**Culturally Competent Health Promotion as a Social Inclusion Mechanism:
A Study of Ontario Community-Based AIDS Service Organizations**

by

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Author's Declaration

I hereby declare that I am the sole author of this thesis. This is a true copy of the thesis, including any required final revisions, as accepted by my examiners.

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Abstract

Ontario is a culturally diversified society. Its population composition has changed drastically in the past few decades to include large numbers of individuals with cultural norms differing from that of the majority. This poses challenges to public health, such as HIV prevention. Identifying practices that promote social inclusion in these communities is an important step toward the maintenance of cultural diversity and elimination of social exclusion. Culturally competent health promotion is one example of socially inclusive practices. *Cultural competence* refers to practices that take into consideration the cultural and linguistic nuances of a specific community or group.

This thesis will be guided by the research questions: (1) What are the main health promotion practices of Community-based AIDS Service Organizations (CBAOs)? (2) How do the activities of these organizations promote social inclusion? This thesis uses qualitative methodology to study the CBAO as the unit of analysis. Data were collected from operators at three ethno-cultural CBAOs in Ontario: South Asian; Black, African, and Caribbean; and Portuguese. CBAOs are organizations within the community that provide HIV prevention resources, as well as support for persons living with HIV/AIDS in the community. The practices demonstrated at CBAOS in these communities illustrate three related mechanisms present that promote social inclusion: (a) community networking, (b) community knowledge and involvement, and (c) community-specific resources. These mechanisms can be used to inform practices at other community-based organizations in Ontario.

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Chapter 1. Introduction

Ontario is a multicultural society where many communities (including certain ethno-cultural groups) relate to cultural norms that are different from majority. The majority culture can be defined as those individuals of British or French background (Saloojee, 2003). *Culture* refers to norms specific to a certain group (including language). Cultural norms and practices influence the way in which individuals access and understand *health* resources and services (Clarke, 2000). These cultural differences can lead to social exclusion that can significantly impact some communities' access to important resources and services, and may ultimately result in health inequalities. Both elimination and prevention of social exclusion in these communities are important means to reducing such inequalities.

One mechanism for the elimination and prevention of social exclusion is practice related to social inclusion. *Social inclusion* is the process of distributing resources to ensure that excluded populations have access to them (Omidvar & Richmond, 2003). This inclusive process can refer to policies or practices. The provision of culturally competent health promotion is an example of socially inclusive practice. *Cultural competence* refers to practices that take into consideration the cultural and linguistic nuances of specific communities. In order to be relevant and accessible, and hence socially inclusive, health promotion materials distributed to particular cultural groups need to be culturally competent (Kreuter, 2002).

This study focuses on Community-Based AIDS Service Organizations or CBAOs as the unit of analysis and describes their culturally competent health promotion practices. It examines (a) the role that CBAOs in Ontario play in bridging the mainstream system and the communities they serve, (b) the health promotion resources and services CBAOs provide, and (c) how health promotion practices can promote social inclusion.

Community-based organizations are best positioned to provide health promotion services to their communities because they are situated within the community and familiar with the community's needs (Takahashi et al., 2007). Specifically, CBAOs are organizations within the community that provide HIV/AIDS related services to their community, including health promotion resources related to HIV prevention. *Health promotion* refers specifically to the practices of providing individuals with materials that educate them about which choices and behaviors may prevent certain health risks. Such practices are often focused on specific issues such as HIV, as they pertain to specific groups who may be more at risk than others. Health promotion goes beyond changing behaviors to creating conditions for communities to have physical, mental and social well-being (Saloojee, 2003). Therefore, health promotion practices are an important component of more general health care practices, which typically deal with the treatment of disease and overall maintenance of health, and refer to therapies and services designed to ameliorate rather than prevent health problems in individuals.

1.1 Problem Area of the Study

Ontario's population composition has changed drastically in the past few decades, and a large number of its new residents are individuals from ethnic minority communities. However, there is often no linguistically and culturally appropriate health promotion services provided to serve these communities' needs. Therefore, minority communities are often excluded due to cultural norms that are differing from the majority.

CBAOs in Ontario are bridging these minority communities and the mainstream system. Their promotion of social inclusion in their communities can help to eliminate health resource exclusion.

1.2 Research Objectives

The main objective of this thesis is to examine the culturally competent health promotion practices at CBAOs and how these practices promote social inclusion. This study will look at practices carried out by community-based organizations, which are focused on HIV prevention.

1.3 Significance of the Study

Because Ontario is a culturally diversified society impacted by the HIV/AIDS epidemic, research in this area should look at how health promotion in ethno-cultural communities be delivered in a culturally sensitive way. Ultimately, providing culturally relevant health promotion to these communities is one part of the solution to eliminating health inequalities exacerbated by social exclusion. Culturally competent methods are extremely important for getting health messages across to these communities and to

ensure their recall. Current research regarding HIV prevention is focused on current priority populations, but attention needs to be given to other at-risk populations. Furthermore, this research is relevant because limited research exists on cultural competence related to HIV/AIDS, in Ontario.

The HIV epidemic is immense on the global scale, and there is opportunity for Ontario to make a difference. HIV will become a very costly disease to the health care system. Those in ethno-cultural groups may find it more difficult to cope with HIV infection because of additional issues associated with social inequities they already face. Members of ethno-cultural communities are likely to face stigma and discrimination. Therefore, exploring culturally competent health promotion practices from the view of community is important for the prevention of HIV infection.

1.4 Limitations of the Study

While there are more than 20 CBAOs in Ontario, this project only analyzed data gathered from three of them. It should be noted that the three CBAOs were chosen because they represent significant portions of the CBAO spectrum in Ontario. This project focused on HIV (disease) prevention, which is only one aspect of health promotion. Furthermore, HIV is a complex issue with relationships to issues such as stigma, homophobia, and poverty, which may not be common to other health issues.

1.5 Conclusion

This project is guided by the following research questions: What are the main health promotion practices of CBAOs? How do the practices of these organizations promote social inclusion? The methodology for this study is detailed in Chapter 3, following the analytical framework presented in Chapter 2. Chapter 4 demonstrates that these communities and organizations facilitate social inclusion through the use of three related mechanisms: (a) community networking, (b) community knowledge and involvement, and (c) community-specific resources.

Chapter 2. Analytical Framework

2.1 Introduction

Social inclusion has been recognized as a key social determinant of health because it can make a positive impact on health inequality. Due to cultural norms and values that differ from the majority, certain social groups are socially excluded from some resources, as well as some societal institutions. Inclusionary practices in the health sector include practices that are focused on cultural awareness, community participation, and the recognition of diversity (Furness, 2005). One example of such socially inclusive practices is culturally competent health promotion practices. These practices are part of the mission and activities carried out by the CBAOs.

Much research, outlined in this chapter, has been done to show that culturally competent health promotion practices are inclusive and benefit those who are traditionally excluded from health promotion resources. Additionally, much of the literature not only examines the barriers experienced by organizations providing such practices, and evaluates the impact of these practices on communities. However, research on the culturally competent practices of these organizations and the relationship of these activities to broader sociological concepts is limited.

The following diagram illustrates the relationship between cultural diversity, social exclusion, and culturally competent practices that promote social inclusion.
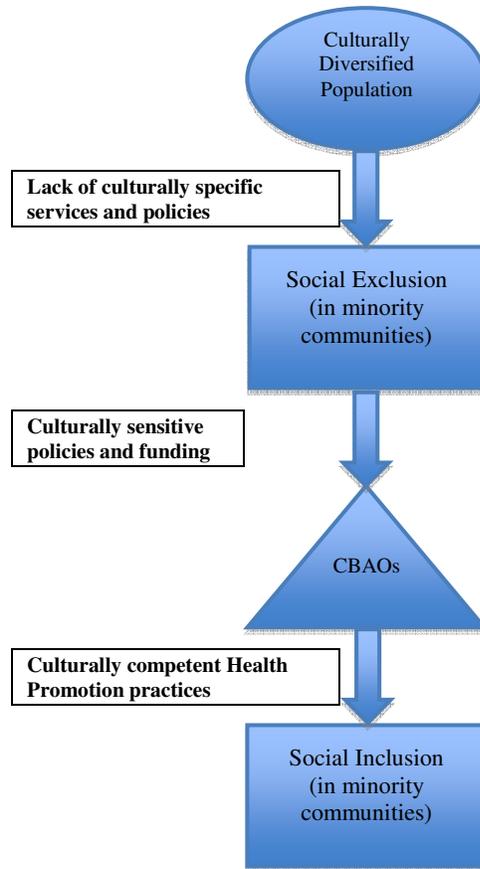
Figure 1. Analytical Framework

Cultural diversity in society can lead to socially excluded minority communities, when there is a lack of culturally specific resources and policies that reflect the multiple cultures present in society. Culture refers to practices, systems of meanings, ways of life, and other social regularities that shape a community's norms. Communities with different cultural norms from the majority may have different conceptions of health and different behaviors related to accessing health resources. As a result, these individuals may become socially excluded. Social exclusion refers to the inability of certain groups to participate fully

in society due to structural inequalities. One example of social exclusion is exclusion from resources, such as health promotion (Saloojee, 2001).

Policies that reflect the need to prevent social exclusion in health have resulted in funding and support for culturally specific organizations like CBAOs. The main mission of such organizations is to provide culturally competent health promotion resources and services. Practices that take into consideration the cultural and linguistic nuances of a minority community are considered culturally competent. Such practices reflect cultural diversity and promote social inclusion by accommodating differences and cultural diversity. Overall, culturally competent practice can work to eliminate social exclusion and promote social inclusion.

The remainder of this chapter describes the analytical framework of this study. The framework includes the relationship between: cultural norms and health (Chapter 2.3), social exclusion (Chapter 2.4), cultural competence (Chapter 2.5), and culturally competent resources as an example of social inclusion (Chapter 2.6). This chapter also provides a description of CBAOs in Ontario, including previous studies done focused on these organizations (Chapter 2.7).

2.2 Cultural Diversity: HIV Prevalence in Ontario

The population of Ontario is very diverse and it has a large number of ethno-cultural populations. Nationally in 2006, 19.8 percent of residents are immigrants—while in Ontario, 27.9 percent of residents are immigrants, and 22.9 percent of the population identified themselves as a 'visible minority.' Of this latest group: 28.9 percent identify as South Asian,

21.0 percent as Chinese, 17.2 percent as Black, 7.4 percent as Filipino, and 5.4 percent as Latin American, as well as those who belong to multiple communities, or other smaller communities. Moreover (in 2006), 2.2 percent of Ontario residents do not have knowledge of either official language (English or French), and 14.9 percent speak non-official languages at home, which is higher than the national average of 11.2 percent (Statistics Canada, 2006).

With respect to the HIV/AIDS epidemic, recent findings indicate that the HIV epidemic in Ontario has not yet stabilized (Remis et al., 2008). Moreover, HIV is a growing issue in Ontario's ethno-cultural communities. Currently, there is no cure for HIV, nor is there a vaccine. Medical therapies can be effective to increase life expectancy, yet can be expensive and are not available to all individuals. Thus, prevention remains the most effective solution to reduce and eliminate HIV infection. As of 2008 and since 1985, 34,941 persons in Ontario have been infected with HIV; 9,116 persons have died, leaving 26,356 persons living with HIV as of 2006. Since 2001, HIV prevalence has increased 6.7 percent annually, due in part to the continued incidence of HIV, as well as to decreased mortality rates. Ontario has the highest number of positive HIV test reports in Canada. In 2007, 44.0 percent of all positive HIV tests were from Ontario (PHAC, 2008). Additionally, in 2007, 71.2 percent of all HIV tests nationally did not have ethnic status submitted. Both Ontario and Quebec do not submit ethnic status information with HIV test requests. Currently, ethnic status is not a required question on the HIV test requisition form prior to having an HIV test. Furthermore, many HIV tests are taken anonymously. As such, it is difficult to estimate the

number of positive tests from individuals from ethno- cultural communities (PHAC, 2008). Excluding data from Ontario and Quebec, positive tests have been attributed the following ethnicities: 58.4 percent white, 10.3 percent black, and 9.9 percent other ethnicity (PHAC, 2008). Nationally, it has been shown that three notable groups that are affected by the epidemic are women, men who have sex with men (MSM), and individuals from endemic countries, including those in Africa and the Caribbean (Remis et al., 2008).

On the basis of these findings relating to the HIV/AIDS epidemic and the provincial demographic data, the AIDS Bureau of Ontario works to implement strategies to deal with the needs of these Ontarians. CBAOs in Ontario have been developed to complement health promotion efforts aimed at the majority in order to meet the specific needs of ethno-cultural communities.

2. 3 Culture and Health

The Public Health Agency of Canada (PHAC) (2002) has identified 12 key, interrelated determinants of health: income and social status, social support networks, education and literacy, employment/working conditions, social environment, physical environment, lifestyle, health child development, genetics, gender, health services, and culture. Due to their cultural norms that differ from that of majority society, some groups may face additional health risks due to the perpetuation of conditions such as marginalization, stigmatization, devaluation of language and culture, and lack of access to culturally appropriate health care and service (PHAC, 2002).

Culture is a defining characteristic for certain ethnic groups. It can shape a group's norms, practices, systems of meanings, ways of life, and other social regularities. Behavioral and social factors like ideas about familial roles, individualism and collectivism may contribute both behaviors related to health (Kreuter et al., 2002). Meanings and perceptions of health and disease vary with respect to cultural views (Tsai et al., 2004). Culture affects the way individuals think about health, access health care, and respond to health promotional information. Anderson et al. (2003) note that culture defines how health information is received, understood, and acted upon. More specifically related to HIV, there are certain culturally based norms related to sexual behaviors (Latkin and Knowlton, 2005) that need to be considered with respect to health promotion materials focused on HIV prevention. Therefore, certain groups have specific relationships between culture, health and health-related behaviors that need to be recognized and understood. Additionally, it has been shown that due to barriers, including language and others relating to racism, discrimination, stigma, mistrust of mainstream providers, and additional cultural factors, ethno-cultural communities are less likely to participate in health promotion programs.

Most health promotion materials and programs only reflect the cultural norms of the majority culture and therefore ethno-cultural communities can suffer as the materials do not meet their cultural needs (Saloojee, 2003). This is important in Ontario where there are many ethno-cultural communities who relate to cultural norms different from the majority. Moreover, there are many ethnic community members who speak the official

languages but do not relate to other cultural norms associated with the majority culture. These communities may become excluded from services and resources aimed that the majority of Canadians.

2.4 Social Exclusion

Social exclusion is one explanation for health inequalities present in the population. Galabuzi (2004) defines social exclusion as the inability of certain groups to participate fully in society due to structural inequalities that prevent their access to social, economic, political, and cultural resources. Social exclusion can arise repeatedly in societies due to structural and economic divisions, discrimination, and historical oppression, as well as self-exclusion (Saloojee, 2003). The result is that certain groups are disadvantaged and excluded from having access to social institutions targeted to the majority and, potentially, from being able to exercise certain rights that ought to be enjoyed by all members of society. These excluded groups often include women, racial and ethno-cultural minority groups, and youth (Labonte, 2004).

Some groups experience multiple dimensions of exclusion, while other groups may be excluded from necessary resources. As such, exclusion from social goods (such as resources) is an important example of social exclusion (Galabuzi, 2004). Some social resources may not be provided in appropriate languages, and/or include information that is inappropriate for certain cultural or religious beliefs (Saloojee, 2003). Therefore some resources may become culturally irrelevant due to cultural barriers or inaccessible due to

linguistic barriers. Some communities will remain excluded from certain resources unless their specific cultural needs are addressed through inclusive practice.

2.5 Culturally Competent Health Promotion

Cultural competence refers to practices that respect the values, beliefs, and practices of the audience (Lister, 1999). Culturally competent health promotion practices are rooted in the recognition of cultural norms and their specific relationship to health. Tsai et al. (2004) points out that for health promotion efforts to succeed in changing an individual's behavior to improve his or her health, the approach must be culturally competent. Cultural competence requires an awareness and sensitivity to these different relationship between cultural and health. Therefore, culturally competent resources are designed to take into account both language and other nonverbal communications that may be specific to certain cultural practices (Anderson et al., 2003). Cultural competence can also be referred to as a set of policies that allow for effective health-related practices in cross-cultural situations (National Health Medical Research Council [NHMRC], 2005). Such practices exist most notably in the United States and Australia but have, over time, been adapted to produce similar results in Canada.

The need for culturally competent health care and health promotion is rising as the number of persons with ethnic minority identity is increasing in Canada, along with the need for an increasingly effective healthcare system. To meet such needs agencies associated with the healthcare system will have to focus on increasing the level of cultural competence in practice. This is important as it is agreed that culturally competent practices

are one strategy for improving the quality of health-related services, as well as addressing inequitable access to services.

Cultural competence can be achieved in a number of ways. It can refer both to the development and delivery of practices. One specific example of how the health sector can be involved in social inclusion is through the use of culturally competent health promotion practices. Lister (1999) presents a taxonomy that explains the development of culturally competent practice in health care. The taxonomy was created to be specific to nursing education but can be applied to the development of practice in other organizations and institutions. This taxonomy is important for this study because it begins with the basic assumption that different cultures have different beliefs related to health, and it uses this assumption as a basis for the development of practice through personal reflection and involvement with the community to be served. The taxonomy consists of five levels that build upon one another: cultural awareness, cultural knowledge, cultural understanding, cultural sensitivity, and cultural competence:

1. Cultural awareness: Practitioners describe how beliefs are shaped by culture and show an understanding that different cultures/ethnicities may validate different beliefs.

2. Cultural knowledge: Practitioners show familiarity with cultural differences among communities in society.

3. Cultural understanding: Practitioners recognize issues that face groups when their values and beliefs are compromised by a dominant culture.

4. Cultural sensitivity: Practitioners show regard for beliefs, values, and practices and awareness of the influence of one's personal cultural background.

5. Cultural competence: Practitioners provide care that respects the values and practices of the individual and addresses disadvantages arising from power relations.

Health promotion practices are only one example of the techniques associated with achieving cultural competence. Brach & Fraser (2000) suggest that other techniques include: interpreter services, training, use of community health workers, including community members, and specific recruitment policies. Culturally competent health promotion materials are especially important because of other barriers to prevention, including specific cultural values that can be widely held by a particular community group (Kreuter et al., 2002).

2.6 Culturally Competent Health Promotion Practices: Example of Social Inclusion

The principles of cultural competence - respecting the values, beliefs, and practices of the community are central to the definition of social inclusion (Saloojee, 2003). Social inclusion is one mechanism to address issues related to discrimination and exclusion, such as access to services and resources.

Social inclusion is a proactive response to the conditions of social exclusion experienced by certain communities (Saloojee, 2003). Social inclusion refers to the development of practices and policies that include members of society by accommodating differences (Saloojee, 2001). The concept of social inclusion suggests that all members of

society are entitled to the same rights and resources, while asserting that specific groups may be different and may require alternate versions of these rights and resources. Saloojee (2003) refers to the importance of conferring recognition on all individuals and groups, which can mean respecting different cultural values associated with the definition of health and the process of accessing resources.

Anderson et al. (2003) confirm that culturally competent health practices will have the potential to reduce health inequalities. Galabuzi (2004) indicates that the health sector (including health care and health promotion) can be directly involved in social inclusion by: increasing access to culturally sensitive and language specific services, providing training on cultural sensitivity, and helping excluded communities to build networks. The provision of such resources through the practice of culturally competent health promotion in excluded groups (such as ethno-cultural communities) is an example and an important component of the processes of social inclusion to access (including an awareness of what is available); a lack of culturally competent resources and services is shown to be a significant reason why immigrants do not seek health care services as much as the rest of the population (Zanchetta & Pourselami, 2006). Overall, cultural norms and diversity are important factors that determine whether communities are excluded or included in services and institutions designed for the general public.

Specific to health promotion, social inclusion also refers to building networks between communities and connections to individuals, and therefore culturally competent practices often originate at the community level and focus on including communities to

determine priority issues and solutions. As well, the process of including communities can refer to providing linguistically and culturally relevant appropriate services and resources.

2.7 Community-Based AIDS Organizations: Missions and Previous Studies

In Ontario, CBAOs developed response to community need for culturally relevant information about HIV/AIDS. They are part of a larger network of community-based organizations, which play an important and distinct role in the delivery of services through strategic and effective partnerships. Community-based organizations are best positioned to provide health promotion services to their communities because they are situated within the community and familiar with the community's needs.

The CBAOs referenced in this project are non-profit organizations that provide health promotion and support services to ethno-cultural communities. While acknowledging the presence and impact of racism, sexism, heterosexism, homophobia and other access barriers - their main mission is to: (a) reduce the spread of HIV infection within communities and (b) enhance the quality of life of people living with or affected by HIV/AIDS.

The CBAOs attempt to achieve this goal by providing resources and services that are culturally competent and accessible. Additionally, their practices can potentially realize the more general goals of health promotion, like capacity building and community mobilization. Coming to an understanding of the effectiveness of their health promotion efforts requires a close look at the challenges community-based organizations must overcome in their communities.

Chillag et al. (2002) used interviews and focus groups to explore the views of staff from 26 American community-based organizations (CBOs) that serve different populations (African American, Hispanic, Asian/Pacific Islanders, and Native Americans). The aim of the Chillag et al. study was to examine barriers that exist in the provision of these prevention services. According to Chillag et al. (2002), the term *CBO* refers to local organizations staffed by persons familiar with the needs of specific communities (e.g., particular racial/ethnic minorities). Examples of CBOs in this wide-ranging study include primary health care agencies, drug rehabilitation centers, homeless shelters, grassroots AIDS service and prevention organizations (like Ontario CBAOs), and community centers. It was suggested that, the organizations in the Chillag *et al.* study were able to deal with four types of intertwined barriers to delivery: structural, socio-cultural, organizational, and individual. Structural factors include: economic issues facing the community (poverty, housing, lack of community development) and the policies related to funding of the organization's initiatives. Socio-cultural barriers include: stigma related to racism and homophobia, distrust of the health care system, culture, community norms and beliefs about HIV/AIDS, and language difficulties. Organizational barriers include: difficulty in recruiting CBO staff members who reflect the community and, importantly, a lack of resources. Those who work within the community suggest that these barriers may be overcome by the establishment of credible relationships with the community by developing knowledge of cultural norms and relevant structural issues. The study done by Chillag et al. was able to demonstrate that

using different education styles related specifically to the needs of the community are more effective than general strategies.

A study carried out by Takahashi et al. (2007) examines the experiences of HIV/AIDS prevention organizations in California that serve Asian/Pacific Islanders. This quantitative study showed that providing culturally appropriate prevention requires organization staff members who are sensitive to the cultural and linguistic needs of the target community and who are able to accommodate challenges faced by their ethnic community members. Such challenges may be individually related or based in social-structural contexts. Moreover, this study showed that staff members are only one component of an effectively functioning organization. Issues such as funding, community and political partnerships, and appropriate knowledge and resources also determine the ability of an organization to provide effective and appropriate prevention programs.

Guenter et al. (2005) conducted a study with 33 individuals from 11 government-funded CBAOs in Ontario. The aim of the study was to use qualitative interview techniques to study the values and skills of the staff members involved in HIV prevention organizations. Findings from this study showed that interventions should focus on both the individual level and the higher systemic level. Priority is given to providing relevant prevention programs that are well received by the community. The ability to achieve this relevance may depend on how many different communities the CBAO is serving. Similar to those of Chillag et al. (2002), the findings suggested that barriers such as language and ethnicity affect the organization's ability to reach certain population groups. Main challenges include providing

services to those who speak non-official languages and represent diverse ethno-cultural backgrounds. Respondents suggested that if CBAOs want to develop trust and break down barriers, they should have staff members or operators who are from these communities and to work diligently to understand the population and its needs.

The changing demographics of the population are a particular challenge for all community-based organizations. Thus, although they do try to be knowledgeable about the populations they serve, the organizations experience difficulty in responding to these needs (Cain, 1997; Chillag et al., 2002; Guenter et al., 2005). Although, it was evident from these studies that community-based organizations are attempting to be knowledgeable and to refocus their attention on a wide variety of risk groups, neither Chillag et al. (2002) nor Guenter et al. (2005) was able to describe clearly how this is being done and exactly who is included in the targeted risk groups.

Community-based organizations are also faced with other problems relating to the professionalization of the health system (Cain, 1997; Guenter et al., 2005). The diminished value placed on grass-roots initiatives (Guenter et al., 2005) makes it difficult to respond to new needs. Thus, these organizations can be influenced more by the political environment in which they operate and by governmental bodies than by the changing priorities of the HIV epidemic in their communities. This is a further problem when specific groups that require specific HIV prevention programs are not viewed as priorities by the government. In fact, according to a study conducted by the Canadian Public Health Agency (2000) ethno-cultural groups are generally viewed as low current priorities by CBAOs, public health

organizations, and governments. This report included responses from members of CBAOs and public health offices, as well as local, provincial, and federal governments. Ethno-cultural communities were placed last or second-to-last on a list of current priority groups. Groups at the top of the list included youth, injection drug users, and the general public. A number of respondents in the study noted the need for culturally sensitive materials for Aboriginal and ethno-cultural communities (CPHA, 2000). Although little explanation is given, according to the report, while ethno-cultural groups are emerging as a priority for CBAOs they are not for public health organizations or governments.

Kreuter et al. (2002) presents an important framework describing the general methods for the production of culturally competent materials, based on a study that focused on health promotion related to African American and Caribbean women and heart disease. On the basis of the findings of this qualitative project, five categories for enhancing the cultural competency of promotion materials are presented (see Table 1 below) and are as follows: (a) peripheral, (b) evidential, (c) linguistic, (d) constituent involving, and (e) socio-cultural.

Table 1. Framework for analyzing culturally competent materials

Type of strategy	Strategy target	Objectives; comments
Peripheral	IMAGES ▪ Color ▪ Text ▪ Images, photos	Convey relevance and establish credibility Attempt to match surface characteristics of group
Evidential	CONTENT ▪ Present evidence that will have impact on group	Increase perceived personal vulnerability
Linguistic	LANGUAGE ▪ Translation to dominant, or native language	Presentation of language as fundamental to communication Requires more than just strict translation to retain meanings of messages
Constituent involving	COMMUNITY ▪ Experience of = community	Involve community members in production of materials Can provide insight needed for other strategies
Socio-cultural	BEHAVIOR CHANGE ▪ Culture-specific conceptualizations of health	Reflect on deep, context-based understanding of culturally normative practices and beliefs Empowerment

Note: Adapted from Kreuter et al. (2002). Achieving Cultural Appropriateness in Health Promotion Programs: Targeted and Tailored Approaches. *Health Education and Behavior*, 30(2), 133-146.

2.8 Conclusion

This chapter provides the analytical framework for the study connecting several concepts relevant to health promotion. The main areas include the relationship between culture and health and cultural competence as an example of social inclusion. In addition, it presented previous North American studies that were focused on CBAOs that were used to inform this study. These studies were particularly relevant to the methodology of this study outlined in Chapter 3 and helped to guide the analysis and finding in Chapter 4.

Overall, this study attempts to answer the following research questions: What are the health promotion practices of CBAOs? How do these practices promote social inclusion? It will fill a gap in the literature on cultural competence in health promotion as an example of social inclusion effort. It will examine practices related to health promotion at CBAOs in Ontario to see how they are related to cultural competence and to the promotion of social inclusion.

Chapter 3. Methodology

3.1 Introduction and Methodological Rationale

The objective of this study is to examine how CBAOs promote social inclusion in their communities through culturally competent health promotion practices. To consider this research objective I chose a qualitative research methodology. A qualitative methodological framework uses techniques to situate the analysis in context and allows for significant contact with the people affected and involved in the phenomena studied in their social environment (Kvale, 1996). This type of research is valuable for investigating complex issues, for achieving a deep understanding of how people think about such issues, and for analyzing what they do in their daily routine. The dialogical process between the researcher and the study participant allows the thoughts of the participants to be the most important and to guide the research process (Guenter et al., 2002).

In this project, in-person interviews were chosen to allow the researcher to speak directly with participants from CBAOs about their understandings and experiences related to health promotion, social inclusion, and cultural competence. The remainder of this chapter will detail the research design, data collection, including the characteristics of the sample, and data analysis methods.

3.2 Research Design

The research design used in this project has been adapted primarily from two studies: a qualitative study of Ontario CBOs by Guenter et al. (2005) and an American study

of CBOs and HIV prevention by Chillag et al. (2002). In the study by Guenter et al. (2005), staff from 11 CBAOs in Ontario participated in semi-structured interviews. When the study began in 2000, 49 Community-based organizations that received funding from the AIDS Bureau and had a focus on HIV education were eligible for participation. In this study, interviews were chosen as the data collection method because of their flexibility and their ability to allow data collectors to get more in-depth information on issues that arise during the interview process. Analysis was done using data management software to develop themes and findings based on a grounded theory methodology. Due to the similarity between this thesis and the study by Guenter et al., their process for data collection was adopted for this study. However, due to the smaller sample size in this project, the process of analysis did not involve the use of a data management system.

The study by Chillag et al. (2002) recruited participants from CBAOs that served a number of populations—African American, Hispanic/Latino, Asian/Pacific Islander, and Native Americans—and that represented more than 20 geographic locations, the majority of which represented areas of high HIV prevalence. These participants took part in both focus groups and on-site, semi-structured interviews as the method of data collection. The Chillag et al. (2002) study of CBAOs dealt with broader samples than those in my study because the questions they were exploring were broader in scope. Despite this difference, I used similar data collection methods to inform the methodology of this project.

3.3 Data Collection

The major source of qualitative data in this study comprises 7 key informants: 6 from CBAOs in Ontario, and one from the AIDS Bureau of Ontario. The CBAO is considered to be the unit of analysis for this study. CBAO operators provide health promotion specifically focused on HIV, as well as support to persons living with HIV/AIDS and their families. It examines how these organizations provide culturally competent health promotion in practice and how these practices promote social inclusion. The organizations are similar as they are community based and focus on communities that are excluded from mainstream health promotional resources because of their differing cultural norms and linguistic barriers. This thesis will focus on the similarities and differences between the chosen CBAOs in relation to these mechanisms. By considering an organization as unit of analysis and looking at their issues and practices in parallel with each other, generalizations at the organizational level may inform other community-based organizations about how to employ similar mechanisms to promote social inclusion.

Each of these organizations serves a community that identifies itself as a particular ethno-cultural group. The three communities that the organizations serve are: Portuguese; Black, African, and Caribbean; and South Asian. For the purpose of this study, these communities can be considered excluded at the provincial level because no culturally specific resources are provided for these groups by the provincial health care system. CBAOs are present in each of these communities and have developed out of the community needs as the HIV/AIDS epidemic changed in Ontario. These organizations have existed in

the communities for the past 20 years and have evolved as the community needs and demographics have changed, as well as HIV/AIDS epidemic. Over time, CBAOs are able to promote social inclusion and prevent these communities from being excluded from accessing important health promotion resources. Additionally, these organizations are able to work with frequently excluded groups within the communities (such as youth and women) and dedicate specific resources to meet the needs of these groups within the large ethno-cultural communities.

The term '*community*' can be problematic, especially when referring to ethno-cultural communities. For the purpose of this study, '*community*' is defined as a group of persons who relate to similar cultural norms. The individuals who composed the specific communities were defined by the community organizations themselves, while the overall population sizes of these communities in Ontario can be estimated (see Table 4 for details).

3.3.1 Participant Recruitment

Upon receiving approval from the Office of Research Ethics at the University of Waterloo, I began the recruitment process. The sampling method I used was purposive. The organizations considered for this project included all ethno-specific organizations run by operators who are primarily from the ethno-cultural community they serve. To identify the CBAOs located in Ontario, I conducted an Internet search of the websites of organizations such as: Ontario AIDS Network, the Canadian AIDS Treatment Information Exchange, and the Public Health Agency of Canada. Due to the relatively small number of 20 organizations that work within ethno-cultural communities, the total possible sample of CBAOs for this

study was limited. Within each CBAO, full time and part time staff members (operators) involved in outreach and prevention education, as well as Executive Directors was considered as possible participants because of their experience with health promotion practices for minority communities. Possible participants were contacted by telephone and email to inquire about their participation in the study and to set up an interview when possible (See Appendix A). The entire recruitment process was challenging due to the small number of persons engaged in such work, and the obligations and commitments that these potential participants had.

Three CBAOs agreed to participate; they represented the Portuguese; South Asian; and Black, African and Caribbean communities. These communities were chosen because of the significant size of their community population in Ontario and because of the size of the agencies and number of staff members involved in prevention activities. Each agency has approximately the same number of persons involved in prevention and outreach work. The interest of the key informants in the project was also a motivating factor. The tables below indicate the characteristics of the organizations involved in this project (Table 2); the characteristics of the participants (Table 3); the characteristics of the communities these organizations serve (Table 4).

Table 2. Selected sample: characteristics of CBAOs

CBAO	CBAO-defined community	Specific target groups	Staffing	Governance	Funding
B	Black Canadian; African; Caribbean origin	Men who have sex with men (MSM), young women (14-29 years of age)	8 Full-Time Staff and 7 Casual Staff: director, PHA support, prevention, outreach, volunteer coordination	Part of larger CBAO	Provincial funding; grants; municipal funding
SA	South Asian: Tamil; Bengali; Urdu; Indo-Caribbean origin	MSM, women, youth	9 Full Time and Part Time Staff director, PHA support volunteer coordination, prevention, public relations	Executive Director, Volunteer Board of Directors	Provincial funding; private donations; fundraising; municipal funding
P	Portuguese-speaking: Brazil and Portugal origin	MSM, youth	2 Full Time and Part Time staff: prevention	Executive Director	Provincial funding; other CBAO; municipal funding

Table 3. Selected sample: characteristics of participants

Participant	Position focus	Duration at agency (yrs)	Gender, age range	Part-time (PT)/ Full-time (FT)
B_1	Female Youth: Prevention and Outreach	2	Female, 30s-40s	FT
B_2	Bisexual Male/MSM: Prevention	1	Male, 20s-30s	FT
SA_1	Youth/Immigrant: Outreach and Prevention	2	Female, 20s-30s	FT
SA_2	Women: Prevention and Outreach	3	Female, 30s-40s	FT
P_1	MSM: Outreach	3	Male, 20s-30s	PT
P_2	Women, Youth, Heterosexual Men: Prevention	Unknown	Female, unknown	FT
AB	Senior Advisor (support for policies related to HIV/AIDS)	5	N/A	N/A

Table 4. Selected Sample: Community characteristics

CBAO	Community size in Ontario (2006) (Statistics Canada, 2006)	Mother Tongue
P	137,000	Portuguese (Portugal and Brazil origin)
SA	694, 000	English, Tamil, Urdu, Bengali
B	474,000	English

Note: Statistics Canada (2006). *2006 Community Profiles – Ontario (table)*. 2006 Census.
http://www12.statcan.gc.ca/census-recensement/2006/dp-pd/prof/92-591/details/page.cfm?Lang=E&Geo1=PR&Code1=35&Geo2=PR&Code2=01&Data=Count&SearchText=ontario&SearchType=Begins&SearchPR=01&B1=All&Custom= (accessed September 1, 2009).

3.3.2 Interviews

In total, seven semi-structured interviews were conducted. Of these seven, two staff members from each of the three CBAOs were interviewed (6 total). In the analysis, these participants are coded. A key informant from the AIDS Bureau of Ontario also participated to the project. The AIDS Bureau is a government organization that acts as a major funding body for CBAOs in Ontario (including the three organizations considered in this study). Therefore, the AIDS Bureau is familiar with the health promotion practices at the CBAOs, and more generally with the HIV/AIDS epidemic in Ontario. Thus, the data gathered from this informant can inform some of the context within which CBAOs operate.

Participants from each of the three selected CBAOs, each participant participated in face-to-face interview at organization they work. At each site, I preceded the interviews with a tour of the location and general discussion of the CBAO with the participant and was introduced to other operators. After the beginning of the first interview, I made brief notes about my observations related to the location. Following each interview, I made notes regarding my observations about each participant.

For each interview, I used the semi-structured interview schedule that I had created (Appendix B). During the creation of the interview schedule, I created a list of key topics to cover during the interview and added probes for each question to ensure in-depth answers. These key topics corresponded to the objectives of the study. I chose semi-structured technique to allow for some flexibility in questioning so that the research could remain exploratory in nature, but yet remain structured in order to answer the research questions

earlier proposed. In order to ensure that no relevant areas of interest related to health promotion were missed the informants were encouraged to address anything not addressed at the end of the interview. As the interviews progressed, previous responses were used to ensure that the interview schedule was appropriately modified for the next interview. All interviews were digitally recorded.

As part of the interview, participants were requested to provide examples of materials that they used in their work with their communities. Participants were asked to go through the materials and comment on the content and appearance, in addition to the processes relating to creation and distribution. The types of materials that were available include posters, postcards, pamphlets, DVDs, and condom packs; the number and types of materials are demonstrated in Table 6.

3.4 Data Analysis

This study was based on the theoretical assumptions that: cultural diversity can result in social exclusion, practices that promote social inclusion can reduce exclusion (and therefore inequalities caused by exclusion). Health promotion practices can promote social inclusion in minority communities. Therefore, the overall guideline for this project was to gather data that describe such health promotion practices. The data that were collected (descriptions of health promotion practices and opinions about social inclusion and cultural competence) were grouped in such a way that reflects the aims of this project to illustrate how culturally competent health promotion promotes social inclusion.

The qualitative data recorded from the interviews were transcribed, and the notes on the setting and participants were compiled. The materials collected at the interviews were also compiled for analysis. To begin the analysis, the interview data collected were reviewed entirely and grouped into relevant themes. These themes were guided by the research questions, and refined from the ideas that emerged from the data. These general descriptions are brought together into three themes, which explain how these practices work to promote social inclusion in the communities. In addition, the materials collected, as well as the descriptions of production and distribution provided by the participants, were considered together. The model by Kreuter et al. (2002) (see Chapter 2.6) was used as a conceptual framework, for comparisons and discussion among different CBAOs. This analysis focused on three categories: imagery, content, and language. In addition, the practices used to produce these materials and the methods for distribution and outreach were considered.

In the findings resulting from the analysis, three mechanisms of the promotion of social inclusion are discussed. The description of each mechanism is illustrated by specific examples of the practices as explained by the CBAO operators and the AIDS Bureau informant. The mechanisms serve to illustrate how culturally competent health promotion practices can promote social inclusion of communities that may be excluded from mainstream services. Part of the analysis, in addition to describing these practices and illustrating how they promote social inclusion, was to consider how these practices illustrate the ideals of culturally competent practice based on a theoretical model. The

taxonomy developed by Lister (1999) (see Chapter 2.5) was chosen because it is one in which each level builds on the previous level, rather than a model such as that of Purnell (2002), which is made up of numerous components.

3.5 Conclusion

The methodological strategy for this project was qualitative. This approach was chosen because of its focus on a context-based understanding of HIV prevention and because it allows for in-depth discussions with those people affected and involved in the issue. The data collection method used semi-structured interviews. Participants were chosen from CBAOs, which are the unit of analysis for this study. Overall, the sample size of this study was small, with 7 interviewees, 6 of whom were key informants from Ontario CBAOs; the seventh participant was from the AIDS Bureau of Ontario.

The analysis identified of three mechanisms each of which was able to promote social inclusion in the community. All three of the findings presented were considered together, to assess whether the mechanisms can be considered culturally competent. These findings are described in the following chapter.

Chapter 4. Findings and Analysis

4.1 Introduction

Culture is one of the social determinants of health (PHAC, 2002). Therefore, practices that take cultural differences into account will potentially influence population health status. This practice can help to redistribute materials resources that may be missing in communities due to exclusion from the majority.

The mechanisms by which providing culturally relevant resources that improve social inclusion can be complex, much like the relationship between culture and health. However, providing easily accessible health promotion materials to individuals is a step towards improving health status through education. Traditionally, providing culturally competent services and materials has been a part of the work done not by the mainstream health organizations but by community-based agencies within each of these excluded communities. In the case of HIV/AIDS, this job falls to organizations known as CBAOs.

This study looked at three CBAOs as examples of community-based organizations that were able to promote social inclusion through their culturally relevant health promotion services. The practice of providing services that are tailored to a specific cultural community is referred to as culturally competent, as outlined in the literature review.

This project sought to answer the question of what CBAOs can do to promote socially inclusive practices in their communities through the provision of culturally competent health promotion related to HIV/AIDS. It is important to note that the findings

presented in this chapter are limited to the three CBAOs and communities involved in the study. However, the findings of this study can inspire other CBOs to use similar mechanisms in their communities.

Although the findings of this research had limitations in terms of sample size and the HIV focus. This chapter proceeds in Chapter 4.2 with a brief summary about the organizations studied and their unique characteristics. Knowing how the organizations are structured and funded provides the context for the findings from the study outlined in Chapter 4.3.

Overall, the study shows that CBAOs focus on health promotion related to HIV. HIV is unique because of its relationship to sexual behaviors and relevant issues. However, as stated earlier, the work of the CBAOs is applicable to other more general health promotional efforts. According to the qualitative evidence gathered from the participants in the study, the CBAOs used three related mechanisms to promote social inclusion in the ethno-cultural communities they serve: community networking, community knowledge and involvement, and community-specific resources.

This chapter continues with an analysis of the mechanisms as practiced by the CBAOs and makes use of a taxonomy for cultural competence (Lister, 1999), and a brief conclusion.

4.2 Organization Characteristics

In this study, *community-based* refers to organizations that are community-focused, community-motivated, and community-identified. Community-based organizations exist

across various sectors. Most are conceived from community-specific needs not met by mainstream resources. Thus, they act to provide resources to community groups often facing social exclusion. Therefore, the work that is done within these organizations can influence practices that cause certain communities to be socially excluded. These socially inclusionary practices can be highly varied and can range from the development of educational materials to advocacy work.

CBAOs are one example of community-based organizations. There are more than 20 CBAOs in Ontario; fewer than 10 such organizations focus on ethno-cultural communities. The participants' words and views are their own personal opinions.

4.2.1 Location

The qualitative data gathered from key informants was collected on site at each of the three CBAOs and the AIDS Bureau. The Portuguese CBAO illustrates a very small organization, while the South Asian and the Black, African, and Caribbean agencies demonstrating larger ones. All of the participants were very enthusiastic about participating in the study and being able to provide with health promotion materials to take home.

The locations of these agencies are well concealed from the public eye in urban areas within office buildings. It is not possible for persons walking by to identify that a CBAO is located within that building. This is done so that individuals seeking resources and services may feel more comfortable about entering the organization, according to informants working there. As such, there is little signage outside of their offices, including any culturally competent health promotion materials.

The South Asian CBAO office was quite small and crowded. When I visited the site, some ongoing work (preparation for a fundraising event) was taking place within the general reception area. Each interview took place within a small office and there was no communal meeting space available. General materials like postcard and pamphlets were kept in the general reception area, while posters and other materials were kept in specific offices.

Similarly, the Black, African, and Caribbean agency was also small but adequate for the number of persons employed. The condition of the office was somewhat run-down and located in an out-of-the-way area. There was a large communal meeting room area that was crowded by posters and other materials. This may indicate that much of the work is collaborative, and that the organization is able to host other CBAO operators for meetings and presentations. However, there was not any reception area, and most of the staff was in their offices working alone while I was on site. The office space of this CBAO was located next to the offices of two other community-based organizations from the Black, African and Caribbean community. One of the two interviews took place within this large boardroom and the other took place in a very small office filled with research materials and health promotion resources. All the resources that were produced and distributed in the organization were located in a small room within the office. The location of the Portuguese CBAO was within a larger mainstream CBAO, and was allocated one or two offices. There was a large general reception area where I was greeted and waited along with other clients for my scheduled interview. While waiting in the reception, I collected a large number of

non-ethno culturally focused pamphlets from a display area. The large room was quite noisy with a number of clients and other operators coming in and out constantly. Posters regarding HIV prevention and HIV/AIDS support were displayed prominently around the room. The interviews took place on a different floor then the general reception, located in a quiet and isolated area with offices for researchers.

The AIDS Bureau is located in a government building, and it is possible to find the offices once you are in the building as they are listed. Access to the offices is locked and requires access from staff members. The interview itself took place in a small meeting room, and I was unable to see much else of the office. There were no materials posted anywhere and there were very few individuals that I encountered.

4.2.2 Organizational Mission and Focus

The focus of the organizations is divided between health promotion resources and services, and support work. Because of their focus on specific cultural communities, their services reflect cultural norms and beliefs, and they focus on identifying and incorporating community-specific issues and attitudes into their prevention services and resources. As certain operators focus on different groups, they may have different areas of expertise. Further, to reflect the diversity of the communities, the operators come from diverse backgrounds.

Both operators at these organizations and the governmental bodies that help support them view culturally competent care as an important function:

There is a large need for this type of work, and it would be impossible to educate everyone with the same resource from the same mainstream ASO… there are so many languages, cultures and religions, and everyone has their barriers that need to be broken down to understand the information, and it's not just the language barrier. – AB

Table 5 below presents some characteristics of the agency as a whole. It indicates the current focus of the CBAOs as related to health promotion, including target populations. It also illustrates the main challenges.

Table 5. Main challenges and prevention focus of CBAOs studied

CBAO	Organization focus	Main challenges
B	Creation of youth/MSM campaign materials; outreach programs within community; support for PHA	Diversity of the population; developing tailored materials (time consuming)
P	MSM outreach; youth outreach; creating new materials	Lack of funding; small number of staff overall
SA	Materials for women/gay community; outreach/workshops; public relations; support for PHA; legal	Diversity of the population; too few key informants; difficult relationship with community

These organizations are not homogenous and they experience different challenges related to the particular needs and norms of their respective communities. All agencies indicated that they struggle with respect to resources, both financial and staffing, as indicated by one operator:

At a lot of organizations, staff members are doing more than one job – we are fortunate because we have all these different roles – but at other organizations my position doesn't exist because the person doing my role is also doing outreach and support … so those are challenges for the field. – B_2

However, the challenges they face are overlapping and indicative of the challenges faced provincially by such organizations.

4.2.3 Funding

Most CBAOs receive funding from the AIDS Bureau of Ontario, which is part of the Ministry of Health in Ontario. Funding from the government and its agencies is distributed, in part, on the basis of epidemiological data gathered at the provincial level. This type of guideline is not in place at this time for all communities in Ontario, including the South Asian and the Portuguese communities. The AIDS Bureau attempts to stay engaged with the operators at CBAOs, who are familiar with the needs of these communities.

> Part of what we do is fund specific work in the community, so there is an African ASO, there's a Spanish-speaking, there's a Portuguese – so by supporting these organizations to create services for their communities, they are able to meet the needs in that sense. We have a good sense of what's going on in the community because we're so connected to everyone doing the work. – AB

All three agencies investigated receive funding from the Ontario AIDS Bureau and other government agencies. Therefore, the organizations are primarily organized at arm's length from the government and compete with each other for funding. Certainly, funding is a major contributor to both the quality and quantity of prevention work, as financial resources provide the time and staffing. Funding that comes from the government requires the agencies follow specific mandates or work on specific projects, and feedback is required

frequently. Operators must work both to satisfy the funding agreements and to continue to engage the community.

> Funding for every project is different – but we will have a funding agreement with every agency that lays out what is expected of them for the funding. Some agencies will get money for prevention and some for support. – AB

4.3 Mechanisms of Social Inclusion

Social inclusion is complicated because it goes beyond just the redistribution of materials and resources. Socially inclusive processes include those that respect diversity and find solutions for means of accessing resources and institutions. CBAO operators achieve success by being able to understand their communities and create prevention materials that reflect and respect their 'community perspective.' On the basis of the evidence provided by the CBAOs in the study, three mechanisms arise as part of their daily practice that provide community services and resources related to health promotion; specifically, HIV prevention and support work.

The first mechanism is community networking, which refers to bridging service gaps and developing relationships with other community-based organizations (including CBAOs) and the government. These relationships may be referrals or shared services and resources.

The second mechanism is community knowledge and involvement, which refers to how the staff in CBOs becomes expert within the community by identifying the issues affecting the community and by engaging the community in their practices.

The third mechanism refers to the production and distribution of community-specific resources, which are materials specific to each community and sub-community. The following explains these mechanisms in more detail.

4.3.1 Community Networking

According to their responses, these CBAOs are involved in community networks. Networks are groups of organizations that work together to share resources and offer support to one another to carry out a specific set of goals. Community networks are those that are community based or focused on a certain group of individuals (such as an ethno-cultural community) and rely on partnerships and collaborations to accomplish their goals. CBAO operators involved in this study indicated that they have partnerships with four types of organizations: other CBAOs, generic, community-based organizations (CBOs), government (federal, provincial, and municipal), and mainstream health centers or clinics.

The CBAOs in the study indicated that building bridges benefits various types of community networks in several ways. The CBAOs studied indicated that they are unable to provide all the services they want to provide and to reach all individuals in need. However, community networks can act as bridges to prevent gaps in service and improve access to available resources. Consequently, CBAOs work to become part of such community-based networks and to participate in discussions between agencies within the same communities to develop a solid understanding of the needs of the communities and where gaps are present. The following comment reflects the interests of CBAOs in community networking:

> That's where the work is being done right now, it's all about building bridges with other agencies, so that we can contact each other for information and resources. – B$_2$

The CBAOs in the study suggested that networks are important for increasing the amount of culturally specific information and the number of community members who can access it. Without this type of bridge, at-risk individuals, who are often isolated, may be deprived of important resources.

Community-based networks can provide access for many individuals normally excluded from the mainstream health system. Because the mainstream services often lack cultural relevance, and they may not reflect cultural and language needs of some ethnic communities. Thus, community networks allow community members to access information about health (including HIV) that reflects these specific cultural norms. Since the CBAO operators are locally based members of these networks, they are aware of these important networks, and able to inform community members of where to access appropriate information, and fill the gaps where services are lacking.

Informants in the study claimed that partnerships enable their CBAOs to provide help in areas beyond their expertise by facilitating the referral of individuals to agencies that have different, complementary types of resources and services, while remaining community focused. For example, mainstream organizations still play an important role in providing programs that CBAOs may be unequipped to provide due to lack of funding or expertise. When necessary, CBOs that focus on housing, poverty, or other structural issues can also be used as referral services. As indicated by two CBAO informants, CBAO operators

are prepared to work together to optimize access of community members to existing

information and resources:

> Most organizations in this sector realize that we have to do this work in connection with one another so most of us know one another, we sit on committees, we contact one another for information and resources, and it's very much a collaborative effort. – P_1

> We think partnership is key. Sometimes it is about access to service, sometimes it's for certain events, or it could be working on a research projects together. – SA_2

Informants also pointed out that the size of a network is important. Network

strength, diversity, and density are important factors that determine how effective

operators are at reaching all community members and providing the range of resources

needed. The larger the network is, the more varied are the types of resources available to

the community. Larger networks are able to secure more resources and provide greater

access through a collective effort. Additionally, larger networks are able to mobilize and

present a strong voice to governments to influence the development of more inclusionary

policies with respect to health, facilitating their health promotion efforts. Additionally,

larger networks can work collectively to influence political will to increase funding to certain

agencies. The following comment from a participant illustrates the essence of this problem:

> It would require political will and new funding because most of our funding is already tied up throughout the province, so the government would have to decide to put more money into HIV and it would take some political advocacy to say there is a need and then some evidence to show it was an important need. – AB

The operators from the CBAOs agreed that it is important that their networks include governmental bodies. The provincial government and its agencies can play an important role in providing infrastructure and funding. For example, in Ontario, most CBAOs have a partnership with the AIDS Bureau. This partnership is important for funding, as well as for assistance in bringing together CBAOs to create resources and discuss common issues.

Biannually, the AIDS Bureau invites representatives across all communities to participate in a centralized collaborative process aimed at producing materials and programs that include posters, TV ads, brochures, and condom packs to be used in their communities. This type of partnership is particularly important for those agencies that are not able to create their own materials due to lack of funding or staffing. However, challenges can arise because of the complexity and diversity of the communities themselves and the difficulty in getting full participation of the full range of culturally diverse community members. The AIDS Bureau-CBAO partnership also is important for advocating for changes in the health system that will further support community-based initiatives and work toward greater inclusion of ethno-cultural groups. The following comment captures the value and the challenge of this exercise:

Because a lot of [CBOAs] don't have the resources to do a campaign, but together we can pool our resources and make something that everyone can use – that they can participate in the development of, and deliver as well. We collaborate across the communities at a provincial level – and so we bring all those people together in a room from all the different perspectives and say how are we going do this – so we try to come to one central point that something all communities are dealing with, and so then we say, for example we only have x dollars and we want to reach all gay men, how do we do that? – AB

The participants also commented on the importance of partnerships within their respective ethnic communities to complement each other's efforts. For example, the Portuguese CBAO is part of a coalition with representatives from a variety of service providers within the Portuguese community. Members of this coalition, including the CBAO, work with newcomers regarding settlement, employment, and other issues, and health may not necessarily be their main focus. Similarly, the South Asian CBAO has partnerships within the South Asian community with legal clinics, women's centers, and other councils. CBAOs rely on other CBOs, like community centers for youth or women's groups, to help them gain access to their community for workshops and outreach work.

4.3.2 Community Knowledge and Involvement

While these CBAO participants agreed that community networking is an important mechanism that provides better access to resources and enhances collaboration among community organizations, they also pointed out the value of engaging with their community. Although the background and learned experience relevant to the community of CBAO staff are assets, involvement with community members is essential to further the goals of CBAOs by making their efforts culturally insightful. Involving the community also

can build community competence, which can, over time, result in community development mediated by community social networks (Brieger, 2006). This type of development can help the CBAO shape culturally competent services that are accessible and appropriate to ethno-cultural communities so that the latter do not have to rely fully on mainstream services, which typically exclude them (by cultural and linguistic barriers).

The approach of CBAOs to this social inclusion mechanism is two-pronged: involving the community and being involved in the community. For example, CBAOs practice a strategy for targeting prevention materials referred to in the literature review (Kreuter et al., 2002), namely, constituent involving. The intent of a constituent-involving strategy is to avoid assumptions about cultural norms. The goals include empowering the community and drawing on the experiences of the community. The CBAOs believe that those who are the most successful at this strategy will be able to have the most insight to practice cultural competence and to create resources that are community relevant. When the strategy is examined in depth, four factors emerge: personal connection to the community (4.3.2.1), investigation of the community (4.3.2.2), community involvement (4.3.2.3), and outreach methods (4.3.2.3).

4.3.2.1 Personal Connection to the Community

Staffing the CBAOs with operators from the community is a main objective at the agencies investigated. Across all of the CBAOs, the majority of the staff members are from the ethno-cultural community served. The CBAO operators who were interviewed see

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themselves as community liaisons—persons with a unique understanding of the community. They believe that being from the community they work for has a large impact on the ability to identify the issues facing the community. In their comments, CBAO workers stressed the importance of having a close community connection to make their services more culturally competent, as the following comment illustrates:

> We hit everybody – 'cause we have staff from every community and we do very different types of work than the mainstream does because of that – and we have the people to do work at this level within our community. - B_1

4.3.2.2 Investigation of the Community

It is evident from the view of the CBAO key informants that health promotion is not strictly about dealing with at-risk behaviors using scientific information. Each ethno-cultural community faces different obstacles to care related to its respective cultural norms. The importance of including such issues in prevention is twofold:

Firstly, framing HIV prevention in the context of relevant, community-specific issues makes it possible for individuals to relate better to the information they receive.

Secondly, individuals' ability to make choices related to sexual behavior is influenced not only by information they receive, but also by practical constraints and societal structures, which makes the application of such information particularly challenging. As one CBAO participant expresses:

It's not just enough to talk about HIV. A major part of it is framing it within the issues that the participants are facing. Cause if you can't relate it to your own life, then you won't think you're at risk – that's the major point. People have to see how in their lives they are taking a risk for HIV, because they are going to want to do something. – B_1

The CBAO informants suggested that it is particularly important that the substance of these issues arise from community members, rather than from external researchers, whose findings are based on broader studies across communities.

It is clear from comments such as the following ones that the three CBAO informants acknowledge that being from the community alone cannot help identify all the issues involved:

For me personally, I know the issues in the community –well I don't know them all, but I study a lot and I try and get information. - P_1

An intimate understanding of the issues is important … I'm still learning about the culture of a lot of African communities, but just knowing about one country and its culture related to sex significantly made a big difference to my work and made it easier for me. – B_1

Thus, to identify and understand issues facing the community, the CBAOs used two methods: community-based research (CBR) and outreach with community members. CBR focuses on empowerment and capacity building. One example of CBR can be illustrated by prevention work done at the Black, African, and Caribbean CBAO, as described by one of the informants:

> I did a report, then I had an advisory committee, which is made up of service providers, who looked at it and the issues in it, added some issues and finalized it. Then we had youth come in, and they said, "These are the issues," and they rhymed off some ideas for us on incorporating them. The whole point of doing the report before was to understand the issues and how it impacts safer sexuality. – B_1

The staff at South Asian and Portuguese organizations used the outreach approach to gather information about relevant issues that are important to the community. They described the approach in this way:

> Well, in my outreach work I talk a lot with people – in these conversations I usually ask questions that will give me some clue about that person or in general about the community…how they are feeling about, for example, HIV infection rates in the community. - P_1

Through the mechanism of community knowledge and involvement, the CBAOs in this study were able to identify a number of issues. The key informants who were interviewed indicated that the diversity and complexity of each community make it difficult to suggest that one community is made up of individuals facing the same issues.

In Ontario, the HIV epidemic began primarily in gay communities. Over the past decades, the change in the infected and at-risk demographic has been enormous. However, views that HIV is a 'gay disease' are still retained in many communities. In addition, both the Portuguese and South Asian CBAOs find that a homophobic-related stigma is a huge barrier. This stigma makes it difficult to reach MSM groups who do not identify as gay because they are not able to speak about their sexual behaviors without feeling stigmatized within their communities:

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> The thing is in our culture being gay is still very stigmatized, it has huge discrimination because we come from a macho culture and because of the influence of the church. Condoms are prohibited and being gay is condemned, so that just leads to marginalization and unsafe sex. – P_1

Ethno-cultural communities may face racism, either personally or within the healthcare settings. Racism may be the primary way through which structure influences ethnic health inequalities (Karlsen & Nazroo, 2002). Mainstream prevention work can be systemically racist by the lack of inclusion or by the failure to practice cultural competence.

> Ethno-racial communities are at risk because of issues like racism, and poverty. HIV is more likely to spread where there is poverty and difficulties with health issues – including mental health issues, and so for sociodemographic reasons we can see these are communities in need. – AB

Perceived racial discrimination in mainstream health care may prevent individuals from wanting to seek out further care. Racism also will affect members of sub-communities. As a result, they can become doubly isolated within their communities. Gender roles and views about female sexuality can contribute to further problems in accessing HIV prevention information. One major similarity between the Portuguese and South Asian communities is the existence of strong taboos regarding sexuality. Both structural and cultural barriers are related to power dynamics in women's relationships with men and control over their own sexuality and sexual behavior. Similar views exist with respect to gender and sexuality and are tied to cultural views of women in society.

Becoming informed about HIV can be especially challenging for women. Additionally, HIV is denied as a problem. Intergenerational barriers prevent the discussion

of the subject within the family. Operators see this obstacle as a problem mainly for youth.

It can be shown to be problematic for heterosexual relationships in which neither partner

feels comfortable seeking information about HIV. Across all communities, HIV was seen a

being a 'disease of the other,' and the communities felt immune to the disease. This denial

and perceived immunity are major problems for prevention work, as they can affect health-

seeking behaviors or involvement in outreach activities.

> In our community, there are notions of it not existing in the community, or it only being related to people who might be living in the LGBTQ community, or promiscuous people, there's a lot of notions… people always see it as happening to other people and not in our own community. – SA_1

> The Portuguese-speaking people from Brazil, they have this false feeling it's not going to happen to them because Canada is a rich country, or because of their class... and the Portuguese people from Portugal think they will not get infected, because they don't identity as gay, and AIDS is a gay disease. – P_2

Because these issues may affect certain groups, such as MSM, women, and youth,

operators must work not only with the community as a whole, but also with specific groups

within the community. The number of different cultural nuances associated with each

community, in addition to those drawn along the lines of sexual orientation, gender, and

age, are enormous, as the following comments illustrate:

> We realize even within the Black community it's very different – there's African, Caribbean, and Black Canadians. Within the Caribbean community, it's divided by island, same thing for Africa – it's a continent. Even within a country there're different tribes, a lot of differences, so we need to consider this. – B_1

> I think because the many nuances associated with each ethno-
> cultural community – we're not homogeneous, and we can
> understand that - so our services and the work that we do can
> take into account the variations of our community, right? – B_2

Both the South Asian and the Black, African, and Caribbean agencies indicated that the populations they serve are so diverse that operators must rely on mechanisms such as targeting distribution to ensure that they can meet the specific needs of individuals or small groups. When using targeted distribution proved too challenging, CBAO operators worked to find common issues affecting the majority of the community so that major issues would be reflected in the materials and programs.

In addition, agencies often based their understanding of the community's cultural norms on the opinion of the few who volunteered to express their views. However, the use of select members of the community is problematic in terms of representativeness. Unfortunately, a limited number of persons are willing to participate in research activities with CBAOs, often because of apathy or a perception of an attached stigma. As one informant states:

> I think there has been a good response, but sometimes we
> experience challenges and people will say "oh you know, why
> does there need to be such an organization in our community?" –
> SA_1

Similarly, the South Asian agency takes the approach that certain issues span all sub-cultures within the community; therefore, it focuses more on similarities than on differences in the discussion of sexuality, hoping that these will reflect the attitudes of the majority of individuals accessing the information. In the own words of one operator:

> It's not a matter of knowing about the culture – historically there has been a taboo in the community about sexuality – partially related to religion. So, this taboo happens to exist, and it's hard to explain – there are differences but there are similarities, so we gauge these and try to be innovative in our work to address this. – SA$_2$

4.3.2.3 Community Involvement

According to the CBAOs studied, getting the community involved has many meanings. It can refer to getting assistance with outreach or fundraising from volunteers from the community, which is a common practice among all agencies. In the South Asian agency, community members can sit on a board that governs some of the decision-making about agency focus and priorities. Volunteers from the community can be trained to do outreach and fundraising activities. The CBAO operators indicated that the community could be involved by participating in focus groups to assist with evaluation or with the creation of prevention materials. Enabling communities to take a significant role in the solution to their health problems not only empowers the community but also alleviates the fear of being viewed as a 'problem community'. As two CBAO informants explained:

> They don't want to just feel like they are part of the problem; they want to feel like they can contribute to the solution as well. – P$_1$

> It's really important to involve the community in this kind of work, to get their opinions. – P$_2$

Involving the community, however, is not without its challenges, particularly with the ethno-cultural communities in which strong cultural views give rise to the denial of the presence of HIV in their communities. Moreover, challenges such as the following arise in attempting to reach the entire community because of its large and diverse composition:

The South Asian Diaspora is huge – it encompasses lots of cultures, we try to be as inclusive as possible and sometimes it's challenging … we try and be aware, and to really reach out to the community at large. – SA$_2$

Participants from both the Portuguese and the South Asian ASOs indicate that whether one is from the community or not, it is challenging to approach community members because of the stigma attached to HIV. Being a member of the community itself is not enough for a member of CBAO staff to break through barriers to get the most accurate information about the community's views on issues related to sexual behaviors and on HIV/AIDS. However, if CBAOs develop a close relationship with the community and hence an understanding of these cultural-norm-related barriers, they can find creative solutions to reach these individuals, rather than just attempting a one-size-fits-all-type approach.

4.3.2.4 Distribution Methods

In most cases, providing information needed by the community is important for getting out into the communities, because people in the community are unlikely to walk into the agency's office to acquire it. In fact, according to the CBAOs, many people in their communities are not interested. They are even afraid of talking to the operators of the agencies, or they are simply unaware of where to find HIV information that they can understand, if indeed they are looking for it. Therefore, the CBAOs depend primarily on outreach work, such as workshops and meetings with individual members of their community.

In addition to presentations and discussions, the CBAOs use these events and channels to distribute materials, which will be discussed in detail in the following chapter.

Increasingly, they are using media, such as television programs, and Web sites to broaden the scope of their outreach.

The CBAOs plan their outreach activities to take advantage of existing community events that are likely to draw an audience in a variety of venues. To find community members, each of the three agencies relies on events hosted within the community. As one agency explained:

> We look at event postings, different ethno-specific papers, the Internet – so maybe we're doing outreach at Caribana, or maybe we're at a Bengali book fair. – SA$_2$

Visiting venues where large numbers of community members are present is a similar strategy:

> The places I do outreach are bars and restaurants – and sometimes I go to venues like hair salons, where I know a lot of Portuguese people will be. – P$_1$

Due to their size and variation, the communities often are not located in a specific geographical area, but there will be spaces (events, venues, buildings) where community members come together. For example, the Gay Pride Parade in downtown Toronto draws an audience from all across Ontario and beyond. On a smaller scale, these may be spaces where groups of sub-communities come together, such as youth or women's centers or anonymous gay venues. These spaces might be considered safe because they are familiar to the individuals and are outside of the typical or mainstream health promotion setting. These locations may have both members from the community and members from other

communities, so organizations may choose to distribute non-culturally specific materials as well. One approach was outlined as follows:

> Generally when we do outreach we use a combination of our own brochures, and ones from other agencies, and then we have the DVD and other promo materials like magnets with our websites. - SA_1

Outreach venues could be formal or informal settings. Depending on the formality of the setting and the number of community members that use the spaces, the importance of following cultural norms would also vary. Often, organizations have an opportunity to speak to members of the community in a setting of their choice and to offer their services and information in an informal manner. When appropriate, typically in smaller settings, operators can communicate orally with their community members to discuss both HIV and other community issues. Important information about the agencies and where to find more information about HIV can easily be conveyed in these settings.

The CBAO operators indicated that speaking with people at events can be challenging, since some people do not want to be associated with CBAO workers, while others are simply not interested in learning about a disease they believe cannot possibly affect them. In certain spaces, particularly those that are not community specific (festivals or bars) individuals may not feel comfortable being singled out by CBAO operators. Likewise, in spaces where there are many members of the community, CBAOs reported that people might feel uncomfortable discussing sexual behaviors and related diseases because they fear how others may view them. The CBAO operators state that these types of

discussions are particularly sensitive in cases of MSM, who do not identify themselves as gay, and women from highly sexually restrictive cultures.

Although all the CBAOs employed outreach as an important methodology, there were many differences reported among them. The South Asian and the Black, African, and Caribbean agencies use organized outreach; the Portuguese agency does not. The Black, African, Caribbean agency makes use of community-centered organizations, such as women's centers and youth groups, as a resource for materials distribution or as a place to give workshops. As they explained it:

> We parachute into other community groups … or else we'll get a phone call saying someone recommended us. We call ahead and find out what demographic we might be serving [in outreach workshops] and we ask: "What issues is your community group dealing with?" so that we know ahead of time what we're going to be talking about, or what information we need to prep ourselves with. – B_1

The South Asian agency is highly focused on getting their contact information known and then waiting for invitations for outreach events. They commonly do workshops at women's centers or at English as a Second Language (ESL) classes in high schools located within the community. This type of distribution is beneficial for two reasons: firstly, it allows the materials to be further targeted, as specific demographics can be assessed beforehand; secondly, persons attending a workshop or discussion group are there because they have chosen to be and thus are interested in the materials. Doing these workshops allows the agencies not only to pass along important basic HIV information, but also to discuss in more depth about the disease and its impact with the community members. For example, it

provides a group of women (who might not normally be able to receive such information) an opportunity to discuss, in a safe environment, their needs and other issues they face.

Another means that CBAOs increasingly use to achieve wide knowledge dissemination is the media, such as television, as well as Web sites. Finding health information on the Internet has become an emerging and important trend nowadays, and these agencies want to take advantage of this trend. The three agencies indicated that they use such media for their work. The CBAOs believe that this alternative is effective because of the importance of anonymity, especially in the Portuguese and South Asian communities, where discussing sexuality is not common. The CBAOs also use ethnic media, such as television and newspapers, to supplement face–to-face outreach activities. They run ads about the agency that include their contact information and promote upcoming workshops and other events that the agency will be involved. These media are pervasive in their communities using the dominant languages of the community to reach community members. The following quotation typifies the practice of the CBAOs in the study:

> We use a lot of media and ethno-specific newspapers to get people to access our services, or certain television programming – this is a way that people can access our services totally anonymously and confidentially. – SA$_2$

4.3.3 Community-Specific Resources

> Being culturally competent means reaching people with a language and imagery, in a space that is going to make sense to them and that they're going to understand… the people working in the communities are the ones that can help us make sense of the cultural and linguistic components, and to resource it properly. – AB

A major component of health promotion involves passing on information. As shown by the CBAOs in this study, this transmission can be done orally, through various media, and through text and images compiled for distribution. Such materials include posters, pamphlets, booklets, postcards, videos, public advertising, and Web sites. Table 6 below, indicates the materials collected during the qualitative interviews. Kreuter et al. (2002) indicate five ways in which prevention strategies can be tailored to meet the needs of ethno-racial communities: peripheral, evidential, linguistic, constituent involving, and socio-cultural (See Table 1). The materials, and their production, from the CBAOs studied in this project were analyzed with respect to the three strategies that are most relevant to materials: peripheral (images), linguistics (language), and evidential (content). The use of these strategies varies between agencies, depending on the characteristics of the community.

Table 6. Culturally Competent Health Promotion Materials

CBAO	Types of community-specific materials available	Number of Materials Collected	Target groups
B	Posters	5	MSM
	Postcards	5	Bisexual Men
	Condom Packs	3	Women
	Information Booklet	1	
SA	Posters	3	MSM
	Postcards	6	Women
	Pamphlets	4	Youth
	Condom Packs	1	
	DVD	1	
P	Posters	2	MSM
	Postcards	3	Youth
	Pamphlets	4	
	Condom Packs	2	

It was suggested from the respondents that prevention materials, especially in written forms, are important because they can serve as a tangible reference. They provide both information about HIV prevention and important contact information for other agencies within the community network. In addition, as one participant pointed out when referring to the development and distribution of materials, they have to be targeted:

> We have to figure out the best way of how to do that in a way that makes sense to each community. – AB

From the responses of the CBAOs, it was evident that several differences arise in the complexity of the processes and the number of resources allocated for the development of materials. Generally, CBAO operators indicated that two main factors affect the material

production process: firstly, having a direct relationship with government in order to make use of strategies for HIV prevention provided by the AIDS Bureau; and secondly, having a specific operator whose job and funding are designated for developing materials. This stratified staffing allows staff members more time to work specifically on developing resources, rather than on outreach and support for HIV-positive clients.

The Black, African, and Caribbean agency is the most involved in creating new resources. Operators are involved in the process from beginning to completion. Currently, they are creating two new campaigns: one for women and one for MSM. These campaigns include posters, pamphlets, condom packages, and Web sites. In 2008, one of these campaigns was focused on community involvement and the identification of service gaps, while a second focused more heavily on incorporating HIV prevention evidence. In describing the process for this latter work, one of the operators said:

> I will be doing evidence-based programs and materials, which are based on some of the work being done by the CDC in the States. – B_2

By contrast, the South Asian agency does not have the same resources to develop its own campaigns. Consequently, the few materials it creates are developed on an ad hoc basis when it has extra resources that can be set aside for prevention materials, rather than prepared for specific outreach-based or support-based activities. Because the agency does not have staff dedicated for developing resources, all operators tend to work together when time and money allow. One of the operators explained it this way:

> Since we are such a small agency, we are all involved in developing resources. – SA_1

The Portuguese agency also struggles with having enough resources for material development. The operators described their situation as follows:

> We do develop some here, but it's very difficult to develop resources because of funding, so if we have extra money we can use that come up with a new resource – or I will be involved in the process, but it's not specifically coming from my projects because I don't have the money. – P_1

Thus, these latter organizations rely more on collaborative efforts, particularly when working with the MSM community, where they can work within the provincial strategy for gay men and MSM. Likewise, the Portuguese agency uses materials from mainstream ASOs because 'it's here and it's ready.'

The process of producing and distributing culturally competent prevention materials is highly complex because of the large number of factors that must be considered to create such materials. The following is a discussion of the three strategies used by the CBAOs studied to create community-specific resources: linguistic, evidential, and peripheral.

4.3.3.1 Linguistic Strategies

The first important component of providing accessible services is dealing with language barriers through translation. Translation has two meanings. One is related to a literal translation of materials written originally in English, and the second is related to translating the content by rewording sections to make them appropriate for the community. According to Kreuter et al. (2002), the objectives of the linguistic component are to translate materials into the dominant language(s) of the community and to rely on information to make word choices that allow for messages to be as meaningful as possible.

Deciding on which languages are to be translated is difficult when dealing with complex communities such as the South Asian or the Black, African, and Caribbean. Both face difficulties dealing with the great variety of languages spoken in the community. Operators are frequently re-examining the diverse makeup of the communities they serve to more adequately address changing needs. Although they would prefer to communicate in the language of new groups coming into their community, at this stage they must focus on the dominant languages to ensure that the largest number of constituents will have access. Currently, the South Asian organization chooses to translate its materials into primarily Tamil and Urdu, as well as Bengali, Gujarati, Hindi, and Punjabi.

> Ethno specific agencies are excellent because they can help with anything that comes to language barriers, like translation –and that's exactly why this organization started because of lack of access and language barriers. - SA_1

Because the community that the Portuguese agency serves has a more homogeneous makeup, all the agency's materials are in Portuguese. The Black, African, and Caribbean agency chooses not to translate anything into other languages at this time, as the following passage indicates:

> The majority of the population speaks English, so it's not a major focus to translate it, and because if we did there would be so many languages to translate into, but it is something we are considering for the future. – B_1

Both the Portuguese and the South Asian agencies translate and use mainstream materials originally written in English and created for nonspecific communities. The Portuguese agency cited one example of this approach:

Two years ago, the provincial government did a campaign, so it was my job to translate everything into Portuguese, and then they printed all the materials, so I could use them in the community. – P$_2$

However, there is a risk when an agency, due to a lack of resources, translates and uses mainstream materials. The content of these messages, chosen by mainstream agencies, often can be ineffective because of a lack of cultural sensitivity.

Translation can also refer to word choice. Following Kreuter et al. (2002), part of the linguistic component of cultural competence includes choosing words and phrases that have cultural significance that makes sense to the community. Word choice and sentence construction are important tools for creating materials that certain groups can understand and messages to which they can relate. Translation may involve using alternatives for technical terms, avoiding offensive wording, and avoiding ambiguities when the same word has two meanings. One word might be appropriate in a certain language or for a certain group (such as the use of slang for the youth sub-community). Word choice ensures that the content selected for materials is presented in the most culturally nuanced way possible. Specific word selection is most important for sub-communities based on age, gender, and sexual orientation existing within the target community.

One of the respondents described how she tried to vet the language of the materials for the youth in her community and use them on posters and postcards:

> I was trying to pull in the youth voice, though I am a youth, I don't fully understand some of the things that a lot of my peers are going through. So I was fortunate to be able to pull in from the community those who did have a better understanding and they were able to advise me for the materials, including the wording. – B_2

The study showed that word choice is important, even within unilingual communities such as the Portuguese community. The Portuguese community consists of two major sub-communities based on their country of origin: Brazilian and Portuguese. Experiences in the CBAO for this community indicated that, in addition to other differences relating to language and behaviors, the Brazilians are more open and the Portuguese are more conservative when discussing sexual behaviors and disease. Hence, operators have to choose whether to reflect the cultural sub-communities in their work, as the Black, African, and Caribbean agency does with respect to youth, for example. Operators suggested that the most efficacious approach is dependent on the person within the agency doing the work, as well as the resources available:

> The previous persons in this position used to develop materials different for the Portuguese and Brazilian communities, so we used to have two things in the same language for the two groups. But I don't agree with segregating, I try and reach both communities by using one material, because to me there's no point of creating two because everyone can understand – it's more resources, it's more costly, and it takes more time. – P_1

Moreover, the reliance on one operator within the agency (such as in the Portuguese and the South Asian agency) to translate the materials may give that person too much credit to his or her expertise in the culture and language nuances.

Despite the difficulties reported, the linguistic strategy is shown to be the easiest of the three strategies for the agencies because it does not involve creating original content or developing appropriate images, as described below. By using collected data or talking directly with the community, operators were able to assess easily which languages were spoken the most within the community. They were then able to use this translated content to create materials (such as those illustrated in Table 6) for their communities. Additionally, the commitment to involving community members reported in both the Portuguese and the Black, African, and Caribbean agencies helped ensure that materials were reflective of sub-community needs.

Although none of the three organizations studied indicated any direct sense of need to empower their communities through their work, translation can have unintended positive consequences. As one operator pointed out:

> Just being in an English-speaking country and seeing all the materials distributed in Portuguese - I think that impacts a lot. They see it's specifically for the community, and that makes a huge difference to how they feel about the issue of HIV. – P_2

4.3.3.2 Evidential Strategies

Evidential strategies refer to the content of materials. HIV prevention materials, like most health promotion materials, cover the same basic ideas, which the agencies call 'HIV 101'. All of the prevention materials from the agencies were found to contain information about the following six items:

1. Methods of transmitting HIV

2. Increased risk factors

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3. Safer sex and protection options

4. Symptoms of HIV/AIDS

5. HIV testing information and locations

6. Contact information for agencies, CBOs, and public health clinics

The CBAOs in the study explained that, in their approaches, the content of the culturally competent prevention materials is not focused solely on presenting the standard information about HIV. They choose content to address issues that are relevant to the community and sub-communities. In the words of one operator:

> We can't address the issues specifically in prevention – we have to acknowledge they exist and we also talk about ways around them.
> – B_1

For example, choosing specific content aimed at reducing the incidence of HIV/AIDS is important and is influenced not only by practices but also by the community's views on HIV/AIDS. CBAOs in the study described how they identify transmission methods and associated risk factors in the population and how they vary across communities and sub-communities. On the basis of this analysis, the CBAOs choose content about protection options and safer sex methods targeted directly to specific audiences in their communities. Where possible, they also choose materials that have the advantage of dispelling myths about HIV in the community. The CBAOs reported that choosing content that anticipates the increase and evolution of the HIV epidemic in their communities could be particularity challenging. As one of the respondents expressed the problem:

> Materials in the past haven't been successful because they didn't
> have a clear message. They tried to please everyone - that's the
> challenge. We need to look long term and say we're not going to
> do that this year, but maybe in two years. If we recognize that
> there are limits on resources, and by thinking long term, we can
> do things over time, and choose things that make sense right now.
> – AB

Beyond that, CBAO operators discussed the importance of presenting the information in creative messages that resonate with each target audience. Attracting interest in the information and generating a response are the first goals of prevention work, as noted by the organizations. The next goal is to educate effectively by taking into account the cultural and linguistic community characteristics. All the operators stressed creativity as a necessary skill and important goal for the process of material development.

The CBAO operators defined the important issues within their communities, and they also were able to identify what they could and could not talk about in particular sub-communities. Therefore, for them, making prevention materials culturally competent involves understanding what content can be placed on a poster and how much the "straight facts" have to be hidden in other messages. The South Asian and the Black, African, and Caribbean agencies experienced different cultural nuances that affected the way they could present information in materials. For example, because of the high degree of stigma associated with HIV and other sexually transmitted diseases, the South Asian organization could not present outright ideas about HIV. Instead, it cloaked them in more general issues related to the community. As one operator described it:

> If we held a workshop on sexual health, or HIV 101 – a lot of people might not want to come to the agency to attend – so we have to be really innovative in what we offer. Sometimes it will be about healthy relationships, and then we can talk about intergenerational conflict and bring up the topic of talking about sex within the family setting…and we never push things, it's always their choice. – SA$_2$

In contrast, the youth of the Black, African, and Caribbean community are more receptive to straight talk about HIV transmission, as exemplified by the following:

> So we're like "if sperm can get through, so can HIV" – nothing like "go think about this idea" - you want to get the message in and out. – B$_2$

For some agencies, though, evidential strategies are a lower priority than others. Overall, the Portuguese and South Asian agencies are more focused at this time on translation because that is an important need for the community, whereas the Black, African, and Caribbean agency focuses its resources on developing the content of the materials to be as specific as possible.

4.3.3.3 Peripheral Strategies

The attitude and practices of agencies in this study are aligned with the suggestion of Kreuter et al. (2002) that the imagery component of materials should establish credibility within the community and should attempt to match the surface characteristics of the community. According to the agencies, they try to use imagery that reflects the composition of the community and portrays ideas that are related to HIV and relevant to the community. Therefore, they carefully select images and present them as part of an attractive design using colors and graphic effects that have an impact, much as advertising

does. For example, the Black, African, and Caribbean agency uses an advisory group to help pose for and choose which photos should be used in the campaign:

> Imagery that looked like them was important to them, not having a supermodel trying to talk to them about HIV, but real people from the community – that really spoke to them. – B_1

Instead of portraying individuals, the Portuguese agency chose for a recent campaign an occupation that has its own imagery and used that to relate to a large part of the community. The operator explained it this way:

> We wanted to create a campaign that really caught the attention of the community, and because the majority of people working in the Portuguese community work in construction – we focused on that, and used it for the content and then images, so they can identify with the campaign and feel some similarity, and get the message to be easily observed. – P_2

The agencies had to take care in developing imagery, considering how it was used and with which audience. For example, in a community where many MSM identify themselves as gay, imagery involving homosexuality could be an advantage in relating to the community. However, sexuality-based images involving members of the South Asian community are often not well received because of repressive views on both homosexuality and women's sexuality. Therefore, the imagery chosen for these campaigns represented women and men from the community were in a more family-oriented manner. To find out the best approach in circumstances like these, the agencies experiment with imagery to find out what works best in various environments. The locations where campaigns were displayed also affect the types of images chosen.

For example, agencies believe that advertising in public spaces, such as public transit or restaurants, cannot be as provocative as in bars or similar venues. Moreover, images chosen are now more like advertisements; the style of images designed must reflect both the community's norms and other advertisements in the community for its effectiveness.

4.4 Commentary: Using a Taxonomy of Cultural Competence (Lister, 1999)

This chapter described the work of the CBAOs that participated in this study. Their work is aimed at providing culturally competent health promotion to facilitate social inclusion in the ethno-cultural communities they serve. Three related mechanisms emerged: community networking, community knowledge and involvement, and community-specific resources. How culturally competent are the mechanisms of the CBAOs in the study? A taxonomy created by Lister (1999) was used to analyze the culturally competence of CBAO practice in health care. Five levels build upon one another: cultural awareness, cultural knowledge, cultural understanding, cultural sensitivity, and cultural competence. These are explained more fully in the literature review. The following chapter contains a commentary that considers each level of this taxonomy and its relationship to the three mechanisms presented in the findings.

4.4.1 Cultural Awareness - Describes how different cultures/ethnicities may validate different beliefs and values

As indicated in earlier findings, the CBAOs came into existence based on the assumption that different cultural communities have different cultural norms and practices. They may affect the way community members define health and access resources. The

CBAOs further recognize, through their use of community-based networks, that there is a need for multiple services besides HIV-related health promotion, ranging from mainstream to community-based services focused on social structural issues such as poverty and housing. Although the diversity of the population and the number of cultures within each community make it challenging, it is evident that CBAOs, both act alone and through collaboration in community networks, validate different community beliefs and values through their work to eliminate service gaps.

4.4.2 Cultural Knowledge - Shows familiarity with the broad differences and similarities among various groups in society

Through the three mechanisms, the CBAOs indicated that they show the most familiarity with the community to whom they provide their services. There is little evidence that they show the same familiarity with communities outside of their own, beyond recognizing the important need for such organizations to exist in all communities across the province. For example, as one participant noted:

> There's always been a recognition that the people who are impacted by the issue [of HIV/AIDS] should be leading the response in Ontario… because of cultural nuances and differences that could not be addressed in mainstream organizations… they knew the importance from the beginning that their services needed to respond in a way that made sense to the people from their communities. – AB

One source of cultural knowledge within the three CBAOs studied is the presence of operators who are members of the communities within which they work. Although this presence can contribute to the CBAOs' insights about cultural norms related to accessing

health resources, this knowledge must be used carefully so as to avoid making assumptions

about one person's ability to represent a particular group. Thus, being from the community

can make it easier to relate to the community, although that role is not necessarily without

challenges. As one of the operators commented:

> Just because a person is from a particular racial background
> doesn't mean they are the best person to do a workshop … but I
> think someone who wasn't from it would have to deal with the
> 'ethnic issue', and the outsider mentality, and it would difficult.
> Just being from one community, and understanding how they
> think about sex, has helped me to do my work. - B$_2$

Being skillful in providing culturally competent health care also is important for

CBAO operators. In addition, they have to be knowledgeable about the 'HIV culture', which

is not community specific. However, the professionalization of the system has impaired the

ability to find persons from the community who are familiar with the community's needs

and cultural values and who are sensitive to HIV/AIDS issues. In the past, mostly people

affected by the disease filled the CBAO operator positions. Now, more and more operators

selected by CBAOs are educated to work in a relevant field (social work or public health) but

have no personal connection with the disease or with the community. Consequently, CBAOs

need to find ways to compensate, as the following example illustrates:

> If someone comes straight from social work school who has never
> been part of the culture [of HIV], you need to make sure that they
> have the right value base and service provider to work with these
> communities, who have already experienced difficulties accessing
> care, so you want to make sure the care and information they do
> get it accessible and open to them. – AB

The CBAOs in this study also gain cultural knowledge through investigation in their own communities, through outreach and CBR methods, and through the direct involvement of the community, as shown in the earlier findings. These methods allow the substance of the issues to come from the community. In addition, community networks are used to tap each other's services to gain information and culture (e.g., community coalitions). Community networks and information sharing help operators to develop a deeper understanding about the community and its cultural norms and values, which may differ from that of the mainstream, and helping their community members to gain access. The cultural knowledge developed by this network has the input of a number of operators across a variety of organizations, including the CBAOs, as well as community members.

4.4.3 Cultural Understanding - Recognizes issues faced by individuals related to culture

It was evident from the study that all of the agencies studied recognize the various issues related to the provision of HIV prevention in their communities. They acknowledge the need to address these issues as they arise.

The CBAO operators in this study described two levels of issues that were arising: social-structurally based and locally based. Social-structural-based issues, such as poverty, require action that is beyond any individual CBAO or its community in the form of broader-based advocacy. Locally based solutions give operators the ability to work one-on-one with community members and to intervene on their behalf—for example, by providing access to services to support immigrants or facilitating programs for job-skills training. Because of their relationship to the community and their interactions in community networks, the

participants in the CBAOs expressed their feeling that they owe the community more than just health information. Therefore, they are concerned with both community issues and health promotion. Importantly, CBAOs in the study are aware of their limited ability to find solutions for the social and economic inequities in their community.

The focus of these CBAOs, as illustrated by their mission statements or by the operators' comments, is providing health promotion and prevention resources in a culturally competent manner. Thus, it is not their intention to attempt to make major changes to broader social issues. Instead, their approach is to frame HIV prevention in the context of issues relevant to the community, making it possible for individuals to relate better to information they receive. Therefore, by achieving cultural understanding, they can begin to have an impact on material inequalities, although it may not change social-structural inequalities significantly. Furthermore, as outlined earlier in the discussion of community networking, in areas where they are unable to work with community members because of lack of knowledge or services, CBAO operators use the community network to increase access for individuals to services provided by mainstream organizations or other CBOs.

Another component of cultural understanding is recognizing the problem associated with the cultural practices of a community being compromised by the dominant culture and developing practices specific to the community or group. The CBAOs responded to this problem by providing community-specific materials. These materials, as illustrated in Chapter 4.3, are tailored to reflect the linguistic, evidential, and peripheral needs of the

specific community that will access them. Both cultural awareness and cultural knowledge inform the development of such materials, as does an understanding of the issues specifically affecting the community that related to HIV. As discussed earlier, there can be problems with the creation of these materials. The failure of translation is most notable when an agency, due to a lack of resources, simply translates materials from the mainstream agencies. The content of these messages can be ineffective because of a lack of cultural insight. Moreover, the reliance on one operator within the agency (such as in the Portuguese and the South Asian agencies) to translate the materials can be problematic. This is because it requires that individual to rely too much on his or her possibly limited expertise in cultural and language nuances. Moreover, lack of community involvement and cultural knowledge based on assumptions can negatively impact the relevance of the materials.

4.4.4 Cultural Sensitivity - Shows regard for personal values; practice development

Cultural sensitivity can mean showing regard for client beliefs, values, and practices. As discussed earlier in the findings, there is ample evidence that operators in the CBAOs design strategies that respect the values, beliefs, and practices of their communities. In their efforts to produce and distribute materials, the CBAOs demonstrated several examples of how choice of content is influenced not only by practices but also by the community's views on HIV/AIDS. Also, the CBAOs choose content about protection options and safer sex methods targeted directly to specific audiences in their communities. Where

possible, they also choose materials that have the advantage of dispelling myths about HIV in the community.

Cultural sensitivity can also mean coming to an understanding of how one's personal position can have an impact on the provision of services. One operator introspected:

> Because I am from the community - it made things easier, but not in all senses. There are a lot of things from the community that I don't understand. I think that even my location, my social location, affects that since a lot of the work I'm doing is with 'marginalized communities', and while I am from the community, there are certain things that I can't always relate to, or fully understand. – B$_2$

Another practice is the use of various outreach methods. To meet the needs of the community, operators will either go into certain settings for organized outreach in community-centered organizations, schools, and other locations or use the media and Internet to reach a broader audience.

4.4.5 Cultural Competence - Provides or facilitates services that show respect for cultural values

Cultural competence involves combining the four previous levels—awareness, knowledge, understanding, and sensitivity—to bring all the practices together as whole within the organization. It also means moving beyond the organizations itself by engaging others in political involvement and professional development.

As shown throughout Chapter 4.3, operators engage their communities in several ways to provide or facilitate services. Aligning with community networks is one important way of improving access to culturally relevant services in HIV prevention and beyond, and

of interacting with their community members. Community involvement—whether going out into the community or encouraging members of the community to participate directly at the agencies or in CBOs—is a part of what the CBAOs do in their daily work. Doing outreach, whether through events, seminars, media, or Internet-based communications in the community, engages community members who would not otherwise come into the organization.

However, for reasons related to the growing gap between resources and the challenges presented by increasingly complex communities, there are several instances referenced in the findings in which the CBAOs are unable to provide culturally competent services to their entire community. For example, the Portuguese community relies on the translation of mainstream content into Portuguese, which does not really address the cultural differences between Brazilian and Portuguese groups in their community. Although they are successful to a certain degree, the incidence of HIV/AIDS in the community continues to increase. The CBAOs need to find resources and innovative methodologies to reach existing audiences more effectively, not only to raise their awareness of HIV, but also to empower them with knowledge so as to change their behavioral practices and avoid infection. In addition, they need to extend their outreach to engage those in their communities who were not reached by their previous efforts.

Additionally, the CBAOs' participants pointed out that they have little political involvement because they do not have the capacity or resources to lobby at such a level.

They also pointed out that they do little in professional development on cultural competence. For example, one key informant noted:

> We do segments on communications, assessment and referral, confidentiality, racism and HIV, gender and HIV, and anti-homophobia. We do address culture, but because it's tricky and no one is really an expert on one culture we try and stay away from cultural competence training for the most part. - SA[2]

Therefore although the focus of the CBAOs studied is to provide services and materials that reflect the cultural norms of the community, training for such practices is not a priority because it is difficult and requires resources.

4.5 Conclusion

On the basis of the analysis of the CBAOs' practices, it is clear that the CBAOs in the study are successful in providing culturally competent support and resources related to HIV prevention. This analysis, coupled with the findings, answers the question of what CBAOs can do to promote socially inclusive practices in their communities through culturally competent health promotion, which is the focus of this study. The findings show that the CBAOs have developed three related mechanisms as part of the practice of health promotion. Moreover, these mechanisms are related to develop social inclusion in these ethno-cultural communities. These mechanisms are community networks, community involvement and knowledge, and community-specific resources.

This chapter detailed these mechanisms using evidence gathered from qualitative interviews with operators from three different CBAOs (South Asian; Black, African, and Caribbean; and Portuguese), which varied in size and staffing distribution, as well as a staff

from the AIDS Bureau. The findings then were analyzed using the taxonomy of culturally competent practice (Lister, 1999). The CBAO operators in the study have achieved the levels of awareness, knowledge, understanding, and sensitivity. The final level, cultural competence, has not been fully achieved.

Chapter 5. Conclusions and Policy Recommendations

This thesis provides an in-depth description and analysis of what CBAOs do to promote social inclusion through culturally competent health promotion practices in their communities. It answers the research questions: (1) What are the main health promotion practices of CBAOs, and (2) How do these practices promote social inclusion?

This study is relevant because identifying solutions to exclusion in communities is an important step toward eliminating health inequalities. In addition, the province of Ontario, which has a culturally diverse population, requires community-based services to meet these demands. Moreover, HIV is a growing issue in Ontario's ethno-cultural communities. Ontario CBAOs are able to meet the needs of ethno-cultural communities. Socially inclusive practice that validate norms and practices (including language) can work to include minority communities and provide important services that might not otherwise be accessible. In addition to accessible and relevant services, social inclusion can increase civic engagement, human development, and the recognition of diversity in society (O'Hara, 2006). Therefore, it is important to continue to study the particular contributions of CBAOs and to explore how their practices can promote social inclusion.

Through qualitative data collection and analysis, this study identified three general mechanisms related to promoting social inclusion based on many practices in common among the three selected CBAOs that serve distinct ethno-cultural communities (South Asian; Black, African, and Caribbean; and Portuguese). These communities comprise

members who have distinct cultural norms, values, and practices that impact the way they access and relate to the mainstream services and institutions.

The following concludes how the findings can answer the two research questions proposed by this study:

(1) What are the main health promotion practices of CBAOs?

The findings indicated three general mechanisms, which represent the practices of health promotion at the CBAOs: (a) community networking, (b) community knowledge and involvement, and (c) community-specific resources. The first mechanism is community networking practices that includes activities relating to: participation in community-based networks, partnerships with government, identifying services gap in the community, and using networks to refer community members to other community-based resources. The second mechanism is community knowledge and involvement. Overall, this refers to the identification of means to access a broader range of community members (outreach and dissemination methods) through interaction with the community to develop insight about community-based issues. It includes four types of interrelated practices: personal connection with the community, investigation of the community through research and discussion within the community, including community members in the development and delivery of services, and outreach/dissemination methods such as ethnic-based media and community venues.

The third mechanism is the production of community-specific resources using peripheral, linguistic, and evidential strategies to make them accessible and relevant to community members.

(2) How do these practices promote social inclusion?

The CBAOs were able to promote social inclusion due to several reasons. Firstly, organizations are from the community and located within the community, and they developed out of community need to meet gaps in service. They also developed community-resource networks within each community to refer community members to appropriate services to prevent gaps and gather more resources. Due to their location and relationship with the community, the operators at CBAOs are able to respond quickly and appropriately to changes within the community. Similarly, CBAOs are able to recognize and target diversity resulting from cultural nuances in different groups within the community (e.g., women, MSM, and youth). Their location within the community allows the organizations to include community members in the development of services, as well as engage the community through various outreach and distribution methods. The organizations also showed that they were able to create materials that were community specific with respect to language, imagery, and content, and thus were culturally relevant and appropriate. Access to resources is an important component of socially inclusive practices and is necessary for community members who may otherwise not be able to read or access to official language resources.

Following the descriptions of the mechanisms, taxonomy of cultural competence (Lister, 1999) was used to show that the practices associated with these mechanisms conform to a large degree to culturally competent practice as described in the literature. Based on data gathered from operators regarding CBAO health promotion practices and material resources, several examples of health promotion practices clearly illustrated the ascending levels of cultural competence as defined by Lister (1999), which were cultural awareness, cultural knowledge, cultural understanding, and cultural sensitivity. In Lister's taxonomy, the highest level—achieving cultural competence—was defined as care that respects the values, beliefs, and practices of the community and that addresses disadvantages arising from power relations. According to Lister's taxonomy, the CBAOs studied were successful in providing services that were culturally relevant and insightful.

For the CBAOs to continue their operations and carry out their health promotional activities, continued funding is necessary to ensure that they can go into the community, do research, and create materials that are more community specific. Moreover, it will be important to maintain AIDS Bureau-CBAO partnerships or develop other similar governmental partnerships. Further study needs to be done to indicate measures of social inclusion and exclusion within these populations.

Other recommendations include increased CBR training in CBAOs (and for other community-based researchers), as indicated through the findings chapter of the thesis, the use of CBR was an effective way to create culturally competent materials and resource. It also will be important to continue to develop provincial-wide resources or tool kits for

material development in order to increase consistency across the provinces and throughout the agencies. Similarly, it is important to find ways to strengthen community-based networks, by providing more opportunities for the CBAOs from different communities to exchange ideas. Finally, increasing cultural competency training in CBAOs will ensure continued work in health promotion that promotes social inclusion. Additionally, the development of different definitions and models for cultural competence may arise from this type of training session.

The mechanisms emerging from the practice of the CBAOs are general means that can be adapted by other CBOs in health promotion efforts. Therefore, the practices of other CBOs, as well as a more sweeping study of CBAOs, will be an important way to contribute to the theory and explanation of the concept and to provide specific examples of practices that reduce social exclusion in communities.

The findings of this study show that culturally competent health promotion practices at CBAOs promote social inclusion. Their culturally competent health promotion practice should be used to guide the development of health promotion practices for other communities.

Although this study focused on the CBAOs and health promotion related to HIV, the conclusions drawn from findings and analysis in this study might be applied to other important health issues. Although HIV is a unique issue because of its relationship to sexual behaviors, which are deeply tied to cultural beliefs and taboos, the fundamental means of

providing accessible health promotion services and resources to the community are not

unique.

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Appendix A. Information Letter & Consent Form

University of
Waterloo

[Date]

Dear [Participant],

My name is Alexandra Stief and I am a student researcher conducting a thesis project under the supervision of Prof. Weizhen Dong. Both Dr. Dong and I are affiliated with the University of Waterloo's Department of Sociology. My contact email is aestief@artsmail.uwaterloo.ca; Prof. Dong can be contacted at 519-888-4567 ext. 37768 or by email at weizhen@uwaterloo.ca.

 The purpose of this study is to examine the current situation of culturally competent disease prevention as provided by ethno-cultural community based organizations. The focus of the study will be to look at the structure and function of these organizations, and the factors that enable them to provide access to effective HIV education prevention resources to their community members. As part of this analysis, it will consider culturally sensitive HIV prevention materials with respect to their content, production, and distribution. It will also focus on the relationship between community-based organizations and the communities they service.

 I would like to include your organization as one of several organizations to be involved in my study. I believe that because you are actively involved in the organization, you are best suited to speak to the various issues associated with HIV prevention for this particular community. I greatly appreciate your participation in the project.

 Participation in this study is voluntary. There are no known or anticipated risks to you as a participant in this study. You may decline to answer any of the interview questions if you so wish. Further, you may decide to withdraw from this study at any time without any negative consequences by advising the researcher. With your permission, the interview will be recorder with a digital recorder to facilitate collection of information, and later transcribed for analysis. Shortly after the interview has been completed, I will send you a copy of the transcript to give you an opportunity to confirm the accuracy of our conversation and to add or clarify any points that you wish. All information you provide is considered completely confidential. Your name will not appear in any thesis or report

resulting from this study, however, with your permission, anonymous quotations may be used in the final report. The data collected will be kept on a secure server, which will be pass-worded and access will only be granted to the student researcher and the project supervisor. All electronic data associated with the study will be kept for 4 years before destruction, while all paper documents will be shredded confidentially after 1 year. At your request, you will be provided with a copy of the final report by mail, prepared by the student researcher, upon its completion.

If you have any questions regarding this study, or would like additional information to assist you in reaching a decision about participation, please contact me by email at aestief@artsmail.uwaterloo.ca, or Prof. Weizhen Dong at 519-888-4567 ext. 37768 or by email at weizhen@uwaterloo.ca.

I would like to assure you that this study has been reviewed and received ethics clearance through the Office of Research Ethics (at the University of Waterloo. However, the final decision about participation is yours. If you have any comments or concerns resulting from your participation in this study, please contact Dr. Susan Sykes of this office at 519-888-4567 Ext. 36005.

I hope that the results of my study will be of benefit to those organizations directly involved in the study, other community-based organization involved with HIV prevention, as well as to the broader research community. I anticipate that outcomes as a result of the analysis developed in this project, as related to the highly important issue of HIV/AIDS will also be relevant to other health promotion and disease prevention activities of community-based organizations in Toronto.

Thank you in advance for your assistance in this project.

Yours Sincerely,

Alexandra Stief

I have read the information presented in the information letter about the session being facilitated by Alexandra Stief. I have had the opportunity to ask the facilitator any questions related to this session, to receive satisfactory answers to my questions, and any additional details I wanted. I am aware that I may withdraw from the session without penalty at any time by advising the facilitator of this decision.

This project has been reviewed by, and received ethics clearance through, the Office of Research Ethics at the University of Waterloo. I understand that if I have any comments or concerns resulting from my participation in this study, I may contact Dr. Susan Sykes, the Director of Office of Research Ethics at 519-888-4567 ext. 36005, or by email at ssykes@uwaterloo.ca.

With full knowledge of all foregoing, I agree, of my own free will, to participate in this session and to keep in confidence information that could identify specific participants and/or the information they provided.

With full knowledge of all foregoing, I agree, of my own free will, to participate in this study.

☐YES ☐NO

I agree to have my interview tape recorded.

☐YES ☐NO

I agree to the use of anonymous quotations in any thesis or publication that comes of this research.

☐YES ☐NO

Participant Name: _____ (Please print)

Participant Signature: _____

Witness Name: _____ (Please print)

Witness Signature: _____

Date: _____

Appendix B: Interview Schedule

Org Code:
Interview #:
Date:
Location:

Impressions of org:

Impressions of participant:

Introduction
   1. What is your personal role at [CBAO]? When did the need for this position emerge?
   2. Is it important to you to be from the community you are serving?
   3. What does community-based mean from your perspective?
Organization Goals & Community
   1. Was the formation of [CBAO] guided by the needs of the community?
      ▪ Current goals, providing resources?
      ▪ Communities its serves; How much of the community?
      ▪ Community response
   2. How has this changed over time? When did cultural competence become important, with respect to ethno-cultural groups specifically?
   3. Do you think that a CBAO can better serve then community's needs than the mainstream public health system? Why/Why not?

Organization Structure & Functioning
   1. How is the structure related to the function (i.e. providing HIV/AIDS education)?
      ▪ Staff : who does what, number of staff
      ▪ Skill sets?
      ▪ PT vs. FT, contracting out
      ▪ Differences between organizations that have difference structures
      ▪ Training, cultural competence training
   2. What sorts of partnerships does [CBAO] have?
      ▪ Other CBOs/CBAOs
      ▪ Community Members
      ▪ Public Health units

Programs/Materials : Content & Production
1. What types of materials/programs do you provide here?
2. Do you create your own materials/programs, or use ones from mainstream sources?
3. What process do you follow?
    - Who is involved? Collaborations?
    - Language
    - Content – to ensure cultural norms & values/wording
    - Images
    - Content vs. Language vs. Images
4. What sorts of evaluation techniques do you use
5. What are some of the problems associated with the current materials? What barriers have you faced in creating them related to culture/external factors?
6. Is it an issue of resources?

Program/Materials : Distribution
1. What levels of access exist?
    - Achieving good distribution
    - Knowledge of info-seeking behaviors
    - Differences within and between communities?
2. What barriers do you face?
3. Do you think this can be improved on?

** REVIEW MATERIALS

General Questions
1. What impact do you think providing communities with culturally appropriate resources can have on prevention of HIV?
2. Where does HIV prevention fit in with other Health Promotion activities?
3. How can HIV prevention deal with other critical issues in the community?
4. Do you think there will always be a need for CBOs within the larger health care system? What is this a result of?
5. Other thoughts?