

# **Legal and Ethical Report**

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# **Discrimination & HIV/AIDS**

in South Asian Communities

Legal, Ethical & Human Rights Challenges

An Ethnocultural Perspective

June 1999

## **Community Research Sponsored By:**

Alliance for South Asian AIDS Prevention [ASAP]

**This project was funded by the AIDS Care, Treatment and Support Program  
under the Canadian Strategy on HIV/AIDS, Health Canada**

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Discrimination & HIV/AIDS in South Asian Communities

## Legal and Ethical Report

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The findings and recommendations of this research report do not necessarily reflect the views of Health Canada or the Alliance for South Asian AIDS Prevention.

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## Legal and Ethical Report

Legal, Ethical & Human Rights Challenges: An Ethnocultural Perspective

# ACKNOWLEDGMENTS

The successful completion of this project is the result of many people working together towards a common goal. Thanks should go first to the participants in the study who talked openly (some of them for the first time), and at length about the impact of HIV/AIDS in their lives, in the lives of their loved ones, and in the lives of their communities. The project report has attempted to faithfully reflect their words, stories and lives.

Much thanks as well to the Key Informants whose systemic perspective was important in determining what is unique about HIV/AIDS in a specific cultural community. A list of Key Informants is provided in an appendix to this report.

This project was guided by a dedicated Project Advisory Committee who met several times over the approximate 3-month timeframe of the project. Half the Committee members are themselves living with HIV/AIDS. The Committee members participated enthusiastically in this project, displaying not only the ability to contribute the perspective of their own constituency, but also a genuine concern for the overall integrity and impact of the project.

Members of Project Advisory Committee: Reeta Bhatia, Shobna Dhurbai, Jose Franco, Usha George, Anthony Mohamed, Devan Nambiar, Meena Radhakrishnan, Muhammad Rafiq, Rakesh Ratti, Fawad Shah and Ajit Singh.

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Indra Ramkissoon, Executive Director of ASAP, and agency staff, particularly Amrita Sethi, Nadia Junaid and Suguna Sivamoorthy, all of whom handled the additional demands on their time with understanding, accommodation and grace.

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Finally, this project has benefitted from a wise, patient and effective Project Team who developed the project methodology, undertook the outreach and interviewing of PHAs and Key Informants, attended all Project Advisory Committee meetings, analysed the data and transformed people's words and experiences into findings and recommendations for action.

Project Consultants: Zubeida Ramji and Betsy Kappel of Kappel Ramji Consulting Group.

Project Associates: Harjeet Badwall, Zavare Tengra, Tazim Virani and Jennifer Walcott.

**Andrew M. Pinto**

Chair, Project Advisory Committee

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Discrimination & HIV/AIDS in South Asian Communities

# List of Acronyms

- ACAS Asian Community AIDS Services
- AIDS Acquired Immuno Deficiency Syndrome
- ASAP Alliance for South Asians AIDS Prevention
- ASO AIDS Service Organization
- CAPIO Canadian Association of Physicians of Indian Origin
- CHAMP Canadian HIV/AIDS Mentorship Program
- CASSA Council of Agencies Serving South Asians
- CHC Community Health Centre
- GWA General Welfare Assistance
- HIV Human Immunodeficiency Virus
- IDU Injection Drug User
- LCDC Laboratory Centre for Disease Control
- MPP Member of Provincial Parliament
- MSM Men who have Sex with Men
- ODSP Ontario Disability Support Program
- OHIP Ontario Health Insurance Program
- OSAP Ontario Student Assistance Program
- PHA Person living with HIV/AIDS
- SAO South Asian Organization
- WHO World Health Organization

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Discrimination & HIV/AIDS in South Asian Communities

# Executive Summary

Recent work on HIV/AIDS and discrimination has been prompted by the realization that discrimination against people with HIV/AIDS

- is still pervasive in Canada;
- touches every aspect of their lives;
- is becoming more subtle and hard to redress; and
- has a significant impact on their health and well-being.

Limited time and attention, however, has been given to the discrimination experienced by people infected with or affected by HIV/AIDS from Canada's diverse ethnocultural/ ethnoracial communities.

The Toronto based Alliance for South Asian AIDS Prevention (ASAP) was funded by Health Canada to undertake a study to:

**Investigate the types and impacts of discrimination and the resulting legal, ethical and human rights issues faced by people infected with and affected by HIV/AIDS in the South Asian community of Greater Toronto.**

Personal, in-depth interviews were conducted with 21 South Asian men and women of diverse backgrounds who are living with HIV/AIDS. Interviews were conducted in the language preferred by the participant and included English, Punjabi and Gujarati.

As well, thirty-one (31) Key Informant interviews were conducted with representatives of legal, health, and social service organizations both from within and external to the South Asian communities. Over 50% of the Key Informants themselves were members of Toronto's South Asian communities.

## South Asian Communities of Toronto

Among the total of 1,338,090 visible minority people living in the Toronto area, 24.7% or 329,840 are South Asian (Census 1996). South Asians are defined as those who trace their origin, directly or indirectly to the countries of India, Pakistan, Sri Lanka, Bangladesh, Burma, Nepal, Bhutan or the Maldives. South Asians speak many languages including Gujarati, Urdu, Farsi, Pashto, Punjabi, Tamil, Hindi, Malayalam and Bengali. The faiths practised by South Asians are diverse as well. Hinduism, Islam, Sikhism, Christianity, Buddhism, and Jainism form the primary faith groups which are represented in different proportions among South Asians in the various countries in the Indian subcontinent and the diaspora.

South Asians in Toronto reflect the cultural, religious, ethnic and class diversity of South Asian communities from around the world. It is not uncommon for people within the community to identify themselves with their religion, their geographic region of origin and their linguistic backgrounds. Religious organizations play a powerful and dominant role in the lives of many South Asians. Community life centers around the family, extended-family networks and the practice of religion and going to the temple or mosque.

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Legal, Ethical & Human Rights Challenges: An Ethnocultural Perspective

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The ideals of cooperation and family loyalty, which require that family obligations take precedence over personal interests, are basic to all South Asian communities. This translates into a strong collective culture or a value system characterized by a strong sense of community, dense social networks, and an emphasis on familial relations.

In addition to supports and services provided to South Asians through their mosques, temples, gurudwaras, churches, jamaatkhanas, and other places of worship, cultural organizations are a vital part of South Asian life. South Asian communities in Toronto are also served by a number of ethnospecific health, settlement, and social service agencies. South Asians are able to access services from many mainstream organizations as well, depending on their ability to speak English and/or fit with admissions criteria or benefit from the program style/format. Racism often prevents people of colour from accessing appropriate health and social services. South Asians who are among the various new immigrants and refugees to Canada, often feel the keenest impact of racism because they have the added disadvantage of language barriers or lack of understanding of how the society works.

## HIV/AIDS in South Asian Communities

Based on the 1996 census figure of a total of 329,940 South Asians in the Toronto area of which about 231,000 or 70% are adults 18 years of age or older. Given the World Health Organization (WHO) prevalence rate of 0.19% for Canada, it can be estimated that approximately 439 South Asian adults may be infected with HIV in the Toronto area.

Discussions with people living with HIV/AIDS and Key Informants characterize life within the South Asian communities as follows:

**I HIV/AIDS is not talked about openly within South Asian communities.**

This is related to social taboos that exist within the communities. The taboos are linked to a series of prevailing ideas geared toward maintaining a strong collective culture and include the following:

- South Asians are monogamous.
- South Asians are not homosexual or bisexual.
- South Asians are not sexual people, particularly outside of marriage.
- Sexual activity is only for the purposes of procreation.
- HIV/AIDS is white people's illness.
- HIV/AIDS is an older white gay man's illness.
- Women do not get HIV/AIDS unless they are promiscuous.
- South Asians do not drink or use injection drugs.
- If you talk about something bad (like HIV/AIDS) it will happen.

While these prevailing ideas are clearly not true, they reflect the dominant values and beliefs held by many within the communities. Together, they contribute to a **silence** within South Asian communities that leads to **denial** that HIV/AIDS is a South Asian disease. Generally people believe that HIV/AIDS is a western phenomenon linked to homosexuality. The only socially acceptable way to talk about being ill with HIV/AIDS is to couch it in terms of a blood transfusion as the cause or using another diagnosis like cancer.

**1 People fear being mistreated, abandoned or isolated if they tell other South Asians about their status.** They fear that if they disclose, no one will be their friend, come to their homes, eat their food, or play with their children. Because of the taboo and fear, it is not uncommon to find partners who do not know their loved one's status for quite some time after a positive HIV diagnosis is received. Because of the collective culture that typifies South Asian communities, people who disclose stand to not only lose the support of their immediate family/friends, but also their relationship with their entire community. If they are relatively new to Canada, or have been here for some time but do not speak English, or have few connections outside of their South Asian community, then the loss is even more acute and far reaching.

**1 Faith is a central part of many South Asians' life and has strong links to their cultural life as well.** Faith communities are often the guardians of the prevailing ideas that contribute to the silence in the first place. They are seen as very powerful vehicles for carrying messages related to social, cultural and spiritual matters. Therefore, most people living with HIV/AIDS do not reveal this information to members of their faith community, even though many would wish to. For some who have revealed the situation to their faith leader, the response has been supportive.

**1 Taboos that exist within the South Asian context are more rigidly applied to women.** There is a greater emphasis on the role of women to protect the family name and reputation. For some women, this makes the disclosure of a positive HIV status harder. They do not want to be held responsible for their family's bad name. They also need to consider their ability to provide for their children on their own if they are ostracized. On the other hand, however, because women are socialized in their role as caregivers/nurturers, they are sometimes more likely to disclose and seek support in order to best fulfil this role for their children and the family.

**1 There is limited experience within the South Asian Organizational (SAO) infrastructure with the range of issues related to HIV/AIDS.** Staff often lack awareness and sensitivity or are not comfortable with the issues, have many of the same fears and misconceptions about transmission as the general public, and do not know where to refer people who are HIV positive for specialized services.

**1 South Asian physicians play a central role in the lives of many in the community but no South Asian doctors with an HIV designated practice were identified by project participants.** This means that South Asians living with HIV/AIDS must get medical attention outside their community.

*1 South Asian people who are HIV positive often go outside of the South Asian communities for their initial testing, bringing them into contact with mainstream AIDS Service Organizations (ASOs).* This is partly because of fear and shame but also because South Asian doctors refer people to specialists like Hassle Free Clinic for testing. As a result, many South Asians are often more likely to first disclose or discuss their status with someone

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outside their community, particularly someone affiliated with an ASO. There are varying reports about how satisfactory this experience has been.

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### Legal, Ethical & Human Rights Challenges: An Ethnocultural Perspective

**I Mainstream ASOs are generally not perceived to be reflective of South Asian communities culturally, linguistically or from a faith perspective.**

ASOs are perceived by many to be "white gay man friendly". Therefore, many South Asians may not be able to identify with most people involved with the mainstream ASOs because of cultural or racial issues or because they do not consider themselves gay.

**I Specific examples of mistreatment and discrimination are cited within the areas of health care, welfare, the financial and insurance industry, employment, housing, immigration, travel and the law.** However, it is hard to understand the degree to which individuals experience discrimination related to HIV/AIDS because of the silence about it within communities and the everyday racism people in the South Asian communities encounter.

The overall findings reported in this study demonstrate that South Asian people living with HIV/AIDS experience **felt stigma** within a silent community that basically denies that HIV/AIDS is a South Asian problem or issue. They also experience everyday racism living in Canada. They have to cope with two kinds of discrimination – felt stigma and racism. Individual's lives are compromised beyond just the HIV/AIDS illness.

The larger implication of these findings is that South Asian communities that are already vulnerable to racism and marginalisation within the broader Canadian context are also at risk for the spread of HIV/AIDS. The denial, ignorance, stigma and silence are all conditions for people to continue to engage in high risk behaviour, and for community education strategies to be rendered ineffective. Overall, this could contribute to the proliferation of a disease that should be controllable.

Based on the input from people living with HIV/AIDS, key informants and ASAP's Project Advisory Committee, the Project Team has formulated thirteen (13) recommendations for action:

**n The pervasive silence on the issue of HIV/AIDS must be broken.** There is a pressing need to reduce the silence and stigma around HIV/AIDS, and to create an environment where disclosure is more the accepted norm.

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**Recommendation #1:** That a broad, multi-pronged social marketing strategy be developed and implemented in South Asian communities to change prevailing ideas and break the silence about HIV/AIDS.

**Recommendation #2:** That a broad-based consortium including key South Asian business people, physicians, media, faith leaders, and people living with HIV/AIDS be established to guide the development and implementation of the social marketing strategy.

**Recommendation #3:** That four areas be targeted for the South Asian social marketing strategy as follows:

- South Asian radio, television and print media including a focus on youth
- Faith communities
- South Asian physicians
- South Asian Organizations

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Discrimination & HIV/AIDS in South Asian Communities

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**Recommendation #4:** That based on a detailed proposal from the consortium, federal, provincial and municipal government bodies and private sector stakeholders fund the proposed social marketing strategy to a level that would make it effective.

**Recommendation #5:** That after developing and pilot testing a social marketing strategy in the Greater Toronto Area, similar initiatives reflecting local realities be implemented nationally in major cities/centres where South Asian communities live in significant numbers.

**n People living with HIV/AIDS need integrated, accessible and equitable support and services right now.** Once the silence has been broken, there will be more people coming forward requesting service. The support system needs to be accessible, seamless, fair and equitable. To achieve this, several changes are needed.

**Recommendation #6:** That funders require mainstream ASOs to become representative of and responsive to Toronto's diverse communities.

**Recommendation #7:** That ASAP develop and pilot a formal, responsive continuum/model of delivering supports and services to South Asians living with HIV/AIDS in partnership with major Toronto mainstream ASOs and other service providers.

**Recommendation #8:** That ASAP improve its own reflectiveness and representation of people living with HIV/AIDS at the governance and staff levels of the organization. Further, that ASAP continue to strive to also reflect South Asian communities' ethnic, linguistic, faith, and socio-economic realities.

**n There is an aggressive advocacy agenda that ASAP must also pursue .**  
Since some

of the issues are large and complex, tackling some of these issues in conjunction with other

communities facing the same issues is advisable.

**Recommendation #9:** That ethnospecific ASOs such as ASAP advocate for change in Canada's immigration policy, specifically as it relates to the denial of OHIP, OSAP and non-profit housing to people on Minister's Permits. Further, that the relevant section of the Immigration Act (Section 19) be challenged.

**Recommendation # 10:** That ethnospecific ASOs such as ASAP advocate to ensure that people of colour and women are included in HIV/AIDS clinical research initiatives underway in Canada.

**Recommendation # 11:** That ethnospecific ASOs such as ASAP advocate to ensure timely, linguistically and culturally sensitive access to Ontario's Welfare process for people living with HIV/AIDS.

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**Recommendation #12:** That the education of health and social service professionals within and outside South Asian communities on the issues faced by people of colour living with HIV/AIDS be promoted as a central ingredient of all relevant health and social service training programs.

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### Legal, Ethical & Human Rights Challenges: An Ethnocultural Perspective

**Recommendation #13:** That ethnospecific ASOs such as ASAP explore the issues of the collection of race based statistics for surveillance and tracking purposes with federal, provincial and municipal governmental authorities so that responsive strategies can be developed for prevention and support initiatives. That central to this dialogue must be recognition of the potential for misuse of this type of information.

With the advocacy agenda, recommendations have been made to change prevailing ideas about HIV/AIDS, support individuals living with HIV/AIDS and make overall systemic change. Implementing these recommendations should result in improved quality of life for South Asian people living with HIV/AIDS and the decreased spread of HIV/AIDS through South Asian communities.

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Discrimination & HIV/AIDS in South Asian Communities

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Legal, Ethical & Human Rights Challenges: An Ethnocultural Perspective

# 1. Introduction

## 1. The Project

HIV/AIDS and discrimination has been the focus of several recent publications produced by the Canadian HIV/AIDS Legal Network and the Canadian AIDS Society. This work has been prompted by the realization that discrimination against people with HIV/AIDS

- is still pervasive in Canada;
- touches every aspect of the lives of people living with HIV/AIDS;
- is becoming more subtle and hard to redress; *and*
- has a significant impact on the health and well being of people infected with and affected by HIV/AIDS.<sup>1</sup>

Work has specifically addressed issues of discrimination in Aboriginal communities<sup>2</sup>, but none has focussed exclusively on women. As well, very little time and attention has been paid to the discrimination experienced by people infected with or affected by HIV/AIDS from Canada's diverse ethnocultural/ethnoracial communities. Given the continually changing face of Canada, work also needs to be done on the experience of these communities.

The Toronto based Alliance for South Asian AIDS Prevention (ASAP), the only well-established South Asian HIV/AIDS organization in Canada, was funded by Health Canada to undertake a study to document the lived experience of people infected with and affected by HIV/AIDS in the various South Asian communities that make up Toronto. The goal of the project was:

**To investigate the types and impacts of discrimination and the resulting legal, ethical and human rights issues faced by people infected with and affected by HIV/AIDS in the South Asian community of Greater Toronto.**

ASAP had a primary interest in looking at the "impact of discrimination within families and communities with particular focus on intergenerational and gender related conflicts, the effect of living in extended families, close community kinship and culturally specific ways of dealing with sensitive topics like sexuality and gay and lesbian issues."<sup>3</sup>

ASAP identified four (4) expected outcomes for the project:

- To stimulate a national and previously neglected dialogue about HIV/AIDS in ethnospecific communities.
  - To further efforts to increase the participation of under-represented populations in AIDS research, in
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1. de Bruyn, Theodore. HIV/AIDS and Discrimination: A Discussion Paper. (Montreal: Canadian HIV/AIDS Legal Network & Canadian AIDS Society. 1998) 1.
2. Matiation, Stefan. Discrimination, HIV/AIDS and Aboriginal People: A Discussion Paper. (Printed from Web Site: <http://www.aidslaw.ca/elements/06TEXTDe.html>) .
3. "Discrimination & HIV/AIDS – Legal, Ethical & Human Rights Challenges: An Ethnocultural Perspective." (Toronto: ASAP funding proposal to Health Canada) 4.

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### Discrimination & HIV/AIDS in South Asian Communities

identifying research priorities, in designing and implementing research projects and in the ethical review of research.

- To bring mutual benefit to both the South Asian, and East and South East Asian communities through partnering with Asian Community AIDS Services (ACAS) on a similar initiative.
- To assist in contradicting the denial of HIV/AIDS as an important reality and priority for ethnospecific communities in general and South Asian communities in particular through the documentation of discrimination.

Personal, in depth interviews were conducted with 21 South Asians of diverse backgrounds. Seventeen (17) people (14 men and 3 women) were infected with HIV/AIDS and four (4) individuals were affected by it. People who are affected by HIV/AIDS include partners, parents, siblings, lovers, close friends – those people whose lives are intimately connected to the life of a person infected with HIV/AIDS. (Hereafter, people infected with and affected by HIV/AIDS will be referred to as people living with HIV/AIDS, or the acronym PHA.). Interviews were conducted in the language preferred by the person living with HIV/AIDS. All interviewees preferred English except for two (2) opting for Punjabi and two (2) Gujerati.<sup>4</sup>

As well, thirty-one (31) key informant interviews were conducted with representatives of legal, health, and social service organizations both from within and external to Toronto's South Asian communities. Over 50% of the key informants themselves were members of Toronto's South Asian communities. For a complete detailed description of the Project Methodology, including its limitations, see Appendix 1.

A scan of relevant literature was also conducted to provide a framework and context for the analysis of the findings. The primary sources of information

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for this study are the voices and experiences of people of South Asian heritage who are living with HIV/AIDS. Key informant input is interwoven to accentuate or add depth to the discussion.

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4. A more detailed profile of the sample is included in Section 3.1.

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Visible Minority Group	Total Population	% Total Visible Minority Population
Chinese	335,185	25.0
South Asian	329,840	24.7
Black	274,935	20.5
Filipino	99,110	7.4
Arab/West Asian	72,160	5.4
Latin American	61,655	4.6
Southeast Asian	48,510	3.5
Korean	28,555	2.1
Japanese	17,050	1.3
Visible minority not included elsewhere ***	45,655	3.4
Multiple visible minority	27,435	2.1
<b>Total visible minority population</b> <small>*The Toronto Census Metropolitan Area stretches from Oshville to Ajax and north to Newmarket and includes Aurora, Brampton, Halton Hills, Markham &amp; Richmond Hill.</small>	<b>1,338,090</b> <small>**includes Pacific Islanders and other visible minority groups</small>	<b>100</b> <small>***includes respondents who reported more than one visible minority group</small>

Among the places of birth of immigrants in Toronto, several countries are listed that could be safely assumed to be countries for South Asians. India, Guyana, Pakistan, Sri Lanka and Trinidad and Tobago are likely where the number of South Asians in Toronto were born.<sup>8</sup> The South Asian language most frequently noted as a mother tongue is Tamil.<sup>9</sup> The Toronto Profile of newly arriving immigrants

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5. Statistics Canada, 1996 Census Data (Web site:ww2.stscan.ca)

6. Abbate, Gay. "Visible minorities will be majority by 2000". Globe and Mail (Toronto, 06/08/1998) A6.

7. Abbate, A6

8. Statistics Canada, 1996 Census data Profile of CD/CSD. (Ottawa:Government of Canada 1997). 1

9. Statistics Canada, 3

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## 2. Background Discussion

### 2.1. The South Asian Communities of Toronto

The Greater Toronto Area had a total population of over 4,000,000 during the last census.<sup>5</sup> Toronto is home to 42% of the total non-white population in Canada, including almost half of its South Asians.<sup>6</sup> As part of the 1996 census, for the first time Statistics Canada asked Canadians about their race. As shown in the table below, of the total 1,338,090 visible minority population living in the Toronto area, 24.7% or 329,840 people identified themselves as South Asian.

#### Visible Minorities in the Toronto Area<sup>7</sup>

Toronto Census Metropolitan Area\* in 1996

shows that India, Pakistan and Sri Lanka were consistently among the top ten source countries between 1994 and 1996.<sup>10</sup>

Statistics Canada (1996) has projected, based on medium-growth assumptions, that by the year 2000, there will be over 470,000 South Asians living in Ontario, accounting for 8% of the population of the province.<sup>11</sup> The vast majority of them will live in the Greater Toronto Area.

### 2.2. History of South Asian Communities in Canada<sup>12</sup>

South Asians in Canada have origins that can be traced to a region stretching from the Himalayan kingdoms of Nepal and Bhutan in the north, to the Indian Ocean in the south and from the western boundaries of Pakistan to the eastern limits of the Indian province of Assam. This includes the island states of Sri Lanka and the Maldives. Indian migration across the British Empire is approximately 250 years old. Thus, South Asian migrants from all areas of Africa, Mauritius, Fiji, the Caribbean, Guyana, Britain and Europe are also included.

South Asians speak many languages including English, Bengali, Farsi, Gujerati, Hindi, Malayalam, Pashto,

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10. Citizenship and Immigration Canada. Facts and Figures 1996 – Immigration Overview – Toronto Profile: Top Ten Source Countries. (Ottawa: Government of Canada 1996). 1

11. Statistics Canada. Projections of Visible Minority Population Groups, Canada, Provinces and Regions, 1991– 2016. Ottawa: Government of Canada, 1996)

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12. The information reported in this section is from "The Need for Community Services: A Study of the South Asian Community In Metropolitan Toronto." (Toronto: Coalition of Agencies Serving South Asians (CASSA), 1994). The complete Chapter 1 can be found in Appendix 2

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Punjabi and Tamil. The faiths practised by South Asians are diverse as well. Buddhism, Christianity, Hinduism, Islam, Jainism and Sikhism form the primary faith groups which are represented in national systems, civil law and criminal justice systems, a free market economy, civil liberty, human rights, and environmental movements, all modelled along British lines.

More recently, the subcontinent has been facing rising fundamentalism and intolerance among the different religious communities. These factors along with poverty, chronic unemployment, natural disasters and unstable political and economic conditions have contributed to South Asian migration.

South Asian immigration to Canada has taken place in three distinct phases:

- 1900–1960: Sikhs began arriving in British Columbia, facing an overtly racist immigration policy.
  - Late 1960s to late 1970s when immigration from non–European countries was liberalized,
- skilled and semiskilled workers from East Africa, Britain and the Caribbean arrived.
- 1980s: Tamil and other South Asian refugees began arriving in Canada to escape civil unrest

in their homeland.

Today, a smaller number of South Asians arrive annually in Canada. Most come as part of the 'assisted relatives' category. Until recently, people from the Punjab region of India have been the largest group of South Asians in Toronto. Tamils now outnumber them.

### **2.3. South Asian Communities as Part of the Mainstream Infrastructure**

In Canada, South Asians, like other people of colour, are frequently targets of racism and discrimination.<sup>13</sup> The overall impact of this racism is the exclusion

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of various groups of people of colour from "mainstream" life including political, economic, cultural and social life.<sup>14</sup>

Racism often prevents people of colour from accessing appropriate health and social services.<sup>15 16</sup> There is ample evidence showing that ethnoracial minorities in general and women of colour in particular, face barriers in accessing health and social services.<sup>17</sup> These barriers include lack of information on services,

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13. Brabazon, Claudia, et al. Many Voices: HIV/AIDS in the Context of Culture – Report of the South Asian Communities. (National Health Research and Development Program, Health Canada and the AIDS Education and Prevention Unit, National AIDS Contribution Program of the National AIDS Strategy, Health Canada, 1993) 8.

14. James, Carl, ed. Perspectives on Racism and the Human Services Sector: A Case for Change. (Toronto: University of Toronto Press, 1996). 27–28.

15. Hardhill, Kathy. "Discovering Fire where the Smoke Is: Racism in the Health Care System". Towards Justice in Health. (1993). 17–21

16. Ministry of Health, Ontario. Time for Change..Immigration, Refugee and Minority Women and Health Care Needs. (Toronto: Government of Ontario, 1993). 2.

17. Ministry of Health, Ontario, 2.

18. George, Usha. "Caring And Women of Colour: Living the Intersecting Oppressions of Race, Class and Gender", Women's Caring: Feminist Perspectives on Social Welfare. ed. Carol Baines, Patricia Evans, & Sheila Neysmith. (Oxford University Press. 1998.) 79

19. Ministry of Health, Ontario. 2

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lack of understanding by service providers of cultural and linguistic needs, discrimination, and prejudice.<sup>18</sup> Province-wide community consultations with women of colour, refugee and immigrant women found that they have significant health care needs but use health services less than other women. This contradiction is partly because of practices and attitudes found in the health care system that discriminate against their language, culture, race, gender, status and class.<sup>19</sup>

The lack of responsive mainstream services has given rise to an ethnospecific service sector in Toronto made up of high quality but poorly funded, stretched services that are expected to fill every gap that exists, whether or not it is in their mandate to do so. While South Asian service organizations do their best, because of chronic under funding and general marginalization within sectors, they are often unable to adequately meet the service demands of their consumers.

## **2.4. South Asian Communities' Infrastructure**

South Asian communities have vigorous cultural and religious organizations which form a vital part of most South Asians lives. In addition to supports and services provided to South Asians through their mosques, temples, gurudwaras, churches, jamatkhanas, and other places of worship, the South Asian communities in Toronto are served by a number of ethnospecific health, settlement, and social services. The Council of Agencies Serving South Asians (CASSA) is an umbrella organization of more than 60 members, many of which are agencies providing services to Toronto's South Asian communities. Among these, several are mainstream organizations where South Asians may be on staff and can deliver services in certain South Asian languages. Alternatively, South Asians are able to access services from many mainstream organizations depending on their ability to speak English and/or fit with admissions criteria or ability to benefit from the program style/format.

ASAP is the only established South Asian AIDS Service Organization in Canada. Although community education and prevention are its primary mandates, it currently provides support services to approximately 40 South Asian people living with HIV/AIDS in the Greater Toronto Area. Advocacy and networking are other areas of focus for ASAP.

## 2.5. South Asian Community Life and the Context of a Collective Culture

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20. Brabazon, 7.

21. Brabazon, 7.

22. Brabazon, 7.

23. George, 73

24. George, 76

25. George, 76

26. Brabazon, 8

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South Asians in Toronto reflect the cultural, religious, ethnic and class diversity of South Asian communities around the world. It is not uncommon for people within the community to identify themselves with the religion they practice, the geographic region where they come from and their linguistic backgrounds.<sup>20</sup> Religious organizations play a powerful and dominant role in the lives of many South Asians.<sup>21</sup> For many, community life centres around the family, extended-family networks and the practice of religion and going to the temple or mosque.<sup>22</sup>

The ideals of cooperation and family loyalty, which require that family obligations take precedence over personal interests, are basic to all South Asian communities.<sup>23</sup> This translates into a collective culture or a value system characterized by a strong sense of community, dense social networks, and an emphasis on familial relations.<sup>24</sup> Selflessness, deference, service, respect, tolerance, obligation, duty, sacrifice and compromise are held in high esteem.<sup>25</sup> The "individuality" taught to young people who are educated in North America is often perceived by elders as conflicting with the good of the family.<sup>26</sup>

### **2.6. Sexual Taboos & Homosexuality in the South Asian Communities**

A number of sexual taboos exist within the South Asian communities. Sex before marriage, especially for women, is not considered acceptable.<sup>27</sup> Some freedom is given to men to experiment with sex before marriage. If a man is found dating a South Asian woman, he may have to marry her to maintain her purity. For these reasons, men are more likely to seek out women from outside the community for casual sex.<sup>28</sup>

There are many myths and strong negative attitudes surrounding non-traditional relationships, such as homosexuality and bisexuality in South Asian communities. Because of this, many gay and bisexual men keep their relationships hidden "in the closet". Some will even go through with arranged marriages to avoid conflict in their families.<sup>29</sup> Those who are "out" or open about being homosexual face not only the same persistent patterns of discrimination as gay men in the general population but the added ostracism from large segments of their community such as religious and cultural life.<sup>30</sup>

The characterization of homosexuality as a Western phenomenon, coupled with the desire and pressure South Asian men can feel to retain their native culture, may result in homosexuality being framed as an abandonment of their South Asian culture.<sup>31</sup> They may come to feel that being homosexual and being South Asian are mutually exclusive, a struggle that may be exacerbated by the more communal nature of South Asian cultures. The conflict of dual identities (South Asian and homosexual) may in part contribute to greater homophobia among South Asian men who have sex with men.<sup>32</sup> Some men who have sex with men will rationalize: "I just got a blow job or I was a top so no big deal"... and will not accept the fact they are gay.<sup>33</sup>

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27. Brabazon, 11.

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28. Brabazon, 11.

29. Brabazon, 10.

30. Comments made by key informants in the project highlight this reality.

31. Ratti, Rakesh. "Cross Cultural Differences in Psycho-social Correlates of High Risk Sexual Behaviour," diss., Georgia State University, Dept. of Psychology, 1997. 3

32. Ratti, 29.

33. Brabazon, 12.

34. Ratti, 9.

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Given the negative attitudes toward homosexuality that exist in both Western and South Asian cultures, a man who has sex with men may believe that he is bringing shame to his community through his behaviour and/or desires. This can result in more negative self-attitudes and increase the likelihood of his engaging in high-risk behaviour.<sup>34</sup>

Despite the stigma and discrimination associated with homosexuality, a number of South Asian men have come "out" and openly identify themselves as gay. Khush, a South Asian gay men's organization was formed in Toronto to facilitate mutual support and connection with other men who are also gay and South Asian.

### 3. HIV/AIDS in South Asian Communities

#### 3.1. Global and Local Prevalence Rates, Stigma and Discrimination

The experience of Toronto's South Asian communities with HIV/AIDS cannot be discussed in isolation of the global AIDS picture or the experience in the mainstream of Canada. South Asians are parts of both realities.

Globally, India is fast becoming one of the world's largest centres of HIV/AIDS . Currently, it is estimated that "8,000,000 people are infected with HIV... One out of every four people in the world who are infected with the AIDS virus lives in India."<sup>35</sup>

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35. Dev Raj, Ranjit: "Health India: HIV Spreads Despite World Bank Project." (Inter Press Service \_ May 2, 1999).  
<http://www.aegis.com/news/ips/1999/IP990501.html>

36. De Bruyn, 12.

37. De Bruyn, 12

38. Hutchinson, J. "AIDS and Racism in America," Journal of the National Medical Association, 84.2 (1992) 119–124.

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In mainstream Canada, while the prevalence rates of HIV/AIDS are considerably lower, stigma and discrimination against people living with HIV/AIDS are prevalent. de Bruyn defines the way stigmatization works: "Stigma is a powerful discrediting and tainting social label... People who are stigmatized are usually considered deviant or shameful for some reason ... and as a result are shunned, avoided, discredited, rejected, restrained or penalized. As such, stigma is an expression of social cultural norms....."<sup>36</sup>

According to de Bruyn, people with HIV/AIDS are stigmatized because: HIV/AIDS is associated with behaviours that are already stigmatized, particularly homosexuality and injection drug use.

- People with HIV/AIDS are thought to be irresponsible for having contracted HIV.
- HIV/AIDS is a life threatening disease.
- People are afraid of contracting HIV.
- The religious or moral beliefs of others lead them to conclude that having HIV/AIDS is a result

of a moral fault, such as promiscuous or deviant sex, that deserves punishment.<sup>37</sup>

Finally, HIV/AIDS and racism are also often linked, particularly in the United States. Examples of how institutionalized racism affects the fight against AIDS, the disproportionate numbers of visible minority people with AIDS and the inability of the health care system to adequately serve them, are all key themes.<sup>38</sup> In Canada, Stefan Matiation in his work 'Discrimination, HIV/AIDS and Aboriginal People: A Discussion Paper' documents the experience of Aboriginal people which, while emerging from different roots, closely mirrors this reality. He says: " It is within the context of Aboriginal oppression in Canada that the issue of discrimination against Aboriginal people living with HIV/AIDS must be approached."<sup>39</sup>

For this study, all of these realities must be taken into consideration. Discrimination and HIV/AIDS in South Asian communities cannot be considered outside of the overall daily life of South Asians in Canada or their larger global connections.

## 3.2. Prevalence of HIV/AIDS among South Asians in Toronto

At the end of 1996, an estimated 40,100 Canadians were living with HIV infection (including those living

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39. Matiation, 3.

40. Laboratory Centre for Disease Control, Health Protection Branch. "HIV Prevalence and Incidence in Canada: 40,100

Living with HIV Infection and 4,200 New Infections Per Year." HIV/AIDS Epi Update. (May, 1999.)

[www.hc-sc.gc.ca/hpb/lcdc](http://www.hc-sc.gc.ca/hpb/lcdc)

41. Laboratory Centre for Disease Control

42. AIDS Virtual Library. "Statistical Reports on the Epidemic: The Current Global Situation of HIV/AIDS Pandemic."

(1995) <http://planetq.com/aidsvl/index.html>

43. Personal Communication with Dr. Robert Remis, Dept. of Public Health Sciences, University of Toronto, May 25, 1999

44. Dr. Remis,

45. Ratti, 3.

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with AIDS).<sup>40</sup> During 1996 there were an estimated 4,200 new HIV infections in Canada.<sup>41</sup> Using data from the Laboratory Centre for Disease Control (LCDC), the World Health Organization (WHO) estimated a prevalence rate of 0.19% for Canada at the end of 1995.<sup>42</sup> While this rate is slightly dated, HIV prevalence has not changed dramatically in the subsequent three-year period.<sup>43</sup>

Various surveillance and research data and methods are used to improve the degree of certainty of estimated prevalence and incidence of HIV. Estimates for specific exposure categories are available for Men who have Sex with Men (MSM), Injection Drug Users (IDU), Men who have Sex with Men *and* are also Injection Drug Users (MSM-IDU), and non-IDU heterosexuals, including recipients of blood and clotting factors. Information regarding the prevalence of HIV/AIDS in specific ethnocultural populations in Canada, however, is limited. Various additional factors need to be taken into account. Different source countries where South Asians have originated have varying prevalence rates. In a country as vast and diverse as India, there are significantly different rates for specific regions as well. Whether the time period during which migration to Canada occurred coincided with the HIV epidemic in source countries is another factor affecting the risk of exposure. Finally, the nature of immigration policies and patterns introduces a selection bias that also has a bearing on calculating the level of risk.<sup>44</sup>

In the Province of Ontario, a recent study carried out on South Asians revealed that 3% of all reported cases of AIDS between 1990 and 1994 were South Asians.<sup>45</sup> Given that South Asians constituted a similar proportion of the Ontario population during this period, it appears that South Asian communities have a similar prevalence rate as that of the overall population of Canada. While the factors mentioned above are important, detailed information about source countries, time of arrival in Canada, etc. is not readily available. Therefore, for the purposes of determining the number of South Asians that might be infected with HIV in the Toronto area, it is necessary to apply the available Canadian rates in several ways to data about Ontario and its South Asian communities.<sup>46</sup>

For the period ending December 31, 1998,<sup>47</sup> there were 19,459 first time positive HIV test results in Ontario. About 6350 AIDS-related deaths have also occurred for the same period to the end of 1998,<sup>48</sup> which means there are about 13,100 people infected with HIV/AIDS currently living in Ontario. Since about 3% of Ontarians are South Asian, 393 South Asians are estimated to be infected in the Province of Ontario, the vast majority of whom reside in the Greater Toronto Area.

Based on the 1996 Census, 329,940 South Asians lived in the Toronto area and approximately 231,000 or 70% are adults 18 years of age or older. When the WHO prevalence rate of 0.19% for adult Canadians is applied, 439 South Asian adults are estimated to be infected with HIV in the Greater Toronto Area.

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46. Dr. Remis

47. Laboratory Centre for Disease Control, Health Protection Branch, Health Canada." HIV and AIDS in Canada

Surveillance Report to Dec.31, 1998." [www.hc-sc.gc.ca/hpb/lcdc](http://www.hc-sc.gc.ca/hpb/lcdc)

48. Dr. Remis

49. Information contained in this section was mainly provided by Ruth Carey, HIV Legal Clinic, Toronto

Characteristic	N=21	Characteristic	N=21
Age		Period of Settlement in Canada	
<26	1	<5 years	1
26 - 35	6	5 - 9 years	2
36 - 45	11	10 - 19 years	7
46+	3	20+ years	11
Country of Origin		Number of Years Living with HIV/AIDS	
India	5	<6 months	1
E. Africa	6	1 - 3 years	6
Malaysia	1	4 - 6 years	8
Pakistan	3	7+ years	6
Trinidad	6		
Faith		Sexual Orientation	
Muslim	8	Bisexual	1
Christian	6	Gay/ homo sexual	8
Hindu	4	Straight/hetero sexual	10
Sikh	2	NA	2
Multi Faith	1		

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### **3.3. Profile of South Asians in the Study Sample**

This qualitative research study is based on the views and experiences of 21 South Asians living with HIV/AIDS. Table 1 provides a profile of the 21 people who participated in the in depth personal interviews.

#### **Table 1: Profile of Study of Sample**

The people living with and affected by HIV/AIDS who participated in this study reflect the diversity of Toronto's South Asian communities. They run the gamut of age and religion and have immigrated to Canada from many of the major source countries both on the Indian subcontinent and the diaspora. The major gaps are in the numbers of women, who are under-represented despite many special outreach efforts, as well as people from Sri Lanka.

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## **4. Findings: Experience of South Asians living with HIV/AIDS**

The following is a discussion of the major themes related to the experiences of people living with HIV/AIDS in Toronto's South Asian communities. Their experience is captured in two sections: 4.1. looks at life inside the various South Asian communities and 4.2. at life in the "mainstream." The views and opinions of key informants are also captured. Together they paint a picture of the lived realities of men and women everyday as they confront HIV/AIDS in their lives. Direct quotes from study participants are set apart in the text in italics and are used wherever possible to capture the tone and context of people's input.

## 4.1. Life Within the South Asian Community

### 4.1.1. Openness of Discussion re HIV/AIDS in South Asian Communities

The unanimous and overriding message that emerged in the course of this project is that issues related to HIV/AIDS are not talked about openly within South Asian communities. A series of social taboos that exist within the communities related to sex and sexuality were frequently reiterated. These taboos are linked to a set of prevailing ideas that are geared toward maintaining a strong collective culture and include the following:

- South Asians are monogamous.
- South Asians are not homosexual or bisexual.
- South Asians are not sexual people, particularly outside of marriage.
- Sexual activity is only for the purposes of procreation.
- HIV/AIDS is a white people's illness.
- HIV/AIDS is an older white gay man's illness.
- Women do not get HIV/AIDS unless they are promiscuous.
- South Asians do not drink or use injection drugs.
- If you talk about something bad (like HIV/AIDS) it will happen.

*If you came to my temple and talked to a group of women aged 30–45, and asked them what they knew about HIV/AIDS they would say: It is a bad disease for bad people. Men do bad things with other men. Women that aren't good get it. Let's not talk about it anymore. We tempt fate when we talk about it. (Key Informant)*

Central to these ideas is the taboo against homosexuality. In keeping with this, it is reported that men from South Asian communities, who for example, go to bath houses for sex with men, flatly deny that they are gay or homosexual. Rather, they define themselves as heterosexual men who have sex with other men.

What is also inherent here is that issues of sexuality are rarely discussed openly between genders or

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between generations in many South Asian communities. Men discuss sexuality in a casual, humorous fashion between men. Women are generally not meant to discuss it at all. Sexual behaviour is reserved for after marriage and any behaviour before marriage is considered immoral. However, men who engage in premarital sex are often excused because they are considered unable to restrain themselves.

*We behave as if we don't have sex. We're not supposed to have sex outside of the monogamous relationship, and God forbid that we should have sex with a same sex partner or that we are an IV drug user. We don't even talk about sex so how can we get HIV? It only happens to gay white men and injection drug users. If we can't accept even the possibility of HIV/AIDS, then how can we deal with it? (Key Informant)*

*Women have a more difficult time as they would be branded as whores. Men, straight or gay, can always say they got it from women.*

(Person living with HIV/AIDS or PHA )

While clearly these prevailing ideas are not true, they reflect the dominant values and beliefs held by many within the communities. Together, these beliefs contribute to a **silence** within South Asian communities that then leads to **denial** that HIV/AIDS is a South Asian disease. Since HIV/AIDS is linked to homosexuality, the only way that is socially acceptable to talk about being ill with HIV/AIDS is to couch it in terms of a blood transfusion as the cause or another diagnosis like cancer. This makes it more acceptable and people living with HIV/AIDS say others are then understanding about their situation.

*HIV is like syphilis. The stigma is not with the disease itself, but more to do with having transgressed social & moral order or norms about sexuality. It is not just an issue of sexual practice, but also sexual orientation.*

(Key Informant)

*In my family, women are trusted, not doubted. They would not think that I'd been with someone else. But if a man was HIV+, they may have some doubt. He's human. Although they'd mainly think it was from a needle or blood.*

Person affected by HIV/AIDS)

#### **4.1.2. Disclosing HIV/AIDS to Family /Close Friends**

The overall silence about HIV/AIDS within South Asian communities contributes to a major difficulty with disclosure. People struggle with whether to disclose their status, and if so, when, how and most important, to whom. People fear being mistreated, abandoned, or isolated if they tell other South

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Asians. They fear that if they disclose, no one will be their friend, come to their homes, eat their food, or play with their children. Because of the taboo and fear, it is not uncommon to find people with an HIV positive result talking about how difficult it is to disclose their status even to their partners. Many families are in the dark and think their child has some other, more acceptable illness. In order to protect the family name and keep the secret, there are reports that loved ones are sometimes sent back to their country of origin to die alone and in secrecy.

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*My children don't know my husband is HIV+. They just know their father is not well and so can't work.*

(Person affected by HIV/AIDS)

*At the beginning, I chose not to tell my friends/family because I was concerned about what they'd think about how I got it ... now I'm concerned that they might be making judgements about why I don't work or why I'm on welfare... I'm not so worried about them knowing about my HIV status but I need them to know I have good reasons to not work – it's not because I'm just lazy... (PHA)*

*I've told my parents that I have cancer. If my mother found out, she'd know that my husband gave it to me. They would want me to leave him and divorce him. But what would happen then? How will they face their friends, the community?*

(PHA)

*I do not feel the need to tell anyone. All the support I need I can get within my immediate family and through prayer. Perhaps this is so because my HIV+ family member is well. My need for support may change if he becomes ill.*

(Person affected by HIV/AIDS)

*I do not tell anyone about it because I fear my loved one will be hurt—physically or emotionally. They killed a gay man in High Park several years ago just because he was gay.*

(Person affected by HIV/AIDS)

The prior relationship within the family has a major bearing on how they deal with the information about the HIV/AIDS status of their loved one. Some families are supportive, sometimes one parent or a sibling is, while the rest are not. Generally, though, once the status is known, there is still not a lot of discussion within families about the illness, its cause and the future that awaits. Beyond the immediate family, there appears to be very little talking about it with extended family or the community at large except, sometimes, when a person becomes very ill or dies.

*We've always been accepting of my brother's lifestyle even though we don't condone it. When we found out he was HIV+, we were worried and felt hurt. But our love for him is unconditional. We all behave normally – we touch, hug, kiss, eat together ... our relationship is as strong as it was before.*

(Person affected by HIV/AIDS)

*My husband didn't want to tell anyone. When he was really sick and in hospital, I had to tell his brother and even then my husband got angry at me. When he died, I had to tell his family.*

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(Person affected by HIV/AIDS)

While the experiences described above is very similar to that of anyone from any community who is living with HIV/AIDS, there is a significant difference. Because of the collective culture that typifies South Asian

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communities, people who disclose stand to not only lose the support of their immediate family/friends if they are ostracized, but their relationship with their entire community.

*When the word spread to her parents' community, people stopped coming to their store .... their business has been affected quite badly ... somehow people are behaving as if they'll get HIV/AIDS if they go buy stuff at her parents' store back there .... she's here in Toronto and has not even seen them since her diagnosis! (Key Informant)*

If people living with HIV/AIDS are relatively new to Canada, or have been here for some time but do not speak English or do not have any connections outside of their South Asian community, then the loss is more acute and far reaching. They have virtually nowhere to turn and no way to recreate a new or different life. The collective cultural experience is all that is known or can be imagined. They are profoundly orphaned.

#### **4.1.3. Spiritual/Faith Context of HIV/AIDS**

Faith is a central part of many South Asians' lives and has strong links to their cultural life as well.

*It was winter when my mother found out I was ill – for 40 days, she stood barefoot out in the snow between 12 midnight and 4:00 a.m., praying with the Quran in her hands. I guess it's her prayers that have given me the strength ...otherwise I may not be here right now.*

(PHA)

*When I went over to my parents to tell them, my whole family was there. After hearing about the HIV+ result, the first impulse for everyone was to fall on our knees and pray. We all did this for about 15 minutes solid. Then it felt like nothing had changed in our relationship – their love for me was just the same. I'm very lucky.*

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(PHA)

People faced with an HIV/AIDS diagnosis move through various stages as they deal with the information. Grief, denial and acceptance are all stages that people both fluctuate between and/or pass through. They describe how one's faith can play three functions in this journey:

1 Faith explains the reason for becoming infected with HIV/AIDS. For some it is Allah's wish for them to die, for others it is a test of their spiritual strength.

*I consider my life as God's gift. Just as Allah gave me this life, he can take it away anytime ...I'm ready for this...I can die anytime. The thing that hurts me the most is that while I'm still alive, my husband not only blames me and rejects me, but also does not care about himself .*

(PHA)

1 Faith gives people the strength and tools to cope with the illness. For some this is a fatalism that death is just around the corner. For others it is an acceptance of their situation and a determination to make the best they can of their life. For still others, their prayer life is enhanced and they pray for miracles or healing for themselves or their loved one.

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*Prayer is a very important part of my day and my family's day, everyday. I believe in miracles, in divine healing. We've left it in God's hands.*

(Key Informant)

*Since I've told my brother, he's changed ...he prays 5 times a day, goes to the masjid even when there aren't any special lectures. He goes to the Flea Market every Sunday and buys birds or small animals and then lets them free ...in the hope that in exchange for their freedom, Allah will return me my health. (PHA)*

I Finally, a person's faith provides them with hope for a better life after death and a decreased fear of death.

*At first I used to think "why me?", "why me?". Now I think that if people are dying everyday in Bosnia... "why not me?" I try to practice putting faith in God. (PHA)*

Faith communities are often the guardians of many of the prevailing ideas that contribute to the silence in the first place. They are seen as very powerful vehicles for carrying messages related to social, cultural and spiritual matters. Therefore, most people living with HIV/AIDS do not reveal this information to members of their faith community, even though many would wish to. For some who have revealed the situation to their faith leader, the response has been supportive.

*The pastor found out when my husband passed away. Everyone was very supportive to me and concerned about my children. (PHA)*

*I turned to a couple of priests at my parish as they run HIV masses every second Saturday. I felt very comfortable. One priest came over to my place and it was good having him around. (PHA)*

### **4.1.4. Women Living with HIV/AIDS in the South Asian Community**

The taboos that exist within South Asian communities apply to everyone but there is a double standard for women. The taboos are more rigidly applied to women because greater emphasis is placed on the role of women to protect the family name and reputation.

*Women are socialized as caregivers of children and to keep the home together. These realities may not allow them to go out to access information or support readily. (Key Informant)*

On the one hand, the rigid taboos make the disclosure of a positive HIV status harder on women. They do not want to be responsible for their family's bad name. Women also need to consider their ability to provide for their children on their own if they are ostracized.

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*An HIV+ status is so much more damaging to women. Women are already on a lower scale and HIV brings them down further. There is the whole issue of the family name being tied to it Anything that discolours the family name is dreaded. We're very caught up with family*

*preservation (PHA)*

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*For women it is more difficult to determine what to do about disclosure, especially if they're in a lower socioeconomic bracket, because they are dependent on their partners for support, and disclosure risks losing the relationship with kids. (Key Informant)*

On the other hand, because women are socialized in their role as caregivers/nurturers, some are more likely to disclose and seek support in order to best fulfil this role for their children and the family.

*Men are more quiet about their status, women are more open amongst friends/family and more connected to services. If they are able to speak English and have phone skills, women are going to AIDS Service Organizations (ASOs) and men are not. I know of one woman who became more connected/open after her husband died. (Key Informant)*

These two differing perspectives on disclosure about HIV/AIDS status presented by women in the project reflect the internal conflict that emerges for South Asian women, depending on their circumstances.

Women are often blamed for the illness even though they may not be the transmitters. It is not clear what the logic is except that, since women are meant to keep their husbands happy, they may also be seen to be responsible if their spouses are unfaithful. Women are also more likely to remain with an infected partner than vice versa. Women are concerned about keeping their families together at least for the sake of the children, not necessarily in order to care for the partner.

*If a woman is HIV+, then her partner often leaves/takes off on her; but the converse is not true ... she usually sticks around to support him, care for him. (Key Informant)*

Even when husbands do remain, there are numerous examples of social controls being exerted over women living with HIV/AIDS.

*Example of a woman living with HIV/AIDS who was constricted by the husband in her movements and activities within the home. She was told to stay*

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*in one room, not allowed to cook for the family, touch the kids, and finally sent back home to her country of origin to die. Another woman was given a whole range of rules to follow. (Key Informant)*

Some women are also directed not to tell anyone about their situation or else suffer the consequences. In one example, a woman who disclosed her and her husband's status to close family friends was beaten up by him when he found this out.

Women living with HIV/AIDS who are in abusive relationships are often also threatened with loss of their children and /or immigration status if they try to leave the situation. These forms of social, physical and emotional control bind women and children in unsafe, unsupported and/or dismal living situations.

Women living with HIV/AIDS who do not speak English often encounter a greater number of barriers when accessing services.

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*When my husband was diagnosed (~3 years), the doctor at the hospital gave me a phone number of someone I could speak to in Urdu. I called this person because I speak no English. I had a ten minute conversation with her. She was very helpful and gave me some good information. I do not know her name and don't know which agency she was from.*

(Person affected by HIV/AIDS)

Women tend to have close women friends and other informal supports. Also, depending on where they were tested/diagnosed, they might get a referral. There are only limited places for women i.e. Teresa Group, Hassle Free Clinic and Voices of Positive Women, but here there are issues of cultural/linguistic access. (Key Informant)

Women's responsibility for the home and children often means that they take less care of themselves. If a woman also has a child who is HIV positive, her needs will usually come second to the child's.

*Women are not always able to look after themselves adequately because they are still expected to do all the household chores same as always even when they are ill. They also expect this of themselves.* (Key Informant)

For women who are affected by HIV/AIDS, the infection of their partner or loved one impacts on their roles as well. Women talk about how they have to calculate every interaction, determine how to make it positive and beneficial for themselves and their children. Women may have to take on added responsibilities for family life.

*Because my husband doesn't go out much anymore, my life has become very busy. I'm now the one responsible for shopping, taking kids to activities/doctor's appointments, and going to social functions on my own with my kids.* (Person affected by HIV/AIDS)

Finally, arranged marriage is still a common practice within some South Asian communities. Because of the taboo against talking to one's parents about sex, young women are worried that they are at risk.

*Arranged marriages still a big part of South Asian culture and HIV testing is not entering the picture. Many couples don't have any idea of their partner's lifestyle, risk levels before marriage and it is not ever considered by families to request HIV testing.* (Key Informant)

### **4.1.5. Interface with Alliance for South Asian AIDS Prevention (ASAP)**

While not everyone involved in the project knew about or had a relationship with ASAP, many people did. As the only South Asian organization in Canada focusing on HIV/AIDS, it is an important service for many people in the South Asian communities. Its primary mandate is community education and information to prevent the spread of HIV/AIDS (See Appendix 3 for a

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Summary of Recent Outreach and Education Activities). ASAP also provides limited direct support services to individuals living with HIV/AIDS and has the capacity to provide services in several languages including Urdu, Hindi, Gujarati, Tamil and Punjabi. For many, ASAP provides needed support and practical services that are highly rated.

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*When I finally came to ASAP I felt so much more at home. People were familiar with the songs of my childhood and other aspects of my cultural heritage. (PHA)*

*Turning to ASAP, I felt comfortable simply because I met other South Asians who were also infected, from a broad section of our community. (PHA)*

For others, ASAP itself has some barriers to overcome before it is fully accessible to the wide diversity of Toronto's South Asian communities. Specific issues relate to the staffing and governance of ASAP and the perceived lack of involvement at these levels of people actually living with HIV/AIDS. There is also concern that the ethnic, faith, class and socioeconomic diversity of Toronto's South Asian communities are not reflected at the governance level of the organization.

Gaps such as these are perceived to have several impacts. One is a muted passion for the cause of supporting people living with HIV/AIDS. Another is the inability to provide services that are fully accessible to the range of needs in the communities. While ASAP gets high ratings for the prevention and education work that it does to reduce the overall community denial that HIV/AIDS is a problem, there is also a recognition that ASAP has limited resources for direct support to individuals living with HIV/AIDS. ASAP is also marginalized as an organization within Toronto's South Asian communities because it serves people who are perceived to have broken community taboos particularly homosexual men. This marginalization can lead to low name recognition of ASAP within the broader South Asian communities.

#### **4.1.6. Interface with other areas of the South Asian Communities**

Due to the fact that relatively few people disclose their status, people in the larger South Asian communities rarely know someone is living with HIV/AIDS. This means that community members are not able to talk concretely about their experience with South Asians who are HIV positive. Overall, there is limited experience within the South Asian Organizations' (SAO) infrastructure with the range of issues related to HIV/AIDS. This means that staff in the SAOs often lack awareness and sensitivity or are not comfortable with the issues related to HIV/AIDS. Many have the same fears and misconceptions about transmission as the general public, and do not know where to refer people who are HIV positive for specialized services. Many SAOs did not participate in this project because they did not have any concrete experience to relate to.

It is clear that many people view the SAOs as themselves reflective of the negative prevailing ideas around homosexuality that pervade South Asian communities.

*ASAP may be seen as a place for men, but there are still issues about confidentiality. A doctor needs to know where to refer and if s/he does not refer to ASAP but instead to a SAO, what's awaiting there for the person living with HIV/AIDS? (Key Informant)*

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People who are living with HIV/AIDS are not likely to reveal their status or seek assistance from such organizations. There are a limited number of South Asian AIDS friendly places besides ASAP. KHUSH, a gay South Asian men's group, and Desh Pardesh, an arts and culture organization, may facilitate education

and dialogue about HIV/AIDS prevention, but are not necessarily venues where people living with HIV/AIDS are open about their status. Also, within the larger South Asian communities they, like ASAP, are marginalized organizations because of their links with South Asian homosexual men and women.

South Asian doctors play a central role in the lives of many people in Toronto's South Asian communities.

*A South Asian woman doctor has been the sole source of information and support for a woman who does not speak English and has chosen not to connect up to any SAOs, even though she has been given information about South Asian Family Support Services. (Key Informant)*

However, South Asian doctors with designated HIV practices were not identified by project participants. This means that South Asians living with HIV/AIDS must get medical attention outside their community. Other professionals such as business people and lawyers are also key community players. In the course of the project, examples were cited of South Asian professionals and employers who abandoned clients or fired employees once their status was known.

Overall, people generally wish that they could access supports and services from within the South Asian communities.

*Having support within the community is like talking to your sister. (PHA)*

*I do not want to go to anyone that doesn't know about HIV/AIDS. If they are ignorant and behave in a disturbing way because they're fearful about transmission ... how can I even talk to people like that? (PHA)*

During the course of this project, several people spoke for the first and only time to someone outside their family about HIV/AIDS. This includes both people infected with and affected by the disease. As well, the study process has led to increased support for some people living with HIV/AIDS and an increased awareness about ASAP. At least one new referral to ASAP for support services has directly resulted from the process. Another individual expressed a genuine interest in volunteering at ASAP. In these small ways, people's deep desire to break their own silence has been highlighted. For these individuals, it was an important and profound step.

## 4.2. Experience Living with HIV/AIDS Outside the South Asian Communities

Generally, people living with HIV/AIDS had less to contribute to this portion of the study. Their overall emphasis was placed on issues related to living with HIV/AIDS inside Toronto's South Asian communities.

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However, there is relevant information to report provided both by people in the sample and key informants.

### **4.2.1. Interface with Mainstream AIDS Service Organizations (ASOs)**

South Asian people who are HIV positive often go outside of the South Asian Communities for their initial testing, bringing them into contact with mainstream ASOs. This is partly because of fear and shame but also because South Asian doctors refer people to specialists like Hassle Free Clinic for testing. As a result, many South Asians are often more likely to first disclose or discuss their status with someone outside their community, particularly someone affiliated with an ASO. There are varying reports about how satisfactory this experience has been.

Some people perceive that the mainstream ASOs provide better support than South Asian agencies. They are more open and empathic and understanding. This is partly understandable since it is the mandate of mainstream ASOs to be expert and sensitive about issues to do with HIV/AIDS. ASOs, on the other hand, frequently are dealing with a gamut of issues including settlement, housing, employment, training, family violence and the HIV/AIDS agenda has to compete with these other priorities. For others, the support they receive is important when they first are diagnosed, but then they feel the need to move on with their life in more typical ways.

*Both Toronto People with AIDS Foundation (PWA) and AIDS Committee of Toronto (ACT) have been wonderful despite everything I have heard. They were supportive, kind, always accommodated my request. They contacted ASAP and got an interpreter to explain things to my mother. (PHA)*

*I went to Hassle Free for my test and then got referrals to a good doctor, Teresa Group, Voices for Positive Women, it was helpful to meet others with same issues as I had, especially things related to children ... I went for knowledge about the best medications and treatment. I also received support and knew that when I left the group, people would keep things confidential. Now I am in a different situation. I know a lot more, I know how to deal with having HIV/AIDS and feel I can handle things better. I don't feel I need the support anymore – besides my face is too familiar in those places. I feel it's too much – too much of feeling like the only identity I have is the AIDS identity .. I feel like an invalid ... I want to shift my focus to my children. My duty is towards them.*

(PHA)

Most people in the project observed, however, that mainstream ASOs are generally not reflective of the South Asian community culturally, linguistically or from a faith perspective. At best there is tokenistic representation of visible minority staff who then are put in the difficult position of carrying the "burden" of being the voice or outreach worker for all ethnoracial communities. In fact, most ASOs have limited experience

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providing services or sharing governance/decision making with any visible minority communities.

*When South Asians are involved in some task forces or networks, there is a cultural gap in issues such as ways of communicating, group dynamics ... such that they are not appropriately included in the discussions and decision making. We are often viewed as not sophisticated enough to handle such forums ... and the players around the table have not taken this as their responsibility to*

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*assist in making us more included.*

(Key Informant)

ASOs are perceived by many to be "white gay man friendly" or a "white man's club." Those South Asians who may have been in decision making roles often feel like tokens and/or marginalized. Some may not be able to identify with the majority of those involved with the organization because of cultural or racial issues while others feel marginalized because they do not consider themselves gay. This means that ASOs are generally not able to provide culturally and linguistically sensitive services to people from South Asian communities. The kinds of barriers people encounter, in addition to language/literacy barriers, include a lack of understanding about the collective culture South Asians come from and the particular pressures or expectations that this imposes on them.

*A woman with AIDS was expected to take care of her family, husband and house. Staff in a mainstream agency pushed her to stand up for herself to not get burdened with these expectations as she needed to take care of herself. Eventually, the pressure from both the role expectations and the staff who were trying to help her was too much and she stopped coming to the agency.*  
(Key Informant)

*An ASO staff member reports not hearing about any discrimination faced by their clients. She recognizes that her agency is not reflective of the clients it serves making it difficult for clients to feel comfortable talking about discrimination with people who have power and privilege.*  
(Key Informant)

*You have to know how to ask for things at ASOs. If you don't ask the right way you won't get it.* (Key Informant)

*Interpreters are not appropriate when the material is sensitive – e.g. mental health, marital issues or HIV/AIDS. You must have workers who speak the language and can provide the services directly.* (Key Informant)

*People will naturally turn to places where there's comfort, sense of connection or if it's a 'safe place'. Many go to different places for different things – they'll use different criteria in selecting where they go for what, depending on what their needs are. They'll go to some places more than others – due to fear of running into people they know. Of course, the more places there are that people can go to, the more entry points there are and the more chances for them to get their needs met. There is, however, also the higher risk of experiencing barriers or discrimination because of people's attitudes/values.*  
(Key Informant)

Finally, there is a recognition in the community that mainstream ASOs are far better resourced compared to ethnospecific ASOs. Some feel that it is the mainstream ASOs' responsibility to do something proactive about the imbalance and lack of equity that exists.

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*ASO's need to look at systemic racism not simply cultural sensitivity!*

(Key Informant)

*Look at the support that ACT and PWA get, accessibility to resources, government support ,*

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*private support. Look at ASAP, just one organization for such a large community and limited resources. (Key Informant)*

#### **4.2.2. Health Care**

A critical aspect of living with HIV/AIDS is the health care that one receives. Generally, people report feeling confident and comfortable with the health care they receive from their physicians. Beyond, perhaps, the initial diagnosis, most are not being treated by South Asian physicians and are referred to physicians specializing in ongoing care and treatment issues of HIV/AIDS. There are no identified South Asian HIV/AIDS family practitioners or specialists in Toronto. There is a feeling that the South Asian and other physicians are not keeping themselves educated about HIV/AIDS, perhaps due to the stigma that is associated with the illness.

It appears that many HIV specialist doctors, because they are the one person who knows about a person's status, also end up providing legal advice, personal counselling, nutritional information, and referrals. This means that the doctors need to be well informed, trained and plugged into the whole HIV/AIDS network. This is particularly important for those people living with HIV/AIDS who do not readily disclose their status to others from South Asian communities. People being treated by non South Asian specialists note that, while these people are excellent physicians, they are not accessible from the point of view of spirituality, family matters and interpersonal issues – all the culturally related areas of South Asian people's lives. Some of these doctors also have a distrust of traditional forms of South Asian medicine (e.g., Ayurveda, Siddha or Unani medicine), although a few do provide lists of complementary treatments that people can access if they wish.

Because of the secrecy within communities, many South Asian people living with HIV/AIDS do not want their family doctor, South Asian or not, to know about their HIV status. This makes it difficult for the specialists to share the case. It can go so far that if patients see other South Asians in the waiting room or working at the clinic they will not come back. Some people do not go anywhere including to their doctors after they receive their diagnosis. They

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think that if they are feeling fine they don't need to risk disclosure by going to the doctor anymore.

*When I got calls from 3 to 4 women all from the same doctor asking me for names of other doctors, I started getting concerned that somehow there were some issues of how the doctor was behaving or treating women with HIV/AIDS. When I probed further, I found out their concern had to do with the doctor having hired a South Asian receptionist. When I phoned the doctor, he said that he had done this deliberately to facilitate overcoming any language and cultural barriers with his South Asian clientele. (Key Informant)*

*In another similar situation, a doctor has gone as far as assuring his patients that all information, test results/reports about their HIV/AIDS status will come to his home address ... to deal with their concern about his South Asian staff person being a threat to the privacy of his patients. (Key Informant)*

There are specific reports of discrimination or mistreatment in the health care system. Examples involving insensitive nurses were cited. In one, a woman in hospital for an abortion was given a bottle of Dettol and

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told to wash off the toilet seat every time she used it. In another situation, a nurse said homophobic things. Nursing staff were perceived to be distant by one individual. He felt they wouldn't touch him because of his status. A situation was cited where a person living with HIV/AIDS got operated on for the wrong thing at a hospital and was referred to the HIV/AIDS Legal Clinic by the immigration lawyer to pursue a legal suit.

*A dentist refused to treat my gingivitis after I revealed my status on paper. He told me he couldn't look after my teeth. He just didn't want to treat me because if others found out he might lose other clients. (PHA)*

Examples were also cited of women being tested for HIV without their permission or knowledge, usually related to a pregnancy. Physicians would have made assumptions about women's lifestyle and risk for infections. In these situations women who discover they are HIV + have to deal with the information which is life changing without having had any preparation or pre-test counselling.

Many people in the community do not know about anonymous testing or where all the various testing sites are. Some people only come to know about them when they are notified by public health workers that their partners have tested HIV positive. This is particularly true for women who find out that their husbands are HIV positive and then must get tested themselves. The anonymous testing sites are important because some people fear that when they have been tested through their family physician, their confidentiality may be breached or other negative things might happen.

*I got tested at a doctor's office in a group practice in the same building as where I worked. A few weeks after my HIV+ result, I noticed that the doctor's office was not sending any business our way ..in the same way as before. (PHA)*

*The first person I told about my husband's positive test was a woman from an infant stimulation program who was working with my baby son because of his weak muscle development. She took me to Hassle Free ... after I found out I was positive, she got an appointment for me at Hospital for Sick Children for my son to be tested. (PHA)*

HIV/AIDS and other relevant health information that is available in doctors' and other offices is not culturally or linguistically appropriate.

*There's a ton of information on various aspects of living with HIV/AIDS... it's not worth anything to those who can't read English. (Key Informant)*

Another area of health care concern is related to the care people receive at Community Health Centres (CHCs). CHCs have, as a primary target group, those people who are unable to access health care through typical avenues due to their socioeconomic situation, immigration status, lifestyle or mental health issues. CHCs provide creative, innovative and accessible health care to their target communities. However, they have limited budgets, especially for procedures that are exceptional.

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People who have problems gaining landed immigrant status to Canada because of their HIV status can receive health care at CHCs. The concern for people living with HIV/AIDS is that their treatment can be costly, putting stress on the CHCs' annual, capped budgets for such things as blood work. These same people may not be in receipt of welfare assistance or Ontario Disability Support Program (ODSP) so may

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not have drug cards. If they are ineligible for the Ontario Health Insurance Plan (OHIP), they also do not qualify for the Provincial special drug program or the Trillium Drug Plan. This can result in a huge financial burden for families. There are questions about whether, under these circumstances, this group of people living with HIV/AIDS are always able to get the most timely and effective treatments.

Finally, in the whole area of HIV/AIDS research, there is an overall absence of women and people of colour. So, for example, clinical drug trials using only white men have resulted in drugs on the market that have been shown to cause a different reaction in some women because of their hormonal structures. Some young women may experience changes in their menstrual cycles. People from racial minority communities have also been known to experience side effects from certain drugs such as noticeable changes in their skin pigmentation or stained fingernails. As well, different medications work best when they are taken with specific types of foods. Foods typically eaten by some South Asians may not be the right kinds of foods. However, the dietary guidelines for taking medications are North American, using examples of appropriate foods such as Corn Flakes or peanut butter. There are no dietary guidelines for people whose diets do not approximate the diets of white North Americans.

#### **4.2.3. Welfare, Financial and Insurance Issues**

With new treatments, people living with HIV/AIDS are enjoying longer lives. This has an impact on their financial situation. Families where a member is living with HIV/AIDS experience more financial crises. Low income families often need to find subsidized housing. Some people are on disability income and it is not easy to get back to work because of fear of losing benefits and fear of disclosure at work. Depending on their income, people who work part time may lose their drug card and drugs can cost approximately \$1,500 every month. As well, if a person is well enough to work but only part time due to doctor's appointments and treatments, there may be difficulties with the requirements of Ontario Works, Ontario's welfare program.

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A person who has previously been healthy and employed often has to make numerous adjustments to his/her self image. For men, especially, there is the shift from earning money and being able to meet their own and their family's needs to being unemployed and requiring assistance. Then they must ask for help to get access to basic things like vitamin regimens. For many this feels undignified and signals a loss of autonomy that is hard to accept.

Ontario's welfare system is confusing, even for knowledgeable people like workers in ASOs and SAOs. People who are living with HIV/AIDS who also do not speak much English or have accents and/or have low literacy levels often encounter rude, brusque, short tempered people on the phones when they call for information. Welfare workers will ask lots of questions on the phone to determine eligibility. The questions are used as a screening device to identify ineligible applicants and decrease the time workers spend completing applications. It is hard for people to always answer/or understand what is meant by the questions. As well, unless the form is filled in and the application process completed, it is impossible to appeal the decision. Generally, the feeling is that the workers are more rigid when they perceive the person on the other end of the phone is a new immigrant, refugee or racial minority person. This means that workers at ASAP and other SAOs often have to intervene on behalf of clients and "work" the system for them. If

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people do not have a worker to intervene on their behalf, they are not sure what to do.

*A client on General Welfare Assistance (GWA) was very ill and should have been on Ontario Disability Support Program (ODSP). The worker contacted ODSP, and had an open discussion about the circumstances and was told the relevant papers would be sent. After several weeks they had not come and so the worker left numerous messages. She called Legal Aid to confirm that ODSP had to send the papers. When they still did not arrive, she called the relevant MPP. On that same day the worker returned the call. The reason she gave for not sending the papers was that there was no signed confidentiality form – even though, in the first conversation, this had never been mentioned and she had spoken freely. One of the things Legal Aid said was the payment is retroactive to the date papers are filed. This is a tactic they use – holding on to the papers so they wouldn't have to pay! (Key Informant)*

Very few people have life insurance either because they are denied due to their HIV status, or their insurance is not renewed after their status becomes known. Those who obtain travel or life insurance often do not disclose their HIV positive status. While they continue paying the insurance premiums, they are unable to collect the benefits when they are in need.

#### 4.2.4. Employment and Housing

Employment and housing are other areas where South Asians living with HIV/AIDS experience discrimination, not only based on their HIV status, but also due to their race.

*I was told: "We don't hire Indian people". (PHA)*

*When I applied for low income housing I faced discrimination from one man from my own community who was handling the case. I did not know whether it was due to my status or he was doing his job. Whatever the run around was about, it was awful. (PHA)*

*My employer (a health professional) was supportive and understanding during the course of dealing with initial symptoms and getting tested. Approximately 4 months later, she asked me to resign because she felt she was becoming preoccupied by possible transmission of my illness even though she knew about precautions. (PHA)*

Some people who are living with HIV/AIDS experience discrimination related more to homophobia.

*My landlord found out I was gay. She accused me of bringing diseases into the world.*

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49. Information contained in this section was mainly provided by Ruth Carey, HIV Legal Clinic, Toronto

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(PHA)

*Bigotry travels in packs. I had a client who was a straight South Asian man who had a red ribbon on his desk for the March for AIDS. He became the brunt of homophobic jokes/taunts. His employer's response was that he should remove the offending ribbon to make peace. He chose not to reveal that he was straight on principle and left the workplace. (Key Informant)*

People report losing their holiday pay and pension fund. Some get little accommodation for their illness when they need time off for medical appointments, fatigue or other health related issues. Problems can also emerge in workplaces if information about one's status is not kept confidential by those processing claim forms, for example. All of these factors lead to high levels of stress for people living with HIV/AIDS.

#### 4.2.5. Immigration and Travel <sup>49</sup>

Until recently, people immigrating to Canada, including South Asians, were tested for HIV/AIDS at the discretion of individual immigration officials at the time of making application. This resulted in testing based on race, country of origin, or assumptions about people and their lifestyles. In other words, white people were less likely to be tested than people of colour, even if they were coming from countries where HIV is endemic. More recently, it appears that at least for people applying for status from within Canada, everyone is being tested for HIV/AIDS whether or not they agree.

Everyone immigrating to Canada must have a medical examination at their own expense as part of the immigration process. If, in the course of the medical examination, it becomes clear that a person is HIV positive, s/he must pay for a second medical examination if s/he wants to appeal the case or pursue alternative immigration status. This creates an additional financial hardship for families wishing to pursue avenues such as refugee status or Minister's Permits.

People who are HIV positive cannot be granted residency in Canada due to medical inadmissibility unless they have a valid refugee claim or are granted landing on a discretionary basis after having lived in Canada for five (5) consecutive years on a Minister's Permit. (It does not appear that the latter has ever happened). One way people who are living with HIV/AIDS can stay in Canada is to get a Minister's Permit. This allows people to stay in Canada for a maximum of three (3) years at a time. However, people on Minister's Permits for medical reasons are not eligible to receive OHIP. Some people with Minister's Permits have been denied Ontario Student Aid Program (OSAP), or the right to apply for rent geared to income housing because of the permits. Other ways to legally remain in Canada include obtaining a valid visitor visa or work authorization. Work authorization makes an individual eligible for OHIP.

This denial of supports creates major problems for those on Minister's Permits in terms of access to appropriate and necessary health and social services. Apart from lobbying the Federal Government to amend legislation, the only other legal way to remedy this situation is to challenge Section 19 of the Immigration Act as discriminatory against people who are HIV positive. Legal challenges such as this are very costly. Therefore, to date, Section 19 has not been challenged by anyone who is HIV positive.

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The alternative is to challenge the lack of OHIP eligibility by appealing to the Provincial Health Services Appeal Board and/or challenge OSAP denial through the Ontario Human Rights Commission. To date, no such cases brought forward have been successful. Housing issues can sometimes be won on an individual case basis because boards of directors of non-profit housing have some flexibility. But, as with all court or tribunal proceedings, the confidentiality of applicants must be compromised in order to win.

People living with HIV/AIDS who are allowed to remain in Canada on Minister's Permits have to renew the permit whenever the time limit runs out. There have been cases of women living with HIV/AIDS who are in abusive relationships but are threatened by their partner that if they do not toe the line, they will be sent back to their country of origin without their children. Therefore women stay in the abusive situation in order to have their permits renewed.

One of the reasons people are so anxious to remain in Canada, besides their families, is their concern that, in their countries of origin, health care for HIV/AIDS is not as progressive or available.

*Often if people are in the country illegally, they overstay their permit. If they're found to be HIV+, then there's increased fear of going home. They know that back home, there's going to be very little support, no health care, no meds, no ..., no..., ...it feels even more hopeless – and, if you're a gay man, then there'll be even more persecution because if you're gay, it's assumed you must be HIV+. (Key Informant)*

People living with HIV/AIDS often have trouble travelling outside of Canada. This is made more problematic because of the medications they need to carry with them but also because of the inherent bias of some immigration border officials.

*Often when I travel with medications I am asked about them. I back up my story by telling them I have leukemia. (PHA)*

*I don't disclose because if I did, I would never be able to travel to ..the US, to many other countries. I love travelling. I have a hard enough time at airports. I've often been pulled aside because I'm young, a man and have a "terrorist" sounding name. (PHA)*

#### 4.2.6. Legal Issues

*Poverty creates most of the legal problems experienced by people living with HIV/AIDS. If a person has money it can insulate him/her from many issues.*

(Key Informant)

Lawyers who were key informants in the project indicated that South Asians are not as likely as white Canadians to seek redress in general. One analysis is that people who are already systematically more privileged are the ones who are litigious. Those who face racial or language barriers are less likely to file complaints, less likely to believe that the system will offer a remedy, and less likely to believe that they have rights generally.

*It is easier to be assertive or aggressive if you are culturally conditioned to be that way! Gay white men know how to stand up for their rights.* (Key Informant)

*Either you are guilty or a victim. If you are guilty, then there is shame which is isolating. If you are a victim, there is shame for allowing yourself to be victimized which is also isolating.*

(Key Informant)

*If you are born in Canada and go to school here and have an understanding of the Canadian value system, you will be more vigorous about getting your rights. If not, you may either have no concept of using lawyers to get benefits, or experience internalized oppression.* (Key Informant)

It appears that legal issues are often left to the last, after medical, financial, and social issues have been attended to. Because they are left to the last, sometimes there is less that can be done. Women from South Asian communities who have legal problems are often reluctant to visit a lawyer on their own. Frequently a family member will insist on coming and acting as an interpreter. This can prevent the woman from speaking about what is on her mind. In these situations, the solicitor–client privilege is also broken.

*After the death of one partner in an interracial relationship, the gay South Asian survivor had problems with the estate. The family of his partner only thought they were good friends so he was hesitant to draw attention to himself. He couldn't make claims against the estate because it would have meant revealing his relationship to his partner's family. Then he found out that he was HIV positive and assumed that he would shortly die. So he left work, went on disability and ran up a lot of bills. But he didn't die so then the creditors came after him, and because they now knew that he was HIV positive he couldn't return to work to earn money to pay off creditors. Only then did he turn to lawyers for help.* (Key Informant)

*A South Asian client needed to have a substitute decision maker with power of attorney to pay bills etc. Because he was gay he had no friends or family from within the community to call on to help him out. Therefore he got someone who didn't know him very well to act as power of attorney and that person*

*stole money from him. (Key Informant)*

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In the tainted blood cases, some South Asians came forward. When they came to apply, there was tremendous secrecy. Several family members would come with a chosen spokesperson who might speak better English or understand the Canadian context better. They would express shame, depression, and some women who were HIV + would weep through the whole interview.

(Key Informant)

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Legal, Ethical & Human Rights Challenges: An Ethnocultural Perspective

## 5. Summary Analysis and Recommendations

### 5.1. Analysis of the Findings

The central focus of this study is HIV/AIDS and discrimination including legal, ethical and human rights issues experienced by South Asians living with HIV/AIDS in Toronto. While information about discrimination emerged, two other major themes eclipsed this discussion.

- People are not able to cite very many examples of discrimination because hardly anyone is disclosing their HIV status beyond the immediate family. What is experienced is **felt stigma** within the South Asian communities. **Felt stigma** refers to the shame individuals feel associated with the illness and the fear of being discriminated against if their status is known. Discrimination or **enacted stigma** refers to actual acts which are hurtful or deny people their legal, ethical or human rights based on the negative social labels.
- South Asians experience **general racism or discrimination** in their everyday lives in Canada. Many have reacted by developing thick skins and not reacting to incidents. Discrimination related to HIV/AIDS is treated in much the same way.

At the outset of this report, it is noted that South Asian communities tend to be collective cultures rather than individual ones. This has a direct impact on the way the communities deal with HIV/AIDS. Prevailing ideas permeate South Asian communities to maintain this strong collective culture. Following are some of the specific ways these prevailing ideas are impacting on the way South Asian communities deal with HIV/AIDS :

- **HIV/AIDS as a social and health issue in the South Asian communities is not well understood.** It is barely discussed. Many people used the word **denial** to characterize the communities' awareness and investment in the issue. The communities are not convinced it is a South Asian problem.

*Even though AIDS might be of epidemic proportions, it's not dealt with within the South Asian community because we don't want to acknowledge that we are even "sexual beings".*

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*Prevention/education is just not done because it's difficult to talk about this.*

(Key Informant)

*We need to reclaim ourselves ...before colonization, our culture was open about talking about sex, family issues ... etc. We have many layers to deal with – classism, sexism, internalized racism, regionalism ...all these impact on how we respond to HIV/AIDS. (Key Informant)*

• **Denial leads to ignorance** about transmission, mortality rates and life expectancy. People then continue in some cases to engage in risky behaviour, increasing the chances of spreading the disease within the community.

*The high levels of denial of getting or having HIV has serious effects on transmission. For example, if a South Asian man hangs out at the bath houses and engages in high risk behaviour, he may get HIV and infect his wife. (Key Informant)*

*People who are not open about their situation often don't make the best decisions related to medications and safe sex. (Key Informant)*

• **Pervasive negative and/or untrue prevailing ideas lead to stigma for those that are infected.** This stigma is both perceived and real. For those who are living with HIV/AIDS, the line is blurred. They have grown up with the same prevailing ideas as everyone else. They have internalized the message that only bad people or homosexuals get HIV. They have experienced the disparaging comments about other people who deviate from the norms and assume, given the atmosphere surrounding the issue, that the same will happen to them and their family if they disclose their status. All of these factors cause individuals living with HIV/AIDS to choose to remain silent and not disclose their status.

*The unwillingness to openly acknowledge that it's HIV because the stigma is so great, places a big burden on immediate family/friends to participate in the conspiracy of silence. This takes away from the grieving process. (Key Informant)*

• **Silence impacts on both individuals and the community as a whole.** For individuals, leading a double life becomes the norm. Often people do not even tell their extended family, including their parents. Rather they tell them they have a more acceptable disease like cancer. They become isolated and alienated. Silence prevents them from seeking supports or services they may need. This may lead to poor quality of life and a speedier death. Some people infected with HIV/AIDS die in secrecy back in their countries of origin so that the name of their families is not affected and the futures of their siblings ensured.

*When you're HIV+, your whole life is affected. For example, how much you socialize, who you socialize with, what impact it's going to have on your son's/daughter's reputation ... there is a web of deception that gets formed ...it's like the ripple effect created by throwing a pebble in still water ... the*

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*ripples take over a greater and greater part of your life.* (Key Informant)

Silence in the whole community perpetuates the denial and the stigma associated with the illness. It

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also contributes to the potential for the spread of the disease through risky behaviours.

- **The denial, stigma and silence** collude so that there is reduced broad public disclosure except for a few individuals who take tremendous personal risks. Those who disclose are often branded as disloyal to their community for having brought shame on it. Those who might become ready or wish to disclose find little support or ways to make this happen positively. This, in turn, **reinforces the notion that HIV/AIDS is not a South Asian problem.**

- SAOs are not immune to these prevailing ideas. Numerous accounts of the difficulties of getting SAOs to take hold of the HIV/AIDS issue within the community were heard. SAOs did not participate enthusiastically in this project. Staff at SAOs repeated the prevailing ideas saying that they have no clients living with HIV/AIDS. While it is no doubt true that individuals are not disclosing their status, SAOs do not seem to believe that HIV/AIDS is a South Asian illness either.

- **The everyday racism that people of colour in Canadian society experience has to be factored in.** Examples of denial of employment and housing were heard in the course of the project. Many people related that the most effective response to racism for them was to develop a "thick skin." This usually means that people just ignore the everyday acts of racism they encounter. It is just a part of their everyday life and for some becomes less noticeable.

*People with HIV/AIDS are already in a bad situation. When they encounter the barriers in the system (like welfare) they become increasingly depressed and lose their self confidence. There are lots of tears after these encounters.* (Key Informant)

*People behave differently with me because I speak "white" English, I don't wear shalwar/khurta, I was raised in Canada, I have an anglicised name ...and I know the AIDS sector.* (PHA)

- **It is hard to understand the degree to which individuals experience discrimination related to HIV/AIDS** because of the silence about HIV/AIDS and the everyday racism people in the South Asian communities encounter.

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While specific examples were cited, the internal community issues of denial, silence, and stigma are more important for people right now.

*For a white gay man who is HIV+, there's a community waiting with open arms to support them. For a woman, a person of colour or person with children ..HIV is only one of many issues they may be concerned with in life.*  
(Key Informant)

*We can't ignore racism at the root even when looking at the history of HIV/AIDS – the fact that Africans were blamed for the disease and similarly there's been scapegoating of gay men, prostitutes, and women . Misogyny – women seen as vectors of disease – men are HIV+ because of woman and so they're deserving of it or not deserving of sympathy.*

(Key Informant)

These findings demonstrate that South Asian people living with HIV/AIDS experience felt stigma within a silent community that basically denies that HIV/AIDS is a South Asian problem or issue. They also experience everyday racism living in Canada. They have to cope with two kinds of discrimination – felt stigma

**Recommendation #1:** That a broad multi–pronged social marketing strategy be developed and implemented in South Asian communities to change prevailing ideas and break the silence about HIV/AIDS.

**Recommendation #2:** That a broad–based consortium including key South Asian business people, physicians, media, faith leaders, and people living with HIV/AIDS be established to guide the development and implementation of the social marketing strategy.

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and racism. Individuals' lives are compromised beyond just the HIV/AIDS disease.

The larger implications of these findings is that the South Asian communities that are already vulnerable to racism and marginalization within the larger Canadian context are also at risk for the spread of HIV/AIDS. The denial, ignorance, stigma and silence are all conditions for people to continue to engage in high risk behaviour, and for community education strategies to be ignored and rendered ineffective. Overall, this could contribute to the proliferation of a disease that should be controllable.

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**Recommendation #3:** That four areas be targeted for the South Asian social marketing strategy as follows:

- n South Asian radio, television and print media, including a focus on youth

- n Faith communities

- n South Asian physicians

- n South Asian Organizations

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**Recommendation #4:** That, based on a detailed proposal from the Consortium, Federal, Provincial and Municipal Government bodies and private sector stakeholders fund the proposed social marketing strategy to a level that would make it effective.

**Recommendation #5:** That, after developing and pilot testing a social marketing strategy in the Greater Toronto Area, similar initiatives reflecting local realities be implemented nationally in major cities/centres where South Asian communities live in significant numbers.

**Recommendation #6:** That funders require mainstream ASOs to become representative of and responsive to Toronto's South Asian and other diverse communities.

## 5.2. Recommendations

Based on the overall input of South Asians living with HIV/AIDS, key informants and ASAP's Project Advisory Committee for this study, the Project Team has formulated thirteen (13) recommendations. Recommendations are organized according to three levels of impact currently being experienced by South Asians living with HIV/AIDS and their communities. There are recommendations related to:

w Prevailing ideas/taboo existing in South Asian communities

w Service/support needs of individual South Asians living with HIV/AIDS

w Policy level and system wide changes in the Canadian mainstream.

Each recommendation is followed by a brief discussion and includes specific suggestions or details suggested by project participants.

### 5.2.1. The pervasive silence on the issue of HIV/AIDS must be broken

in South Asian communities.

There is a pressing need to reduce the silence and stigma, and to create an environment where disclosure is more accepted and the norm.

The process of developing and implementing such a strategy has to be driven by South Asian communities jointly in order to maximize its effectiveness. While ASAP already does much work to break the silence, the strategy recommended here is broader and cannot be undertaken by ASAP alone. Because of its limited resources and focus on a stigmatized illness, ASAP is relatively marginalized within the South Asian communities. A broad social marketing strategy is also a large, and complex undertaking. For greater success, larger segments of the South Asian communities need to be involved

**Recommendation #7:** That ASAP develop and pilot a formal responsive continuum/ model of delivering supports and services to South Asians living with HIV/AIDS in partnership with major Toronto mainstream ASOs and other service providers.

**Recommendation #8:** That ASAP improve its own reflectiveness and representation of people living with HIV/AIDS at the governance and staff levels of the organization. Further that ASAP continue to strive to also reflect South Asian communities' ethnic, linguistic, faith, and socioeconomic realities.

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### Legal, Ethical & Human Rights Challenges: An Ethnocultural Perspective

A consortium that includes individuals who are perceived to have power within South Asian communities will result in greater attention to the initiative as well as increase the likelihood that South Asian people will attend to the messages. In the Greater Toronto Area, aligning with mainstream players such as Public Health Departments is also advisable to increase overall reach. The consortium would approve the key messages that are promoted in the various strategies. Members of the consortium would also facilitate links to their own networks for dissemination of the messages and mobilization of their communities.

The recommended overall social marketing strategy needs to be focussed to be the most effective. Based on the findings from this study, the following is recommended:

**South Asian Media:** People involved in the project had numerous ideas about how to launch an effective social marketing campaign. Following are some of the suggested strategies:

w Integrate education into all aspects of South Asian cultural life and pop culture i.e.. cricket matches, kawali programs, Caribana, Amitabh Bachan/ Shah Rukh Khan concerts, mosques, etc.

w Target the young and older generations.

w Find ways to increase the presence of South Asian portrayals in mainstream campaigns.

w Develop videos like "Bolo bolo" prepared by ASAP/KHUSH, targeting young South Asian gay

men and men who have sex with men.

w Develop and run commercials/ads on Hindi movie rentals (short clips at the beginning).

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w Place stickers on South Asian rental video tapes.

w Recruit film makers/film celebrities to support/endorse/produce relevant films with appropriate messages. This could extend internationally to Bollywood (Indian commercial film industry).

**Faith Communities:** The first challenge is to change the attitudes of faith leaders towards HIV/AIDS and to their role in delivering messages about the disease. It is important that the messages are positive, non stigmatizing or marginalizing. Co-ordinating a day or week when these messages are delivered to a wide range of congregations all at the same time could be effective. Involving faith leaders in developing a package for circulation or display at mosques, temples, gurudwaras and other places of worship will also be key to successful implementation of the faith based strategy.

**South Asian Physicians:** South Asian physicians play a critical role in the lives of South Asians in To

**Recommendation #9:** That ethnospecific ASOs such as ASAP advocate for change in Canada's immigration policy, specifically as it relates to the denial of OHIP, OSAP and non-profit housing to people on Minister's Permits. Further, that the relevant section of the Immigration Act (Section 19) be challenged.

**Recommendation # 10:** That ethnospecific ASOs such as ASAP advocate to ensure that people of colour and women are included in HIV/AIDS clinical research initiatives underway in Canada.

**Recommendation # 11:** That ethnospecific ASOs such as ASAP advocate to ensure timely, linguistically and culturally sensitive access to Ontario's Welfare process for people living with HIV/AIDS.

**Recommendation #12:** That the education of health and social service professionals within and outside South Asian communities on the issues faced by people of colour living with HIV/AIDS be promoted as a central ingredient of all relevant health and social service training programs.

**Recommendation #13:** That ethnospecific ASOs such as ASAP explore the issues of the collection of race based statistics for surveillance and tracking purposes with federal, provincial and municipal governmental authorities so that responsive strategies can be developed for prevention

## 5.3. Conclusions

This project was intended to build on work done in mainstream communities on HIV/AIDS and discrimination. In addition, four other intended outcomes have been achieved:

i. This report provides a greater understanding of the lived realities of members of one of Canada's largest ethnospecific communities. Through the words of 21 people living with HIV/AIDS and the views of key informants, of whom over 50 % were also South Asian, an assessment of the current situation within South Asian communities and strategies for change have been highlighted. The information can now be shared and analysed within South Asian communities and more broadly so that the Canadian AIDS Movement overall can grow, develop and increase its effectiveness and representativeness. This project is a first step in stimulating a national dialogue on HIV/AIDS in ethnospecific communities.

ii. This project was developed, directed, facilitated and approved by South Asians representing both people living with HIV/AIDS and others. The project piloted several different effective ways of locating and including people living with HIV/AIDS who might otherwise not participate in research such as this. For some, being involved in this project was the first time they had ever spoken and/or shared their situation outside their immediate family. The views and opinions of South Asians living with HIV/AIDS directly influenced the recommendations, making them meaningful and relevant. The process undertaken by ASAP increased the participation of an under-represented population in HIV/AIDS research.

iii. ASAP worked along with Asian Community AIDS Services (ACAS) who was undertaking a similar initiative. The sharing of information, tools, and overall outreach strategies strengthened both projects. As well, looking together at relevant recommendations strengthens the overall voice of people of colour living with HIV/AIDS in Canada.

iv. Perhaps the single most important outcome of this project is the clear demonstration that HIV/AIDS is an important reality for South Asian communities. Through documenting the voices of South Asians living with HIV/AIDS, it has been shown that this is a pressing and serious issue for South Asian communities. It also points to the serious risk the communities are at for the spread of the disease if South Asians do not break the code of silence and denial that exists.

This study was an ambitious, intense undertaking for ASAP. The results are far reaching. Taking leadership and acting aggressively on the recommendations is the joint responsibility of various stakeholder groups within South Asian communities, ethnospecific ASOs such as ASAP, mainstream ASOs, as well as policy and funding bodies. Moving forward will enhance the overall well being of South Asian individuals living with

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HIV/AIDS and their communities. As well, there are opportunities for collaboration which will benefit people living with HIV/AIDS from many other communities in Toronto and across Canada.