parents and relatives said he was dead...” [FGP]

Many South Asians frequently construct South Asian culture as “family oriented” rather than “individual oriented” and they view the individual as a representative of the family. In this context, the emphasis on notions of “shame”, “honor” and “guilt” attain a different meaning whereby failures of the individual result in the loss of face or honor for the entire family. Individuals do not reveal HIV-positive status due to the fear of being stigmatized by their family and community. There is a tendency to hide problems for fear of individual, family,
and community reaction particularly in the form of ostracism and isolation. Fear of being labeled a failure, sexually promiscuous, or a drug user, and fear of bringing shame on the family all become major cultural barriers in accessing information and utilizing services. Individuals are reluctant to access the system for fear that their morality will be questioned and their character dissected and scrutinized by members of the community. People also fear abandonment and the loss of emotional support.

Patriarchal Norms and Values

“I have a feeling sometimes from things that I overhear when somebody offers information. Our women, even here, are dominated by men. They can't ask their husbands to use condoms even if they wanted to or even if they were afraid because men kind of consider it an insult. You know, women telling them to do a certain thing...that kind of disparaging attitude towards their wives or women leads to consequences.” [FGP]

Women’s access to information and utilization of services is limited by their dependent position within the family. Patriarchal norms and negotiation around sex limit women’s ability to make certain choices about sexual health and intimacy with their partners including their use of condoms. Patriarchal assumptions of men’s rights to women’s bodies may lead to non-consensual sexual activity and thus increase susceptibility to sexually transmitted diseases. Unequal gender relations and women’s defined roles within the context of marriage are also barriers.
Structural Factors

“I have one thing to say for the undocumented persons. The undocumented women want to be become documented in this country and if they do have an inkling that they have HIV and AIDS they will never approach the system.” [FGP]

“There is a tremendous fear among the community to utilize any government services whatsoever.” [FGP]

“I mean the current administration, there’s been a lot information sharing [with] a lot of government agencies which they are not supposed to be doing, that have caused a lot of fear.” [FGP]

“So after one month I was really sick and was in the hospital and then I got the hearing date [immigration hearing], the second hearing date, but I didn’t go because I was scared about my disease and if I disclosed I thought they may send me back to India. So, I didn’t go for my court hearing and so I don’t know about my status, maybe they closed the case.” [FGP]

Lack of Access to Free or Affordable Health Care

“Coming to Medicaid most of the community knows about immigrant issues and if they ever want to be documented then they should not have Medicaid and then that creates problems too. I think they are all more aware of these immigrant issues than these AIDS issues.” [FGP]

Data from focus groups and personal interviews with community experts and service providers note that many South Asians do not have any form of health coverage. This becomes a major barrier to prevention and early diagnoses. This lack of access to low-cost or free health care is a major barrier to prevention and treatment. The sections in the street survey and pre-focus group questionnaires that solicit opinions on the importance of issues in the South Asian community show that health care coverage was the most important issue. Lack of health care coverage leads to ignoring health problem and prevents timely treatment. The need for members of the community to access free, convenient, or affordable quality health care, including health insurance is critical and a major structural impediment to HIV/AIDS prevention and treatment.
Lack of Linguistic and Cultural Competency in Service Delivery

“In the subways you see a lot of ads in English and Spanish telling young girls to use condoms and things but I don’t see them in any other languages. They have other things in Hindi and Urdu like for the World Trade Center they even had mental health ads in all different languages but not for this issue.” [FGP]

“I was very sick at the beginning and she had lot of barriers to talk to the doctors, talk to the hospital, so she needs at that time interpretation, so they got the interpreter and everything was easier.” [PI]

Accessing services is limited by language barriers, lack of correct information, and lack of sensitivity in addressing cultural concerns among health care institutions. There is also a paucity of any systematic institutional outreach strategies specifically geared toward the South Asian communities. This failure to address language translation and cultural sensitivity on the part of public institutions has major consequences on the communities’ HIV/AIDS awareness, prevention and treatment.

Street survey data [See Table 4] indicate that South Asian immigrant women and men are unaware of services available in their communities. On a scale of six items to assess respondents’ knowledge of services available in their community, results show a low level of knowledge of service provision. However female respondents’ knowledge of services was higher (42%) compared to male respondents (27%).
Approximately 50% of the female respondents and 25% of male respondents knew of HIV/AIDS counseling services. Similarly about 50% of female respondents knew of confidential and/or anonymous HIV/AIDS testing compared to 31% of male respondents. 47% of female respondents and 25% of male respondents answered “yes” to having knowledge of HIV/AIDS Hot Lines, Relationship Violence Counseling and HIV/AIDS Support Groups. However, there was a low knowledge level about information and services which was reflected by the fact that only 6% of both male and female respondents answered “yes” to the question, “Do you know of any HIV/AIDS services for the South Asian Community?”

Pre-focus group respondent data also indicate a low knowledge of information and services among focus group participants. Lack of knowledge of services was partially attributed to language barriers, as well as lack of adequate outreach to the diverse communities. APICHA was the service provider name that came up most frequently followed by the Gay Men’s Health Crisis (GMHC) and Bellevue Hospital. Sakhi for South Asian Women was also mentioned by some participants in the broader service context.
Mistrust of Public Institutions

“Immigration status is now becoming a really big thing... you know with Asians that is a big, big issue and language, they think okay, we go, [for testing or treatment] and some INS people will come and this doctor many be working for INS, and that is a very, very big issue after 9/11...very big issues...” [FGP]

The rising anti-immigrant sentiment in the United States, anti-immigrant policies like the Patriot Act and the potential threat of deportation create a sense of fear among segments of the population. This exacerbates a sense of vulnerability and becomes a barrier to information, access and utilization of services. Large segments of the South Asian community mistrust governmental agencies, including health agencies. Fear of breach of confidentiality leads to silence and potential under reporting. There is a strong perception among many South Asians that health agencies share their data with other agencies, particularly with the Department of Homeland Security Bureau of Citizenship and Immigration (previously known as I.N.S.). The focus group participants frequently mentioned how racial profiling and anti-immigrant sentiments prevented people from accessing health agencies. Mistrust and concern about information sharing that could have implications on immigration status or lead to potential deportation was seen as a barrier to accessing health services.

Thus, cultural barriers in accessing information and utilizing services includes stigma and fear of negative reactions by family, friends and their community. For immigrant women, patriarchal norms, negotiations around sex and perceived low vulnerability based on cultural assumptions around fidelity were also discussed as barriers. Participants in focus groups and personal interviews indicated the reluctance by some people within the community to utilize services from South Asian healthcare providers due to the fear of breach of confidentiality.
Strategies for Education, Prevention and Treatment

“If you are going there, if you are outreaching to them, you have to go with a plan, so if you find 100 HIV positive people, you should be ready to provide them services.” [FGP]

“If there were more services, not just in areas like Jackson Heights and Coney Island [but] wherever there are pockets of South Asians.” [FGP]

The South Asian community is comprised of diverse communities and there is considerable variation across class, ethnicity, religion, language and nationality and immigration status. Data from focus groups and personal interviews consistently point to the need for a range of diverse strategies for outreach in terms of education, prevention and treatment. Underlying this notion is that any monolithic “cookie cutter” approach would not work, given the heterogeneity in the South Asian population in terms of class, ethnicity, religion, region, age, educational level, occupation, gender expectations, and immigration status. Focus group participants and personal interviewees offered a variety of potential strategies for education, prevention and treatment. Underlying these diverse comments was the need for the government to work more closely with community-based organizations to identify and promote appropriate strategies for this heterogeneous population. The following were identified as some potential strategies. In all focus groups, the use of both mainstream and ethnic media to outreach was seen as playing a critical role.
Role of Media

“I mean, it’s a very media savvy community. They are big media consumers, so I’ve yet to see a PSA on any India channel or station.” [PI]

Participants spoke of the importance of using popular culture to outreach to the South Asian community. They emphasized the large role that media plays in South Asian homes. A potentially effective strategy would be to have advertisements and information on prevention and treatment through television, videos, ethnic magazines and newspapers. Focus group members pointed out the importance of having this in English and multiple ethnic languages. They spoke of the need to disseminate information using popular culture strategies. Another effective strategy to reduce denial and stigma within the South Asian community is to have well known celebrities participate in educational campaigns increasing HIV/AIDS awareness and encouraging testing. A media announcement by ethnic celebrities before home videos or in movie theaters showing ethnic films was seen as an effective outreach tool. In addition, the use of public service announcements on mainstream and ethnic channels and advertisements about free and confidential HIV/AIDS testing services in multiple languages in subways was also noted as important.

Public Venues

“We have basically everywhere ads in the supermarket from building construction to some rice which is sold for 10 lbs bags.. we never have [AIDS] advertisements there.. then people would look at it.” [FGP]

Public venues as a mode of education includes leafleting, placing posters in grocery stores, performing street plays and advertising at street fairs as effective avenues to provide information. Focus group participants spoke of the use of leafleting, distributing flyers and posting large posters in grocery stores and other public venues. In addition, public forums on social issues, street plays and short videos in multiple languages were also noted as part of a multi-pronged approach.
Access to Information Through Websites

“Personally I go to internet too, because there is a doubt now that saliva may be a carrier.” [FGP]

Using websites as important information resources to increase HIV/AIDS awareness and providing information on service delivery was also emphasized as an important strategy. Websites provides an important mechanism for answering questions, accessing information and attaining updated information locally and globally.

Education Outreach through Schools

“The Asian youth who are born here have a generation gap. We need to reach out to schools and to Asian teens who are born here. They can sometimes take information to their mothers and fathers...they are the people to educate their own parents and make them understand...” [FGP]

Discussion in schools about sex education and HIV/AIDS awareness, prevention, and treatment were also noted as important strategies. Using students to inform their parents through brochures, education forums and encouraging intergenerational discussion were also discussed. Sex education and outreach in schools was also seen as important in the context of sexual activity and potentially risky behavior among the younger generation. Many respondents advocated a proactive rather than a reactive approach in order to reduce risk behavior on issues around sex and drug use.
Religious Leaders and Religious Sites

“Try to focus on people inside of the community, in different religious centers, mandirs, gurudwaras, mosques, talk to them, and they will open up. Now things are changing.” [FGP]

“I think that faith-based organizations specifically should play a huge role…” [FGP]

“I think it will work, people will listen, especially when it is the temple, everyone will listen to it. They had a lecture about cancer, so like that but about HIV/AIDS, other diseases, and women’s health.” [PI]

Participants suggested encouraging segments and leaders within the community most resistant to addressing gender relations and sexuality to become more proactive in increasing HIV/AIDS awareness. Thus they can be active stakeholders in the health and wellbeing of the South Asian communities. Involving religious leaders in educational outreach and prevention was seen as an important outreach strategy. Outreach in religious sites included dissemination of information on HIV/AIDS at cultural events associated with temples, mosques and churches. Having pamphlets or encouraging religious leaders to talk about HIV/AIDS and reducing risk behaviors was seen as an important strategy.
Increasing Capacity of Community-Based Organizations

“I think our community organizations can play a role. A lot of these organizations have social gatherings so they can educate them (community) on many different occasions and they can also distribute some booklets about AIDS and many people will go there and get these free booklets.” [FGP]

Increasing the capacity of community-based organizations (CBOs) and involving the various CBOs in conscious raising and service provision was seen as an important strategy. This included educating and training members in various CBOs on HIV/AIDS awareness and providing them information about resources available within and outside of the community. This fits the notion of an integrated or broad-based coordinated approach. It is also important in reaching diverse segments of the South Asian community such as cab drivers and undocumented workers and in addressing multiple interconnected issues such as domestic violence, sexual violence, immigration issues, women’s health and many more.
Access to Free and Affordable Healthcare Coverage

“There is a problem because many people don’t have access to health benefits.” [FGP]

As noted earlier, health care and the lack of access to free or affordable health care coverage was seen as the biggest concern for South Asians. It is also a major barrier to prevention and treatment. It prevents early diagnoses and treatment of the problem. Focus groups and personal interviews emphasized the importance of an integrated services approach which incorporated HIV/AIDS prevention and treatment within the context of addressing other health issues including asthma, TB, diabetes, blood pressure and nutrition and women and men’s health related issues. Using the opportunity to outreach to women when they go to health centers for their children’s health care was seen as one potential way to inform women on HIV/AIDS issues. This could be as simple as having informational brochures in multiple languages at these sites.

All focus groups pointed out that at this juncture, given the communities’ relative lack of open discussion and perception of HIV/AIDS as a stigmatized disease, any outreach on prevention and treatment must be done in a broader context. Participants pointed out the value of “integrating medicine with culture.” Information, access to free condoms and prevention outreach at health fairs were also seen as an effective strategy. Success of this strategy in other contexts was noted in personal interviews and by focus group participants. A related prevention and treatment strategy was to have free or low cost mobile health clinics that incorporate confidential HIV/AIDS testing and treatment within a much more broad based health and nutrition framework. It was noted that there would be no stigma or less fear among the members in the community if HIV/AIDS services were incorporated with more commonly perceived health issues. Through mobile clinics people would have easier access while reducing the fear of being labeled. Participants consistently pointed out that any prevention and treatment sites solely directed toward HIV/AIDS issues may prove to be unsuccessful as an outreach strategy. They also noted that these sources must also be provided by main stream providers who are culturally competent as there is still some reluctance among South Asians to go to South Asian health providers on issues that the community sees negatively due to fear of breach of confidentiality. Therefore building trust and ensuring a safe and supportive environment is critical to the efficacy of many of these prevention and treatment strategies.
The following are some recommendations to address the issues identified in this exploratory study based on valuable input from the community:

**Recommendation 1**

*Improve Data Collection and Reporting to Develop a Reliable Baseline*

- Improve systematic collection and reporting of disaggregated data for South Asians in the U.S. by federal, state, and local government agencies and factor in undercounting and under-reporting.

- Develop a reliable baseline to assess ongoing changes given the large and growing South Asian population, particularly in New York City.

- Standardize definitions used for data collection for consistency and to avoid misidentification and incorrect categorization.

- Address the diversity of the South Asian communities by collecting data on country of family origin, country of birth, ethnicity and primary language.

- Support HIV/AIDS research for the South Asian communities while minimizing the potential negative impacts of research on minorities.
Recommendation 2
Address Barriers to Access and Utilization of Services in Policy and Practice

• Develop a comprehensive integrated healthcare approach to HIV/AIDS prevention and treatment programs.

• Increase information and access to free and low-cost health coverage to avoid the greater social, health care and economic costs in the long run.

• Address the problem of ethnic discrimination and increase trust of the community in governmental agencies by developing in policy and practice a system of no sharing of health or other information between agencies that can potentially threaten the well being, safety, and legal status of individuals with HIV/AIDS.

• Make services user friendly and available through increased language translation availability, cultural competency, confidentiality assurance, and having a diverse staff from both within and outside of the community in government funded institutions to address cultural and language barriers.

• Create a safe environment for those infected and affected by HIV/AIDS and hold public health and service agencies accountable for providing services and quality care for the underserved and marginal communities.
Recommendation 3

*Increase Community Collaboration and Input*

- Collaborate with the South Asian communities particularly community-based organizations in addressing effective strategies for risk reduction, prevention and treatment approaches.

- Involve representatives of the community as important stakeholders at the local, state and national level.

- Develop strategies with community-based organizations to increase the pool of trained and culturally competent service providers for the South Asian communities and develop resources including language material, directories, research initiatives, and networks.

- Collaborate with community-based organizations in educational and outreach programs to address gender issues, taboos, stigmas, sex education, risk behavior, HIV/AIDS and related preventative health care issues.

- Seek the input of HIV-positive individuals and community-based service providers in planning and implementing programs for South Asian communities.

- Work with members who have established trust and have a record of working in the community.
Recommendation 4
*Develop a Multilevel, Multi-Strategy approach to HIV/AIDS Education, Prevention and Treatment*

- Dedicate resources for cultural and language-specific education and prevention outreach strategies.

- Use popular culture as an effective medium to increase HIV/AIDS education, prevention and treatment.

- Use multiple sites such as health fairs, cultural events, religious sites, schools, social gatherings and grocery stores for education and prevention.

- Create mobile clinics that incorporate HIV/AIDS testing and treatment with other basic healthcare issues.

- Build a safe and supportive environment for free and confidential testing.
Recommendation 5
Change Community Outlook

• Emphasize the importance of a community-based response to increasing HIV/AIDS awareness, prevention and treatment.

• Organize community forums to strategize and eliminate negative community attitudes like denial, taboo, stigma, homophobia, and othering that hinder access and utilization of services.

• Create a coalition among community-based organizations to develop a coordinated response to HIV/AIDS within a healthcare and social justice framework.

• End the silence and denial about multiple partners particularly within “heterosexual monogamous” defined marriages.

• Draw upon community strengths and use the cultural concepts of “strong family values” and “family unity” to foster support rather than isolation for those living with HIV/AIDS.
Recommendation 6
Consider Gender throughout the Design, Implementation, and Evaluation of HIV/AIDS Programs

• Involve women, particularly those impacted by HIV/AIDS in developing strategies for the planning and implementation of policies and programs.

• Educate program managers and providers about the impact of gender issues and HIV/AIDS susceptibility.

• Challenge patriarchal norms that impact gender relations and increase women’s vulnerability to sexually transmitted diseases.

• Empower women to talk about health and intimacy with their partners.

• Address sexual violence and HIV/AIDS susceptibility issues.

• Create a safe environment for women to access information and service delivery.
It is high time that the status of the HIV/AIDS epidemic within South Asian communities in the U.S. is given attention so as to ascertain the scope and magnitude of the problem. The Centers for Disease Control (CDC) justifiably calls for new strategies for prevention for stemming the AIDS epidemic in 2004. Central to this strategy is reducing barriers to early diagnosis of HIV infection. This strategy is essential to reach the large and growing South Asian population in the United States as many individuals may be unaware of their HIV status or face barriers to accessing effective prevention services.

To implement the recommendations of this report there needs to be a commitment and delivery of resources. There also needs a commitment by the government, health agencies and the South Asian communities to provide and promote a comprehensive, timely, coordinated plan of action. To move forward there must be coordination and commitment among policy makers, federal, state, local institutional agencies and community-based organizations to ensure that policies and programs are appropriately linked to address the needs of the South Asian communities and to enhance the overall quality of life. There must be a commitment to assessment and evaluation that includes some indicators to measure success and efficacy of policies and programs. Strategies need to be reviewed and revised based on the lessons learned as various changes occur within the South Asian communities and in the development of the HIV/AIDS epidemic. This is best done by linking research, policy and practice in addressing HIV/AIDS in underserved communities such as South Asians in the United States.
Endnotes


3 This is an under reporting since Census data does not include large numbers of undocumented individuals. Separate statistics are not available for Nepal and Bhutan.


5 Raj, Anita and Danielle Tuller (2003) HIV-Related Knowledge, Risk Perceptions, and Behavior among a Community-Based sample of South Asian Women in Greater Boston. (Unpublished)

6 In 2002 the New York City Department of Health and Mental Hygiene AIDS surveillance database did not collect demographic data on ethnicity but only on country of birth. Based on this criteria as of 1/9/2002 the reported full-blown HIV cases in NYC were as follows- India: 102 (identified race: 9 white, 12 Black, 81 Other/Unknown), Pakistan: 16 (identified race: 16 Other/Unknown), Bangladesh: 14 (identified race: 14 Other/Unknown). Thanks to Dr. John Chin at the New York Academy of Medicine for providing this information.

7 This table does not include numbers for Bhutan and Nepal. It is an under reporting of the total South Asian population. It does not include many undocumented people and misidentified by race/ethnicity.

8 A major challenge for this study was the RARE mandate that the study be completed within three months. The diversity of the South Asian communities, a small budget and time constraints presented difficulties for data collection and analysis. This needs to be addressed in future funding for such projects.

9 In addition to the official list of participants, other individuals and groups were contacted at the outset of the project but were unable to participate due to prior commitments.

10 Approximately 20 community based organizations/service providers were contacted.

11 Twenty-two were excluded due to substantial portions of missing data.


14 This could be due to the high education level among a majority of the focus group participants.

15 Strongly agree = 4.9%, agree =21.3%, slightly agree =4.3%, slightly disagree =4.3%, disagree =8.5%, strongly disagree =29.8%.

Appendix: Research Team & Community Working Group

RARE Project Team

**Margaret Abraham** is the Lead Researcher and Project Coordinator for this project. She is a Professor of Sociology at Hofstra University and author of the book, *Speaking the Unspeakable: Marital Violence Among South Asian Immigrants in the United States* (RUP 2000). Margaret has worked as an action researcher in the South Asian community, has published and presented extensively in numerous journals and has been honored for her work on domestic violence. She has served on the Board of Directors in community-based organizations including Sakhi for South Asian Women and APICHA. She is an advisory member and consultant on national research projects related to violence against women.

**Roopa Chakkappan** is the Lead Field Member for this project. She is a Research Associate at NYU School of Medicine. Previously, she worked on various public health projects including the HIV/AIDS capacity building project at Sakhi for South Asian Women. Roopa obtained a Masters in Public Health from Boston University’s School of Public Health.

**Malabika Das** is a Field Team Member for this project. She recently worked at Sakhi for South Asian Women as the Development and Economic Empowerment Coordinator where she raised funds and implemented computer and technical classes for South Asian survivors of violence. Prior to that, she was a City Planner in Chicago administering community revitalization programs where needed. Malabika obtained a B.A. in Urban and Regional Planning from the University of Illinois at Urbana-Champaign.

**Sung Won Park** is the APICHA-RARE liaison for this project. Sung serves as the Associate Director of Prevention at APICHA. Currently, Sung oversees the Prevention Unit comprised of the Young People’s, Young MSM, Gay Bisexual Transgender, and Women’s Projects. Sung obtained a B.A. in Race, Politics and Healthcare from Mount Holyoke College.

**Sapna Patel** is a Field Team Member for this project. She worked as a Law Clerk at the NAACP in their Legal Aid Clinic for underprivileged local residents with HIV/AIDS and conducted research for detainees in pursuit of political asylum while at the Human Rights Documentation Exchange. Sapna holds a J.D. from The University of Texas School of Law and has a B.B.A. in Marketing from The University of Texas Austin.

Community Working Group Members

**Mamatha Bhagavan, MBBS**, is a Research Associate in the Office of Special Populations. She is the project coordinator for the Study on Asian Community Institutions, a project that evaluates the role of Asian community institutions in creating, maintaining and/or challenging social norms that may assist or impede HIV prevention activities.

**Ranu Boppana** is an Adult and Child Psychiatrist currently practicing in New York City. Until last year, she practiced at the Asian Outreach Clinic of Queens Child Guidance Center and has worked with several hundred South Asian families.
Gurpreet Clair is a Program Manager with the New York State Department of Health’s AIDS Institute. She is on the Steering Committee of the National South Asian HIV/AIDS Network (NSAHAN), which works to strengthen HIV prevention, treatment, and care programs for South Asians in the US.

Gregory Huang-Cruz is in Training and Technical Assistance at Cicatelli Associates Inc. and also an advocate for HIV/AIDS prevention education and awareness. He is presently the Co-Chair of the Policy and External Relations Liaison Committee of the New York City HIV Prevention Planning Group (PPG). He is a Board member of the Urban Coalition on HIV/AIDS Prevention Services (UCHAPS).

Fran Gau has been working as the Director of Counseling Services for New York Asian Women’s Center since 1998. As Director, she trains and supervises all counseling and hotline staff. Prior to this, she was the Center’s Children’s Services Coordinator for four years.

Christopher Lobo is a marketing manager for Cab Watch, a program of Citizens of NYC that mainly works with Taxi & Limousine drivers in the tri-state area. He represents Cab Watch at many workshops and meetings on HIV/AIDS and STD’s at APICHA.

Surabhi Kukke is an Evaluation Coordinator at Planned Parenthood of New York City’s Margaret Sanger Center International and currently works on an evaluation guide for sexual and reproductive health programs in the developing world. She has provided technical assistance for HIV/AIDS prevention strategies in South Asian communities in the U.S.

Robina Niaz is a Social Worker and a Civil Rights Activist. Since 9/11, Ms. Niaz has worked to raise consciousness about its backlash on the South Asian, Arab and Muslim communities by organizing with the Not In Our Name Project and Justice for Detainees.

Purvi Shah is Executive Director of Sakhi for South Asian Women. She has been active with Sakhi for the past eight years and has twice served on the Board of Directors. She is a member of the Association of Asian American Studies and a poetry editor for the Asian Pacific American Journal. Ms. Shah is fluent in Gujarati, Hindi, and Spanish.

Suki Terada-Ports became involved with AIDS work in 1985 by starting the Minority Task Force on AIDS, the first minority AIDS service organization in NYC. She also helped to start Iris House, APICHA and the Family Health Project and VOW, both advocacy organizations for women of color.
APICHA HIV Primary Care Clinic
Free-of-cost or sliding scale fee-based comprehensive HIV medical care
Comprehensive primary care
STD screening and treatment
Dental care referrals
Mental health assessment and treatment
Referrals to specialty care

Supportive Services
for People Living with HIV and AIDS (PLWH/A)
Acupuncture treatments by a licensed acupuncturist
Interpretation/translation and off-site service escort
Legal advocacy
Emergency financial aid
Food pantry
Nutrition risk assessment and counseling
Support groups in English, Mandarin, Japanese, Art and Tea, and survival skills

HIV Testing and Counseling
On- and off-site testing using OraQuick rapid tests, OraSure, and Home Access

Access to HIV information
Via our multilingual Infoline 866-APICHA9 or 866-274-2429

Prevention interventions
Designed for young people, men who have sex with men, bisexuals, heterosexual women and men, and persons of transgender experience
Outreach
Workshops and conferences
Leadership training
Informational brochures, movies and other fun and educational activities